

**Designing dying well:  
towards a new approach to the co-production of  
palliative care environments for the terminally ill**

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Dedicated to the loving memory of my mum,  
Joanna Bellamy,  
who I miss everyday



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## Abstract

[key words: dying, hospice care, co-production, architectural ethics]

This thesis brings forth a new awareness of the in-patient hospice to enable shared understanding between architectural and healthcare professionals in the UK. A timely study, inasmuch that there continues to be a reliance on the third sector to provide end-of-life (EoL) and respite care for the terminally ill as the contextual landscape of UK in-patient hospices and the way Britons die rapidly changes. The architectural identity and approach to the design of in-patient hospices is little studied, particularly as a building type, with a relatively small literature base that has yet to be meaningfully translated into practice. Foregrounding architectural perspectives on the in-patient hospice, this thesis disseminates a shared understanding contributing to a new and empathetic approach to their design.

Original research was informed by fieldwork undertaken in several Welsh hospices and founded upon the researcher's personal experience of a hospice in England. The study deploys a mixed methods methodology and practice-led approach drawing upon methods from ethnography and design research, such as post-occupancy building observation and in-depth interviews. Here the presence of commonplace architectural design tools, such as physical models, facilitated research by breaking down disciplinary barriers, particularly between architectural and healthcare professions. Centred on the experiences of multiple hospice organisations in Wales, this study highlights vital clinical and non-clinical voices from a third-sector case study setting to inform the understanding of the requirements of the in-patient hospice.

Contextual analysis of the evolution of the hospice typology, from historical predecessors to modern developments, informed design analysis observing that contemporary environments of palliative care are still heavily influenced by historic models that cannot cater for the shifting context and delivery of contemporary hospice care. A scoping study of three in-patient hospices in Wales uncovered diverse impressions of the role and subsequent value of architectural professionals, with each establishing a range of distinctive relationships and strategies with their respective architects. Where genuine co-production manifested, typical design practice was challenged for the better. The central case study explores a setting that is typical of 'everyday' palliative care environments, as opposed to an architectural exemplar or new build; it presents a dichotomy between those whose care practice supported patients and the hospice building itself. The perspectives of rarely

consulted members of staff emphasised hidden expertise and a sense of duty. Furthermore, it exposed the significant issue of tension between design approaches for short- and long-term change, and the preparedness of meeting changing requirements set out by national guidance for EoL.

Substantial ethical challenges in gaining access to palliative care environments required the researcher to radically modify their language and tone to fit in, thus highlighting vital methodological lessons for not only inter-disciplinary research, but architectural practitioners during early stages of the design process. The study emphasises the power of empathy - within not only architectural research but practice - advocating it as a crucial skill to move beyond the assumption of design as a 'silver bullet'. To avoid architectural tropes or clinical inefficiencies this thesis posits a new approach for the design of palliative care environments that must be based on the premise of co-production to share both architectural and healthcare insights. This thesis is therefore a provocateur - challenging first, architects to critically engage with the ethical practices of hospice organisations as stakeholders and active participants in the design process, and secondly healthcare professionals to embrace meaningful inter-disciplinary discourse and collaboration.

## INTRODUCTION

*drawing the 'insider'*

*practice note*



### PART ONE

**CARE CONTEXT**

2. *hospice as a concept*  
3. *hospice as a typology*

*models as tools*

*practice note*



4. *hospice as an organisation*

### PART TWO CASE STUDY

5. *hospice as a lived experience*

*precedents & publicity*

*practice note*



**DESIGN ANALYSIS**

5. *hospice as a designed environment*  
6. *hospice as a field of study*

### PART THREE

*beyond co-production*

*practice note*



## CONCLUSION

The proposed structure of the thesis, with its distinctive parts, and the practice notes interspersed between. This also demonstrates how the first part of the thesis works as a contextualisation of the topic and case study, before moving to the fieldwork in part two, before finally considering design more holistically in part three.

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## 6 Hospice as a designed environment






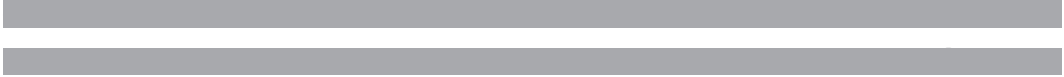
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## Glossary

### *Clinical [spaces]*

These are the spaces within which medical care is provided, for example a patient bedroom. However, this extends to spaces that support care, drugs stores, sluices and so forth.

### *Co-production*

Defined as 'collaboration between a professional or technical provider and a service user...[and] requires users to be experts in their own circumstances and capable of making decisions, while professionals must move from being fixers to facilitators'<sup>1</sup> Co-production furthermore seeks to generate new knowledge from the combination of two or more areas of expertise.

### *Dignity*

Defined as the conceptual state or quality that is 'being worthy of honour and respect'<sup>2</sup> but also includes a feeling of self-respect and personal worth.

### *End-of-life care (EoLC)*

Is defined as a stage of specialist palliative care that seeks to support those that are thought to be in the last year of their life; however, this time frame can be very difficult to predict and plan for.<sup>3</sup> It seeks to help those approaching the very end of their life the opportunity to live well and die with dignity.

### *End-stage*

What is considered the final phase of a progressive illness that leads to the physical process of dying, i.e., an indication that a person's death is imminent.<sup>4</sup>

### *Hospice [philosophy]*

A holistic approach to care that not only looks to care for and manage the physical symptoms of those with terminal illnesses, but also psychological, emotional, and spiritual care for the person

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<sup>1</sup> Alba Realpe and Professor Louise. M Wallace, 'What Is Co-Production?', (London: The Health Foundation, 2010)

<sup>2</sup> "Dignity - Definition Of Dignity In English | Oxford Dictionaries", Oxford Dictionaries | English, 2016 <<https://en.oxforddictionaries.com/definition/dignity>> [accessed 1 November 2018].

<sup>3</sup> Marie Curie. (2018). What are palliative care and end of life care?. [online] Available at: <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care> [Accessed 10 Oct. 2018].

<sup>4</sup> Dying Matters. (2018). Glossary. [online] Available at: <https://www.dyingmatters.org/page/glossary> [Accessed 18 Oct. 2018].

and their family.<sup>5</sup> It is the concept that has driven the formation and acceptance of specialist palliative care teams as a defined medical team.

### *Hospice [building]*

This is a colloquial term that is also used to refer to the buildings that offer different types of 'hospice'. This term applies for example, to both in-patient (residential, for respite or end-of-life care) and out-patient (community care, complimentary therapy services) buildings.

### *In-patient*

Patients receiving medical care will do so either as an in or out-patient. An in-patient is defined as someone 'who goes into hospital to receive medical care, and stays there one or more nights while they are being treated'.<sup>6</sup> This implies a degree of residential care, such as a bed, food and drink and access to sanitary facilities.

### *Non-clinical [spaces]*

These are the spaces that do not support the provision of clinical care, such as receptions, offices, and communal areas. However, some areas where clinical care does take place, such as patient bedrooms, also accommodate non-clinical activities depending on the users present.

### *Palliative care*

WHO defines palliative care as an 'approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illnesses. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual'.<sup>7</sup> The motive of palliative care is typically associated with symptom control.

### *Specialist palliative care*

As defined by NICE, specialist palliative care is the supportive framework to seeks to alleviate the burden of illness, that includes hospice care but is not limited to 'specialist advice support and care

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5 Hospiceuk.org. (2018). What is hospice care | About hospice care | Hospice UK. [online] Available at: <https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care> [Accessed 16 Oct. 2018].

6 Cambridge Dictionary, In-Patient (n.d) <<https://dictionary.cambridge.org/dictionary/english/inpatient>> [accessed 12th May]

7 WHO, Palliative Care Factsheet (2020) <<https://www.who.int/news-room/fact-sheets/detail/palliative-care>> [accessed 9th May]

such as that provided by hospital palliative care teams<sup>8</sup> and may include for example occupational therapists, physiotherapists, bereavement care specialists. Palliative care is operated on a need's basis; open to anyone with a progressive terminal illness, and at any point from diagnosis onwards.

### *Post-occupancy evaluation (POE)*

The Building Research Establishment defines POE as 'the process of obtaining feedback on a building's performance in use'.<sup>9</sup> This might cover a range of investigations, such as investigations into the buildings environmental condition and performance, sustainability credentials and experiences of the occupants and clients.

### *Practice-led research*

Common within creative fields, this type of action research is 'concerned with the nature of practice and leads to new knowledge that has operational significance for that practice. The primary focus of the research is to advance knowledge about practice, or to advance knowledge within practice.'<sup>10</sup> Therefore, research following this approach would be less concerned with design as an outcome, but a process.

### *Terminally ill*

This phrase refers to a patients condition and is defined clearly by Marie Curie as being an illness that 'cannot be cured and is likely to lead to someone's death'.<sup>11</sup>

### *Typology*

Collins Dictionary defines the term typology itself as both the 'the study of types' and as 'a system for dividing things into different types'.<sup>12</sup>

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8 Nice.org.uk. (2018). End of life care for adults | Guidance and guidelines | NICE. [online] Available at: <https://www.nice.org.uk/guidance/qs13/chapter/quality-statement-10-specialist-palliative-care> [Accessed 2 Oct. 2018].

9 BRE, Post-Occupancy Evaluation (Poe) (Building Research Establishment, n.d) <<https://www.bre.co.uk/page.jsp?id=1793>> [accessed 13th May]

10 Linda Candy, Practice Based Research: A Guide (2006) <<https://www.creativityandcognition.com/resources/PBR%20Guide-1.1-2006.pdf>> [accessed 17 May] p.2

11 Marie Curie, What Is a Terminal Illness? (Marie Curie, n.d) <<https://www.mariecurie.org.uk/who/terminal-illness-definition>> [accessed 12th May]

12 Collins Dictionary, Typology (Collins Dictionary, n.d) <<https://www.collinsdictionary.com/dictionary/english/typology>> [accessed 28th July]

## Prologue

I am by education an architectural professional, who since a young age has held a fascination with the buildings that we inhabit, and how these hold the power to shape our lives. It is through my personal experience of the in-patient hospice however that led to my academic interest, passion, and study of such a setting that still causes discomfort and awkwardness to most.

I grew up feeling intimately familiar with healthcare environments. I was 7 when my mum - henceforth referred to as Jen - was first diagnosed with myelodysplasia, a rare form of blood cancer and subsequently chronic myelomonocytic leukaemia and systemic mastocytosis when I was in my teens. Over this time, and during the times she spent in hospital, I remember visiting, absorbing the atmosphere of the place. Our local acute hospital, a large and influential teaching hospital, was everything that architecturally you come to expect from such clinical places, long corridors, the mixture of sickly smells, a cold blue and green colour palette and the feeling of plastic everywhere. Throughout her subsequent treatments over the years, it was always home that my mum wanted to be, and understandably surrounded by home comforts and family. It was in 2013, shortly after I had completed my undergraduate architectural



studies, however, that my mum's illness progressed and she moved to our local hospice, where shortly after she died. The experience of being in the hospice during those last few days was something I remember as being so distinctly different from my memories of the hospital; yet at the same time, they were the very same.

Losing my mum at a relatively young age, not surprisingly made a significant impact on my life, and gave me a new perspective on the environments that surround us. I had always had an interest in architecture that responded to humanist principles, exploring notions of memory and tactility in my undergraduate dissertation – and this interest only found more momentum after this. Enrolling onto a Master of Architecture programme a few years later, and having read Atul Gawande's *Being Mortal*, I decided to use my dissertation as a platform to explore my own experiences as part of an architectural investigation into the hospice. The study was perhaps naïve and being still so close to the loss of my mum, resulted in a large amount of vulnerable work that was never read or seen by my supervisor. Yet during the viva, despite the shortcomings of the dissertation, I was positively encouraged to consider taking the topic further. Entering onto an academic path of study was not where I had seen my life, but the opportunity to potentially contribute to a positive change was something I was not able to turn down.

# 1

## Introduction

This section provides the opening dialogue for the thesis, setting out the research context, background, and key aims of the research. The introduction summarises the implications of previous work by the researcher and outlines the scope and focus of the thesis.

## Introduction

As an architectural professional with lived experience of the in-patient hospice as a place of care this thesis began to take shape at a time when the experience of death and dying - though still a taboo topic in most western cultures - was finding a renewed interest. The impact of the COVID-19 pandemic brought to light the experience of death and dying to contemporary society, shifting perspectives on the way in which and where we die. Even prior to the pandemic, the contemporary landscape of care practices at end of life were shifting in response to changing demographics, contexts of care and a growing awareness of the overmedicalisation of death. Echoing this the 2022 report of the Lancet's Commission on the Value of Death called for 'death and dying [to] be recognised as not only normal, but valuable. Care of the dying and grieving must be rebalanced.'<sup>13</sup> As Libby Burton, an architect and founder of the Well-being In Sustainable Environments research group at Warwick University stated:

unlike a piece of fine art hanging in a gallery, which people can choose to go and see or not, people have to live and work in buildings. The built environment does affect people, whether we like it or not, so we have a responsibility to them.<sup>14</sup>

Therefore, the specificities of architecture's knowledge, practice and modes of representation need to be continually renewed and refreshed in relation to the contemporary situation<sup>15</sup> of how and where people are dying in the UK to ensure that architectural professionals can meet spatial, environmental, and clinical requirements in support of 'not just a good death, but a good life to the very end'.<sup>16</sup>

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<sup>13</sup> L. Sallnow and others, 'Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life', *Lancet*, 399:10327 (2022), 837-84, p.838

<sup>14</sup> Institute of Health Warwick University, 'Health @ Warwick: An Update', Institute of Health, Warwick University, 2010)

<sup>15</sup> Igea Troiani and others, 'Architecture and Culture: Architecture's Disciplinarity', *Architecture and Culture*, 1.1 (2013), 6-19, p.12

<sup>16</sup> Gawande, A. (2014) *Being Mortal: Medicine and What Matters in the End* (First edition. New York: Metropolitan Books, Henry Holt and Company, pg. 245

## Background

As we witness the shape of societal living and the nature of how we die change– so can it be observed that appropriate places of death are at risk of institutionalisation. The VOICES 2016 survey of bereaved people recorded that 82% of the UK's population expressed a desire to die at home. Yet the reality of dying in the UK will see 50% of the population dying within institutional settings.<sup>17</sup> It is in-between these two typologies that sits the in-patient hospice; an environment that seeks to combine the safety and security of traditional healthcare settings with the intimate and domestic scale of home for those at the end of their life. It can be observed that the way we now die is affected by many different factors; the advancement of medical care and technology extending average life expectancies, diminishing family units less able to provide in-situ multi-generational care and complex co-morbidities presenting additional medical challenges.

Across the United Kingdom, Hospice UK, the national charity for hospice care estimate that over 200,000 people access palliative care services in some form.<sup>18</sup> However, a recent study predicts that by 160,000 more people across United Kingdom will require palliative and end of life care (EoLC) by 2040.<sup>19</sup> Wales acknowledges that '0.75% of the overall population have palliative care needs at any one time'<sup>20</sup> - this being far beyond the current capacity of its current palliative care services. At present these challenges are perceived as wider issues for the healthcare community on shaping the future of hospice care. Though some positive changes are occurring within policy and legislation toward EoLC, and some hospitals are embracing a more open culture and attitude toward death as a failure of medicine, the financial precarity of hospice care means that there are still vast disparities in provision, with affluent regions better served and many areas with no specialist service at all.<sup>21</sup> However, there is growing momentum for change toward the provision of EoLC and palliative care in the United Kingdom.

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17 Office for National Statistics, National Survey of Bereaved People (VOICES), 2015, <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>.

18 HospiceUK, 'Briefing: Open up Hospice Care', HospiceUK, 2017) p.3

19 S. N. Etkind, A. E. Bone, B. Gomes, N. Lovell, C. J. Evans, I. J. Higginson, and F. E. M. Murtagh, 'How Many People Will Need Palliative Care in 2040? Past Trends, Future Projections and Implications for Services', *BMC Medicine*, 15 (2017), 102

20 NHS Wales / Welsh Government (2017). End of Life Care : Annual Statement of Progress. [online] pg 2. Available at: <https://gov.wales/docs/dhss/publications/171220end-of-life-reporten.pdf> [Accessed 26 Oct. 2018].

21 Sophie Olszowski, 'Hospice Care Is a Right, Not a Luxury', *The Guardian*, 20th February 2022

A core message of the 2022 report of the *Lancet's Commission on the Value of Death* emphasised that death and dying in the twenty-first century has fundamentally changed, becoming overmedicalised and with the role of family and communities degraded<sup>22</sup> thus requiring radical change to rebalance wider societal attitudes. This position was reiterated by an article published in the UK's Guardian newspaper proclaiming that 'hospice care is a right not a luxury.'<sup>23</sup> Furthermore the Lancet report's call to arms coincided with the Health and Care act<sup>24</sup> currently moving through UK parliament that seeks to outline how the NHS operates moving forward. Quoted in the Guardian article, Baroness Finlay, a member of the UK House of Lords, Vice President of Marie Curie Cancer Care and professor of palliative medicine described how the bill 'will launch 42 integrated care systems in England, new geographically defined health and social care partnerships, yet doesn't mention palliative care.'<sup>25</sup> Though the above does not describe concrete change to the provision of EoLC it represents a move toward radical change as advocated by the Lancet's report that is further supported by HospiceUK's *Future Vision Cymru* report launched in 2022 that outlines the 'future of integrated community palliative care...that will contribute towards an equitable "Wales offer"'.<sup>26</sup> However, as strategic policies are tested and instigated by national and local healthcare commissioners, the impact on the architectural approach of architects and designers in response to infrastructural changes in care services and provision must be critically understood.

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22 Sallnow and others, 'Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life', *Lancet*, 399:10327 (2022), 837-84

23 Olszowski, 'Hospice Care Is a Right, Not a Luxury', *The Guardian*, 20th February 2022

24 UK Parliament, 'Health and Care Act', (2022)

25 Olszowski, 'Hospice Care Is a Right, Not a Luxury', *The Guardian*, 20th February 2022

26 HospiceUK, 'Future Vision Cymru: Seamless and Sustainable: Report on Engagement Discussions and Ways Forward', (London: HospiceUK, 2021) p.2

## Research question

It remains evident that there is a lack of research that brings together the relevant aspects of in-patient hospice environments. The *Lancet's Commission on the Value of Death* calls for research on death and dying to be undertaken by those from a 'broad range of areas and disciplines beyond palliative care'.<sup>27</sup> It is here that this thesis seeks to contribute to the field of knowledge; to clarify and build upon the current state of research by drawing together the realms of architecture and healthcare. The research question of this thesis asks:

to what extent might shared understanding between architectural and healthcare professionals generate greater awareness of the requirements of in-patient hospices?

Focus is given to the organisational experience of the hospice building, by situating the voices and experiences of those who contribute to the running of the hospice, and moreover the role of architects and architecture in conjunction with this. This draws parallels with the approach of architect and former nurse Karen Keddy's doctoral study<sup>28</sup> that employed multiple tactics to undertake research that did not suggest how architectural design could increase operational efficiency but rather as Groat and Wang summarise 'to provide a more holistic understanding of "the physical nature of nursing work and the physical environment from the nurses' perspective"'.<sup>29</sup> The focus on the operational experience of the hospice building thus led to the interest in the concept of co-production and the relationship between the expertise of healthcare professionals to support architects, and vice versa, to better design spaces and places that are in harmony with the needs of occupants, both care givers and receivers. Realpe and Wallace define co-production as being:

based on the sharing of information and on shared decision making between the service users and providers. It builds on the assumption that both parties have a central role to play in the process as they each contribute different and essential knowledge.<sup>30</sup>

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<sup>27</sup> Sallnow and others, 'Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life', *Lancet*, 399:10327 (2022), 837-84, p.876

<sup>28</sup> Karen Keddy, *Embodied Professionalism: The Relationship between the Physical Nature of Nursing Work and Nursing Spaces* (The University of Wisconsin-Milwaukee, 2006)

<sup>29</sup> David Wang and Linda N. Groat, *Architectural Research Methods*, Second edn (New Jersey: Wiley & Sons, 2013), p.220

<sup>30</sup> Realpe and Wallace, 'What Is Co-Production?', (London: The Health Foundation, 2010) p.5

As the way in which we die shifts and the demand on palliative care services inevitably increases, this thesis - as an architectural commentary and interrogation of the in-patient hospice - aims to provide relevant and robust support of approaches that counteracts the suggestion that 'architecture is mute'<sup>31</sup> in the context of care. However, it is vital to note that in parallel to this we must acknowledge that co-production may help form a relationship that counteracts and dispel beliefs that 'good' design alone can solve problems within inherently complex contexts. Furthermore, as McLaughlan and Kirby write, care must be taken to not 'valorise design innovation as a magic bullet for achieving patient and family comfort and inclusion at the end of life'.<sup>32</sup>

## Aims and objectives

The following aims and objectives provide a framework by which this study can uncover the extent to which shared understanding between architectural and healthcare professionals:

### Aims:

- To develop the knowledge of a little studied building typology rarely engaged with by architectural researchers and non-specialist practitioners to inform and contribute to an updated understanding of the role of co-production in the context in which UK hospice buildings exist.
- To understand how hospice organisations in Wales have previously worked and engaged in co-production with architects to commission, design or re-configure, and deliver hospice environments.
- To use an experience-led approach, including observation, to seek to understand the perspectives of various clinical and non-clinical stakeholders, especially those that are rarely consulted, and the role of co-production in a case study hospice building in Wales.
- To facilitate a cross-disciplinary awareness of the hospice's environment of care that furthermore incorporates an understanding of the subsequent impact, on not only future architectural design practice, but academic research within the field.
- To build on personal experiences of the field, to contribute to the author's future work as researcher, teacher and/or practitioner.

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<sup>31</sup> Adams, A. *Medicine by design: the architect and the modern hospital, 1893-1943*. London: Minnesota UP, 2008

<sup>32</sup> Rebecca McLaughlan and Emma Kirby, 'Palliative Care Environments for Patient, Family and Staff Well-Being: An Ethnographic Study of Non-Standard Design', *BMJ Supportive & Palliative Care* (2021), [bmjspcare-2021-003159](https://doi.org/10.1136/bmjspcare-2021-003159)

## Objectives:

*Undertake*

- To explore and document the conceptual frameworks that underpin contemporary hospice care
- To investigate the current context of hospice care, including the impact of the COVID-19 pandemic, and implications for the spatial and social architectural requirements of hospice buildings
- To undertake a review of the historical origins of the hospice, from 2<sup>nd</sup> millennium BCE to the mid twentieth century, as a building typology and place of care
- To conduct a literature review of current policy that explores the strategic context of hospice care in Wales
- To undertake analysis of the case study setting's physical evolution through planning and design documents.

*Engage*

- To engage with key stakeholders from hospice organisations across Wales and document their perspectives and experiences of co-production, working with architects and the process of commissioning design and construction.
- To engage with the ethical and governance aspects of undertaking research within hospice settings and to critically reflect upon the barriers and enablers encountered
- To document the experience and design agency of multiple members of staff within the case study setting drawing on ethnographic practices

*Reflect*

- To reflect on the nature of architectural practice that influence deep considerations of the requirements of a hospice building
- To undertake observation of the case study hospice setting to interpret how it functions and it is interacted with
- To implement design analysis to explore the infrastructure of care including perspectives of key stakeholders
- To visit and reflect upon one exemplar architectural precedent as a mode of understanding current and international design approaches and practice



## Research context

It has long been recognised that our experience of the environment is inextricably linked to care and well-being. Environments of care have long been a point of sustained interest to the architectural community; with the relationship between our environment and the concept of holistic well-being documented across practice and academia. Roger Ulrich's pioneering study of surgery patients in Pennsylvania Hospital, USA in 1984 was one of the first to provide data supporting the link between the built environment and patient well-being.<sup>33</sup> Ulrich's study revealed that those given a hospital room with a view on trees recovered in faster time and required less pain relief than those assigned a hospital room whose view was a brick wall. This relationship has also become well-recognised by those outside of the architectural profession, noting the general public's aspiration for 'better healthcare facilities'<sup>34</sup> the Conservative Party pledged in their 2019 election manifesto to build forty more hospitals by 2030, which did not transpire. In addition, the focus of the 2021 Wolfson Economic Prize commissioned by Policy Exchange, a UK based think-tank that 'seeks out new ideas and challenges orthodoxies in economic policy-making'<sup>35</sup> was the future of hospital planning and design. Asking entrants<sup>36</sup> 'how would you design and plan new hospitals to radically improve patient experiences, clinical outcomes, staff wellbeing, and integration with wider health and social care?'.<sup>37</sup> The points above highlight that there is a growing awareness at a strategic level into the impact of the built environment on care practices and how this might be tackled. The ongoing impact of the COVID-19 pandemic has furthermore instigated a surge of interest in the shape and design of our healthcare environments. Interviewed by the Architect's Journal, a popular platform in the UK for mainstream architectural journalism, a UK based architect contemplated that:

it was 'almost inconceivable' that hospitals, clinics or GPs' surgeries would remain unchanged by the pandemic... when there is a chance to take a breath, there will be a major rethink of hospital design.<sup>38</sup>

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33 Roger Ulrich, 'View through a Window May Influence Recovery from Surgery', *Science* (New York, N.Y.), 224 (1984), 420-1

34 Robert Ede, *White Elephant or Anchor Institution? It's Time for a Debate on the Future Hospital* (Prospect Magazine, 2021) <<https://www.prospectmagazine.co.uk/politics/white-elephant-or-anchor-institution-its-time-for-a-debate-on-the-future-hospital>> [accessed 14th July]

35 Wolfson Economics Prize and Policy Exchange, 'Wolfson Economic Prize 2021: Guide for Entrants', 2021) p.4

36 Typically, the Wolfson Prize sees entries from design professionals, not limited to architects, but master planners, urban designers, landscape architects etc and often sees multi-disciplinary teams with relevant areas of expertise enter.

37 n.a, Wolfson Prize (Policy Exchange, 2021) <<https://policyexchange.org.uk/wolfsonprize/>> [accessed 7th September]

38 Richard Waite and Greg Pitcher, 'How Will Covid-19 Change the Design of Health Facilities?', *Architect's Journal* (2020), <<https://www.architectsjournal.co.uk/news/how-will-covid-19-change-the-design-of-health-facilities/10047080.article?blocktitle=coronavirus&contentID=25133>> [accessed 1st June 2020]

Whilst the above examples allude to 'healthcare', most research interest is focused on the acute hospital as the primary setting for care. Sarah Russell, former Head of Research at Hospice UK, the national charity for hospice care, in communication with the researcher stated that 'there is a paucity of evidence-based tools and resources in this area...to improve the lives and experiences of dying people'.<sup>39</sup>

It is evident that there is a surplus of architectural research regarding the broad category of 'healthcare' architecture, covering such typologies as hospitals and care developments for the elderly. For example, of the 44 books listed under the 'Health buildings and hospitals' category on the Royal Institute of British Architects official bookshop<sup>40</sup> - there are only two that relate specifically to hospice design.<sup>41</sup> The in-patient hospice as a building type thus sits in a unique position that so far lies largely undocumented in architectural research, with little relevant to future directions of care that has had a measurable impact on architectural practice. This contrasts with the comparative success of *Silver Linings*, a RIBA publication that presented design thinking regarding on the urban fourth age. This publication has become a 'significant touchstone for the UK architectural profession'<sup>42</sup> and has collated a wide literature base for those designing environments of care for older people. However, this is not to say that the in-patient hospice is completely without interest; with a growing number of national and internationally recognised hospice buildings such as the children's hospice by Renzo Piano Building Workshop in Bologna, Italy gaining coverage in the architectural press. Furthermore - and perhaps linked to a heightened awareness of death and dying due to the COVID-19 pandemic - Beebreeders, a company that commissions global architectural competitions<sup>43</sup> recently ran a competition entitled 'Hospice - Home for Terminally Ill', see Fig 1-1. An excerpt from the statement of purpose describes that:

this architecture ideas competition is to design a space in which those facing a terminal illness can go for respite, recuperation, and receive support in whatever form they may need it while they are battling their illness. Hospice – Home for the Terminally Ill would act as a centre where patients can visit daily to get advice,

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<sup>39</sup> Dr Sarah Russell, to Annie Bellamy

<sup>40</sup> Anecdotally, the RIBA bookshop is a well-known resource within the architectural community for literature not only regarding administrative practice (such as contracts and agreements) but also best practice in design.

<sup>41</sup> RIBA, Health buildings and hospitals [Online] Available at < <https://www.ribabookshops.com/books/health-buildings-and-hospitals/010503/> > Accessed 27 June 2019

<sup>42</sup> Annie Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969

<sup>43</sup> It should be noted that these competitions are predominantly ideas based, though some winning entries have gone on to be built.

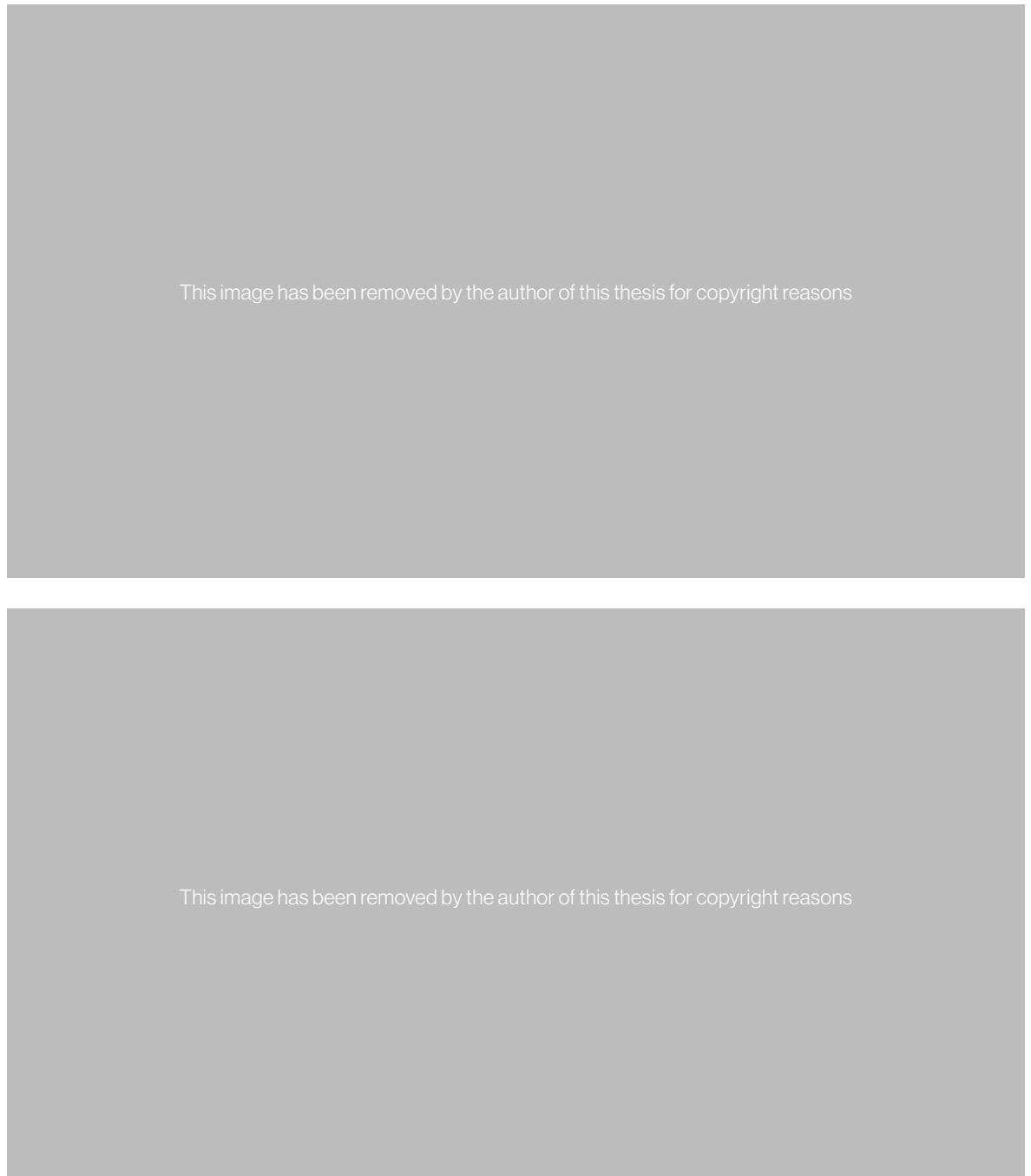


Fig. 1-1 Hospice competition brief

The competition brief published by Beebreeders, an international competition organiser. The brief emphasises language around homeliness rather than clinical care, potentially further confusing the concept of hospice.

guidance, and companionship while they're going through treatment. This competition is a chance for participants to explore how architecture can be used as a tool to help people and demonstrate how architecture can offer psychological relief to those who are suffering.<sup>44</sup>

Whilst we might consider it encouraging to see hospice and hospices reaching a global platform, it is pertinent to note that throughout the brief of the competition, 'home' is a repeated term of reference. This is reflective of the general popularity of the word and concept of 'home' when referencing the architectural aspirations for the hospice environment as an effort to counteract the institutional hospital setting. It is suggested that this a recurrent theme within architecture of palliative and EoLC to frame the perceived 'problem' of these environment. However, without this theme and the resulting design strategies being critically appraised it poses the risk of being misrepresented or superficially applied as an aesthetic finish to buildings rather than a holistic approach to 'homely' design.

## Research motivations

### Personal circumstance

A unique aspect of this thesis is that the researcher occupies not only the identity of an architectural researcher investigating the in-patient hospice, but has personal experience of the in-patient hospice, as a family member of a dying person. Embracing this dual positionality, the researcher seeks to utilise this as a reflexive tool. However, expressing such a close connection to the topic of research is not typically found in academic research, and moreover may not be regarded as contributing value or importance within an academic study. Hockey expands on this stating that personal experience being the driver for academic studies of death all too often results in an 'accusation that the researcher has unfinished business which perhaps should be dealt with via a counsellor'.<sup>45</sup> Traditional models of qualitative research in academia conventionally discourage the use of researcher's own position in their findings and analysis and 'instead encourages defined space between the 'researcher' and the 'field', see Fig 1-2, asserting that the removal of the subjectivity of the researchers' own positionality is evidence of rigour that protects against bias'.<sup>46</sup>

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44 Architecture Competitions, Hospice - Home for the Terminally Ill (2021) <<https://architecturecompetitions.com/hospice/>> [accessed 1st July]

45 Ibid, pg. 439

46 Annie Bellamy, 'The Insider Vs the Outsider: Architectural Investigations of Palliative Care Environments as Both Researcher and Daughter', in AHRA Young Researchers Symposium (Newcastle University 2020) p.2

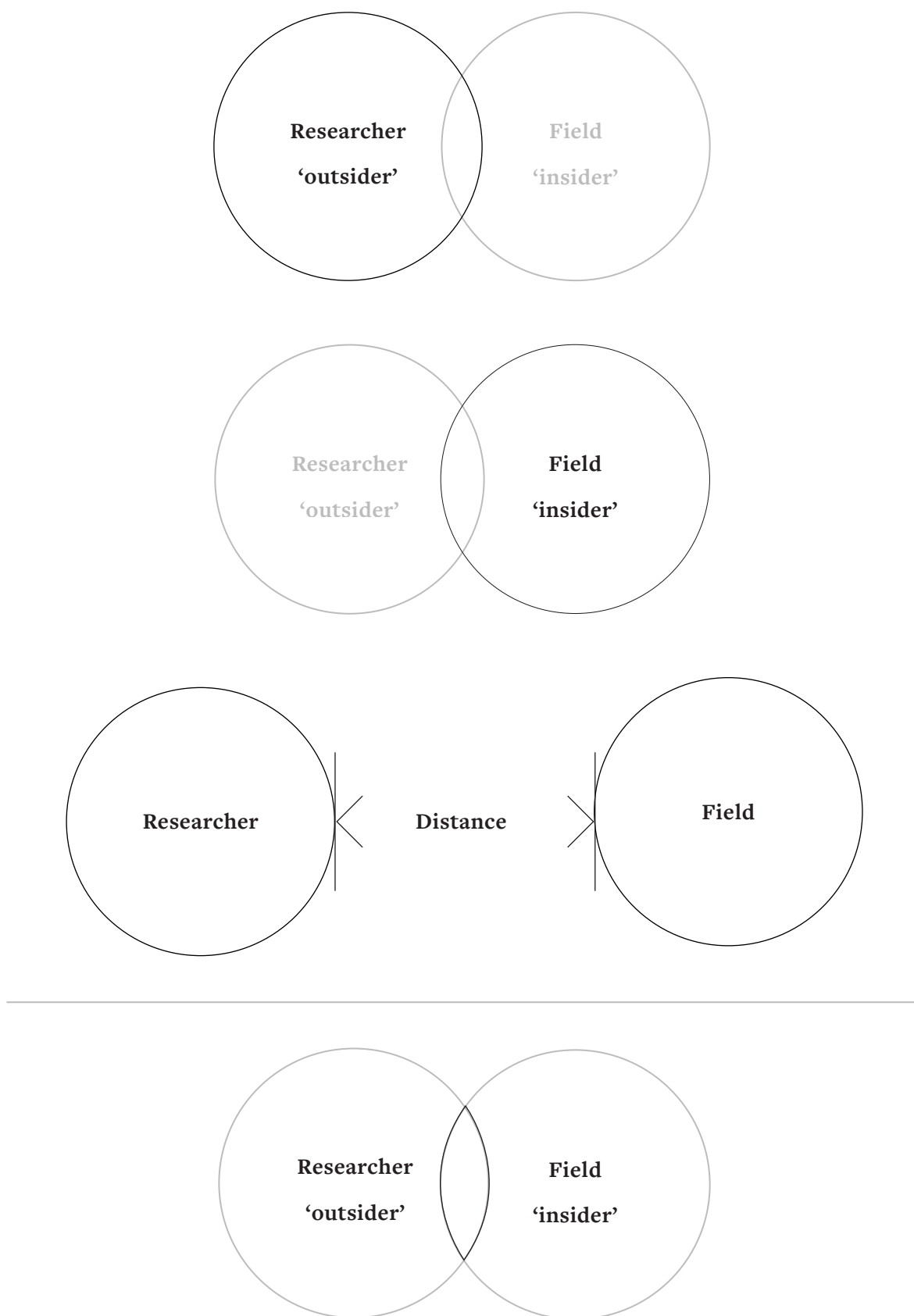


Fig. 1-2 Researcher positionality

The first three diagrams on this page demonstrate the typical relationship between insider and outsider positionalities between a researcher and their field. Traditional academic encourages critical distance between the two to lessen bias, with the researcher as an outsider to the 'inside' field of study. However the researcher of this thesis takes the unique position of intertwining these two worlds as part of a reflexive and reflective approach.

Architects and designers have access to tacit and lived experience of more commonplace building typologies, for example schools or libraries, that helps inform the design process and consequently understand more intimately the specific building requirements of the user. However, unless through a prior bereavement experience, it is unlikely that architects and designers are afforded access to the same tacit knowledge and lived experience of palliative care environments and in-patient hospices. It is vital to acknowledge however, that tacit knowledge is not the sole means of knowledge generation but that the underlying lack of literature and case study analysis in this sector can find benefit in this. It is this combination of lived experience and architectural background that this thesis exploits. By fully engaging with the 'insider' and 'outsider' position firstly it is hoped that this will contribute to a 'theoretical illumination'<sup>47</sup> of an architectural building typology that sits outside common knowledge. Secondly, that the kinship of lived experience might contribute to co-production and therefore the generation of shared understanding between the researcher from an architectural background and the healthcare-based research participants. In the context of this thesis, the researcher is very much in a position of undertaking the research through what Hochschild coined as emotional labour, 'the effort a person invests in expressing or coping with his or her emotions so as to achieve objectives pertaining to his or her work'.<sup>48</sup> Mirroring the conclusion of Emerald and Carpenter, the researcher here sees the emotional labour of this thesis as commitment and ambition to the research; an opportunity to create a discourse on understanding the hospice building rather than merely knowing about it.

## Previous study

This thesis builds upon a previous study undertaken by the researcher as part of the graduate programme of study for the Master of Architecture at the Welsh School of Architecture, Cardiff University. The study was disseminated internationally at the 4S Society for Social Studies Annual Conference in Boston, USA. Entitled *A Place of Mortality*, the study comprised a comparative qualitative study between three in-patient hospice environments investigating the phenomena of 'dwelling' within the hospice environments and formed a contextual background to this study. Three case studies were explored using different ethnographic research methodologies to investigate the lived experience of the environments. The first was a hospice in an urban setting that employed

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<sup>47</sup> Karp, D. (2016). *Speaking of Sadness*. Oxford University Press.

<sup>48</sup> Nutov, Liora & Hazzan, Orit. (2011). Feeling the Doctorate: Is Doctoral Research that Studies the Emotional Labor of Doctoral Students Possible?. *International Journal of Doctoral Studies*. 6. 019-032. 10.28945/1354.

auto-ethnography, the second a hospice in a suburban location that interviewed volunteers, the third being in a rural setting which was investigated via a desktop study and a walking interview with the architect. The study identified co-production as a concept critical to the production of in-patient hospice space. As noted by a key member of staff of the rural hospice - 'building a new hospice is not a vision in itself. What is visionary is what our new premises will mean for patient care and support.'<sup>49</sup> The involvement of the care team of the hospice, from staff, volunteers to local community members through steering groups mapped against stages within RIBA's Plan of Work enabled the architects to draw on the expertise of the clients and users.

## Scope and focus

The focus of this doctoral study is the in-patient hospice; here defined as the environment that provides care for those with terminal illnesses for respite and end of life care. In investigating the in-patient environment as a building typology devoted to EoLC, its position as one of many, perhaps infinite, places of death must be acknowledged. The in-patient unit sits within a much wider field of what James A. Sidaway describes as 'death-scapes'<sup>50</sup>. The in-patient unit provides a place of death for a distinct population of dying persons; those that are actively receiving EoLC as part of a care pathway. The in-patient hospice does not provide a place of death for those involved in unpredicted accidents, tragedies, or violence. The researcher has defined limitations to the scope of this thesis by setting parameters to the building type, the location of the research and the proposed research participant. As outlined above, the attention of this thesis is the in-patient hospice, and this therefore excludes day hospice facilities and Maggie's Centres. Day hospice facilities deliver vital community-based palliative care and serve as important centres for those suffering from terminal illnesses to access care services that may not necessitate visits to larger medical facilities, for example lymphoedema treatments or to see a nutritionist. Many day hospices occupy the same buildings as in-patient units; however, these will not be included within the scope of this research as they do not constitute places of residential care. Similarly, Maggie's Centre's - a UK initiated charity that commissions and runs centres internationally that provide day-care (but not home visits) for those diagnosed with cancer - will not be included for the same reasons. However, the researcher acknowledges the relative importance of Maggie's Centre's in the discussion of

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49 Jessica Taylor, A Fresh Approach To Palliative Care – Sustainable Design (Housing Learning and Improvement Network, 2015) <[http://www.housinglin.org.uk/\\_library/Resources/Housing/Practice\\_examples/Housing\\_LIN\\_case\\_studies/HLIN\\_CaseStudy\\_109\\_SustainableHospice.pdf](http://www.housinglin.org.uk/_library/Resources/Housing/Practice_examples/Housing_LIN_case_studies/HLIN_CaseStudy_109_SustainableHospice.pdf)> [accessed 18 September 2016] pg.1

50 Avril Maddrell and James D. Sidaway, *Deathscapes: Spaces for Death, Dying, Mourning and Remembrance*, 2016)

architecture in support of EoLC, as they have 'steadily become the 'go-to' reference for designers involved with places for death and dying'.<sup>51</sup> Though they will not be discussed in detail and are not a clear comparison to the in-patient hospice, the architectural approach will be discussed in Chapter 3 as part of a dialogue on the development of the in-patient hospice building typology.

In its geographical context, the research project's scope is defined by basing the fieldwork and case study within hospice settings in Wales, referencing information from the broader context of the United Kingdom where necessary. Wales was identified as a convenience sample owing to its forward-thinking approach to EoLC and palliative care and variety of available provision that captures a cross-section of Welsh society. The choice of the case study setting, the Cardiff and Vale Hospice was determined because of the relative lack of other EoLC provisions in the region and the spectrum of deprived and affluent areas served by its catchment area. Though the data will be from a single country, in being reviewed against the proposed future of hospice care this thesis seeks to disseminate findings that are relevant to architects and designers from international audiences. The original scope of the research project was to involve multiple hospice sites as part of the fieldwork, however due to logistics, the required ethical procedures, and the need for repeated visits it was decided that the fieldwork would be divided into two workstreams: the first being a series of scoping visits to hospices that were able to facilitate the meeting, the second being an in-depth study of a single hospice. All facilities offering in-patient care in Wales were eligible to be part of the scoping visits, with the convenience sample further defined by their availability to take part. At the time, two of the six hospices were undergoing major renovation works and were not open. The remaining three located in the university health boards (UHB's) to the north, west and east of Wales were willing to participate.

The second stage of fieldwork, an in-depth study of a hospice building identified purposively, owing to its geographical closeness in reasonable proximity to the researcher making the necessary repeated visits viable. This was furthermore chosen owing to the professional relationship of the research supervisor as a key member of staff who was able to contribute to the practical organisation of the fieldwork. However, it is necessary to here emphasise that the case study chosen is not regarded as an exemplar of architectural design for palliative and EoLC. As the aim of this thesis is to not comment on the outcomes of design, but rather the practice of architecture

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<sup>51</sup> Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969, p.4



regarding the in-patient hospice – it is not the scope of the study to assume a position of design authority on what constitutes 'good' or 'bad' design. Rather, as the fabric of the hospice case study chosen is typical of many hospices in the UK – that is, built around the late twentieth century and has seen alterations to this over time allows the researcher to explore the day-to-day reality of a more standard hospice environment in comparison to an exemplar built to current standards of regulation and design expectations. Furthermore, the inclusion of a singular case study affords the researcher generosity of time to invest in forming relationships, understanding processes and familiarity with the hospice building – the researcher acknowledges that care must be taken to not overly generalise findings as fully representative of hospice care.

Lastly, the final parameter for focus within the thesis are the user groups that the researcher engaged with as research participants for data collection. The initial research proposal sought to engage with three user groups, staff, patients, and visitors to develop a rounded picture of day to day lived experience. However, ethical challenges precluded patients and their visitors from participating. Whilst this means that their voices remain silent in this thesis – there are moments of auto-ethnographic reflexivity by the researcher that offers an insider perspective on the hospice environment. The researcher would like to clarify that this is only used where suitable to not misappropriate their subjective experience. The focus therefore of this thesis are the staff members of the hospice facility, vital to the concept of co-production being explored. In seeking conversations with those that provide care, the researcher has been clear in recruiting staff members with a variety of roles and responsibility, such as housekeeping and maintenance and is not limited those who only those who provide clinical care.

## Methods

Troiani and others write 'it is architecture's very situatedness that makes it such a porous discipline, one with blurred edges, open to all that surrounds it'.<sup>52</sup> As an inter-disciplinary piece of research, the thesis utilises a mixed-method approach with qualitative methods that embrace research methods from both architectural design and health and social science aims to create discourse between the two fields of architecture and healthcare using principle of co-production. Expanded analysis of the methods used can be found in subsequent chapters discussing the fieldwork.

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<sup>52</sup> Troiani and others, 'Architecture and Culture: Architecture's Disciplinarity', *Architecture and Culture*, 1.1 (2013), 6-19

The inter-disciplinary approach takes heed from principles of co-production in the generation of shared understanding. Martin and others, summarise the methods of anthropologists Tim Ingold and Sarah Pink, as approaches that:

urges researchers to not only produce 'thick description' but also work collaboratively with study participants to co-produce knowledge. This is a methodological approach used in recent studies on building construction to make visible the 'spaces and practices of work that are otherwise hidden' This 'co-production research', 'where researchers and practitioners generate new knowledge together', draws together the different ways of knowing of those involved in the design and construction of buildings<sup>53</sup>

The holistic approach to the design of the thesis research falls within the remit of practice-led research. In a comprehensive review, Mottram and others somewhat broadly, defined this as 'research in which the professional and/or creative practices of art, design or architecture play an instrumental part in an inquiry'.<sup>54</sup> However, it is critical to note that practice-led research as broadly defined above should not be misinterpreted as being in and of itself a research method or methodology. Instead, the acknowledgement of, in the case of this thesis, architecturally related practice, is a means that contributes to the research process and question.<sup>55</sup> A more refined definition of practice-led research by Linda Candy, author of the *Creative Reflective Practitioner*, states that practice-led research is:

concerned with the nature of practice and lead[ing] to new knowledge that has operational significance for that practice...the primary focus of the research is to advance knowledge about practice, or to advance knowledge within practice.<sup>56</sup>

This thesis does not set out to find or suggest innovative design solutions in response to palliative and EoLC but rather seeks to invest time in understanding rich meanings of how the hospice building and the expertise of its inhabitants might contribute to the practice of their design. We might consider that there is a distinct gap between professional and academic practice in architecture, sometimes with little dialogue occurring between the two sides. Practice-led research, that is the

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53 Daryl Martin and others, 'Architecture and Health Care: A Place for Sociology', *Sociology of health & illness*, 37 (2015), p.9

54 J. Mottram and others, 'Ahrc Research Review: Practice-Led Research in Art, Design and Architecture', (2007) p.11

55 Ibid. p.11

56 Linda Candy, 'Practice Based Research: A Guide' (2006) <<https://www.creativityandcognition.com/resources/PBR%20Guide-1.1-2006.pdf>> [Accessed 17 May 2018]

generation of new understandings, relationships or modes of 'practice' offers a potential route to bridge the perceived gap that can enrich the 'socio-cultural context'<sup>57</sup> of the hospice building for architects. It is hoped that this approach and the research methods used will culminate in what eminent cultural historian Christopher Frayling describes as 'action research...where the action is calculated to generate and validate new knowledge or understanding'<sup>58</sup> that is both 'into' and 'for' design.

In response to the practice-led approach of this thesis, it is proposed that methods typically used in ethnography will be used to uncover the day-to-day and lived experience of the research participants; as Pallasmaa summarises Eileen Gray's description of the 'minute situations of daily life'.<sup>59</sup> Ethnography, a well-established methodology finds its origins in anthropology, and has seen its application in many other disciplines such as sociology, human geography, organization studies, educational research, and cultural studies<sup>60</sup> and is seeing increased application within the field of architecture. Sarah Pink, an eminent design anthropologist, explains ethnography is not a method of collecting data but rather:

a process of creating and representing knowledge (about society, culture and individuals) that is based on ethnographers' own experiences. It does not claim to produce an objective or 'truthful' account of reality but should aim to offer versions of ethnographers' experiences of reality that are as loyal as possible to the context, negotiations and intersubjectivities through which knowledge was produced. This may entail reflexive, collaborative, or participatory methods. It may involve informants in a variety of ways at different points of the research and representational stages of the project. It should account not only for the observable, recordable realities that may be translated into written notes and text, but also for objects, visual images, the immaterial, and the sensory nature of human experience and knowledge.<sup>61</sup>

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57 Leon Anderson, 'Analytic Autoethnography', *Journal of Contemporary Ethnography*, 35.4 (2006), 373-95, pp.390

58 Christopher Frayling, *Royal College of Art Research Papers 1993/4: Research in Art and Design*. 1 vols. Vol. 1 (London: Royal College of Art, 1993).

59 Juhani Pallasmaa, *The Eyes Of The Skin: Architecture And The Senses* (Wiley, 2012) pg. 62

60 Wang and Groat, *Architectural Research Methods*, Second edn (New Jersey: Wiley & Sons, 2013) p.224

61 Sarah Pink, *Doing Visual Ethnography*, 3rd edition. edn (Los Angeles, Calif. London: Los Angeles, California : SAGE, 2013)

This methodology, in combination with the researchers own insider/outsider positionality draws inspiration from the work of Atul Gawande, a surgeon, writer and public health leader and author of the seminal *Being Mortal: Medicine and what matters in the end* – a highly reflective account of both his professional and personal experiences of ageing and death. The book, sits in between non-fiction and research, written in an academic yet accessible tone creating unique insights on the topic. Building upon this idea, this thesis, in parts will bring the researcher into focus as a practitioner surrounded by key stakeholders of the field that 'asks why a person is doing something, and then what that action means in the group's larger system of meanings'.<sup>62</sup> This is achieved by the introduction of fragments of work that the researcher has titled 'practice notes' that are interposed between each of the parts. These practice notes are curated excerpts of related practice-led research activities undertaken in support of the primary fieldwork. The intercepting sections privilege visual material and document 'extra-curricular' moments from the research process and journey. As episodes of applied practice-led research they demonstrate engagement of the researcher with outsider or non-typical research activities, such as documenting informal visits to sites of interest.

They provide a space for supporting work - such as an auto-ethnographic account and a site visit to an architectural precedent - to fit within the narrative of the thesis. By removing the content outside the main body of the thesis, they work by overlapping the knowledge and data presented as a reflexive and reflective practice, encouraging a back-and-forth dialogue between the unique insider and outside position and perspective of the researcher. These include an auto-ethnographic exploration demonstrated using non-standard architectural 'sketches' that do not follow orthographic principles with the freehand quality stressing the 'remembered' and subjective quality of environment and experience; the documentation of model-making, as a typical tool in architectural representation to encourage a re-imagining of spaces for research participants; a field visit to an architectural exemplar is examined via fieldnotes capturing the phenomenological experience and a collation of documents that highlight the relationships fostered with EoLC and palliative care professionals in support of the study.

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62 Galen Cranz, *Ethnography for Designers*, 2016) p.5

## Structure

The thesis diverts from the traditional academic structure of a separate and distinct literature review that is used as the opening dialogue and contextualisation of the research. As the research draws upon different fields, relevant literature is instead used thematically throughout the individual chapters, engaging with the different scales and areas of research. The thesis structure has been designed such that it acts by 'zooming' in on its context, building upon the literature and data of the last, to inform the next. Furthermore, the thesis has been organised into three parts; the first explores the context of care with a view on design, the second presents the case study and fieldwork, before concluding with the third and final part that undertakes elements of design analysis. Following on from the methods and broad structure outlined above, the thesis is structured as follows:

- Chapter 1 provides an overview to the research and its context, and set outs key aims and objectives, methods, and structure
- Practice Note 1 documents the insider positionality of the researcher as one with personal experience of the hospice environment.

### *Part One:*

Chapter 2 presents a commentary on the concept of hospice. The chapter explores the historical origins of the hospice movement, before presenting the status of hospice through the frameworks of EoLC and palliative care with regards to contemporary attitudes and approaches to death and dying. This chapter will discuss potential future issues that hospice may face and will begin to detail the landscape of hospice care in Wales. Chapter 3 is an in-depth investigation into the in-patient hospice as a fundamentally unique architectural typology and moves the discussion to the realm of the built environment and architecture. The analysis of typology consists of a historical study of the origins of hospice buildings, an overview of current functions and occupants and a literature review of available design guidance and precedent.

- Practice Note 2 offers insights into how architectural models were utilised as research tools during the fieldwork

*Part Two:*

Chapter 4 shifts the focus to the primary fieldwork of the thesis. Exploring the regional context of hospice care, this chapter presents scoping visits to in-patient hospices located in three health boards in the north, west and east of Wales. Taking the form of walking interviews these visits provided a contextual background to the approach and role of architecture and design in hospice organisations prior to the primary case study discussion. Chapter 5 covers the main case study and fieldwork of the thesis. Dyad interviews are presented as five research encounters with members of staff with differing roles that detail the organisational and lived experience of the hospice building case study. In each research encounter themes relating to the built environment and the commissioning and delivery of architectural design are discussed, highlighting aspects of co-production.

- Practice Note 3 documents a visit to a hospice building in Denmark and discusses the importance of field visits in understanding architectural precedent

*Part Three:*

Chapter 6 considers the case study setting as a built environment and reflects on the 'designerly' changes that have been made. The planning history of the case study setting is presented before moving into an analysis of three recent design changes of varying scales; that considers the way in which change occurs and is organised by the members of staff. Chapter 7 shifts the narrative of the thesis towards a consideration of the in-patient hospice as a field of study and the difficulties this posed toward architectural practice and research. Here we discuss the process of entering the hospice, the challenges faced and the implications for undertaking inter-disciplinary research.

- Practice Note 4 discusses the involvement of the researcher with the broader hospice community and healthcare professionals

Chapter 8 concludes the thesis, presenting the research findings, statement of originality and possibilities for further research.

# Practice Note 1

## Drawing the ‘insider’

As the first in the series of practice notes interspersed throughout the thesis, here the researcher documents and presents their persona insider positionality through a series of informal sketches and non-orthographic drawings. This visual catalogue details their personal experience of the hospice environment with their mum, Jen.

Home, for the 13 years that Jen was ill, was a sanctuary and a safe place for our entire family. It was a place that had seen our family grow up in but had also overseen the arc of her illness. As Jen's illness developed, foreign travel became increasingly complicated and my parents invested in the home, one such change was the upgrading of floor finishes from carpet to engineered timber to reduce allergens and cleaning time. As the visits from the community nurses increased, a key-box appeared under our house number by the front door, the lampshade in our dining room became a makeshift IV drip holder, and the hum of the oxygen tank became background noise. Yet despite these small nods to the more clinical interventions needed by Jen, the house remained the ideal. Even as the illness took a further grip on her mobility and triggered more frequent stays in the hospital, she would always want to be at home.

I am close to the topic of my research in many ways, but none perhaps are more important and motivating than the personal connections I have to the unique field of my studies. My experience with the hospice is one that I will never forget - and one that I feel a peculiar responsibility toward. I know very few, if any of my peers who have experienced the hospice first-hand, and to be able to share the experience with others feels like a bizarre privilege. Though my personal experience of the hospice is not directly presented within the thesis, my insights and reflections are a part of my positionality as an architectural designer undertaking a PhD in the same field. My experience, is of course thoroughly subjective, and is the result of my family's social and spatial context. In spite of this subjectivity - and by objectively recognising it, an analytical auto-ethnographic approach to the supportive work behind the scenes of the formal research process allowed me to find a place within the academic context of this thesis to be authentically reflexive on my personal and professional experiences.

It is hoped the following pages, laid out in an almost archeological manner, will shed light on the work undertaken in support of understanding the context and built environment of the in-patient hospice and the insider status of myself as the researcher of this thesis. The work relating to my own experiences do not accurately replicate the psychical built environment but rather highlight the phenomenological impression and atmosphere of certain areas. Furniture, perspectives and textures are emphasised in order to 'to take us somewhere we couldn't otherwise go to'[1]. These recordings of memories are captured in a purposefully loose hand-drawn manner to emphasise their bias, and unreliability as formal research objects. This application of auto-ethnography in essence acts as what Schwalbe describes as a 'a doorway and a mirror'[2] providing a method for me to consider my insider and outsider status.



Legend:

[1]  
My current dining room table, and the third that has seen me scribble, write, procrastinate and reflect during my doctoral studies. This table, set apart from the desk in my flat and the office I used on campus became a vitally important and much needed space ‘away’ for me to put aside my formal researcher headspace and take time to consider my own personal and emotional place in the research process. This physical space enabled me to not compartmentalise my insider status and accept that it bore influence not only on my perspective but the formal processes of research.

[2]  
The sketchbook shown here was a formative companion during the early formative years of my doctoral studies - acting as my aide-mémoire for ideas, quotes, fieldnotes, and reflections on the topic, aims and objectives of the research. Sketchbooks have always been a companion to my research and studies, for my MArch dissertation I used one in a similar but more emotive manner, used as a place to record lengthy personal reflections that were unseen by my supervisor. From this I would skim to try and find relevant architectural anecdotes that could be used in an academic setting.

[3]  
Work in progress sketches, model ideas - early on in the process I spent time exploring ways in which I could describe my experience and the experience of hospice buildings in three-dimensions. This sketch in particular was the first experimenting with an idea of making maquettes similar to the Viewmaster childrens toy that encourages you to bring the viewfinder up to your eyes to mimic the sightlines of patients. [These models would subsequently become instrumental in conversations with laypersons as explored in the second Practice Note.]

[4]  
Notes from the ‘4S Society for Social Studies of Science’ conference I attended to present a paper adapted from my MArch dissertation. This was my first experience of an academic event and taught me the importance of developing myself a community of practice, of others who are interested in areas that touch upon death and dying.

[5]  
Amongst other things, such as my sketchbook, coffee has been a constant companion throughout my doctoral studies - giving me time and space to step away from my work and reflect.

[6]  
This sketch, one of many, done in the first year of studies, are my personal explorations of capturing and recording moments from my memories of both the hospice Jen died in and our family home noting the differences between their environments. These sketches driven by my memory are a form of fieldnote, with their looseness helping to distinguish the emotive insider perspective from the formal outsider. This sketch captures the essence of the view from Jen’s bed in the family home, showing a connection to the world beyond.

[7]  
The collection of these drawings is made visible by the bulldog clips - these drawings elicited aspects of my insider status that could help inform my research - but needed to be censored for their relevance to the thesis. As number [6] this sketch is of the approach and threshold to Jen’s bedroom within the family house from a double height space that connected to the dining room below offering Jen a means of connection to everyday family life.

[8]  
Memories of a communal seating area at the hospice where Jen was. Situated by the reception desk, the main entrance, and opposite the chaplain’s office - this area offered no privacy, for ourselves or other visitors, and I remember an intense feeling of alienation and guilt at being present during sensitive times for other visitors.

[9]  
The corridor of the hospice, arranged around a central courtyard, felt off-limits, the window sills were too high for patients in beds or wheelchairs to see out of. The homogenous material palette and strip lighting elongated the corridor, making it seem repetitive and disorientating.

[10]  
Reflecting on the threshold between the corridor and Jen’s room at the hospice, it felt like a room of it’s own, the tiniest buffer between the open and public corridor and the privacy of the bedroom. I retreated to this space when I couldn’t manage being in the room - but this was at the expense of my visibility to others.

[11]  
Shown here, are the contrasting depictions of Jen’s bedroom at home, and at the hospice. One showing the multiple long and short distance views and connection to the rest of the home - and the other showing a direct view onto another patient bed and the suspended ceiling tiles, her final tableau.





Legend:

[1]  
Our dining table, in addition to offering personal space away from the formal research process, was also the background to endless reflective conversations with my partner. Though close to the research in as much he was witness to my process as an architectural practitioner himself, he acted as a critical voice - questioning me on his perspective of design in practice.

[2] + [3]  
Following on from the memory sketches, I undertook exercises of considering the spaces of the family home and the hospice using more pragmatic approaches tracing over surveyed orthographic plans. Identifying for example where in the family home clinical interventions were made and their implications on the experience and inhabitation of space. These included the potential retro-fitting of a stairlift to a corner staircase and the mechanics of housing an oxygen machine in a domestic environment.

[4]  
Continuing on from measured sketches, digitally drawn plans helped to convey a sense of formality to understand the physical dimensions and environmental aspects of the spaces, such as orientation. Moving into the realm of precision as implied by CAD drawings turns these exercises into a form of spatial analysis as an architectural designer and researcher - moving on from the implicit and subjective experience of myself as a daughter as seen in the sketches. These drawings went through a few iterations to suggest different features of the rooms. This drawing was an attempt to photoshop on the materiality of Jen's bedroom at the hospice - though accurately depicting the uniform vinyl flooring the resulting drawing was clunky and awkward.

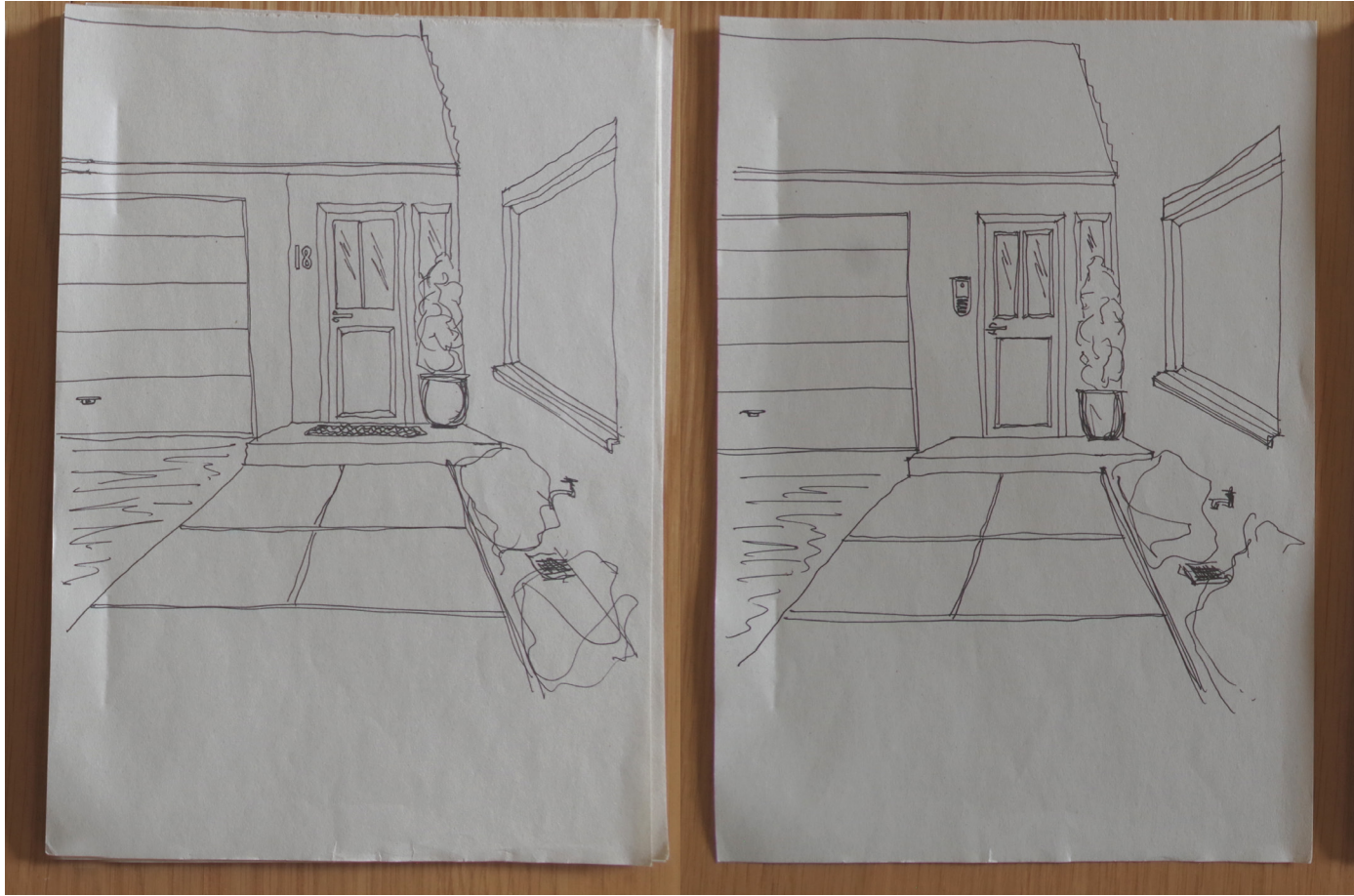
[5]  
The piles of tracing paper here are the remnants of all the different drawing exercises and experiments collected over the course of the period of study. Much work was done 'behind the scenes' that whilst was not abortive, was supportive work to the formal research processes that was not intended to feature directly in the thesis. Perhaps it could be considered as thoughts out loud, a way of conceptualising and positioning myself physically as an insider whilst moving externally as an outsider.

[6]  
The before and after of my family home's front door - with one simple change. The introduction of a key lock box so that external visitors to the house could get in. It's a small but powerful memory that I carry with me that captures a feeling of the clinical encroaching on the domestic - but a wider sense of the role of hospice care and those that care for those at the end of their lives.





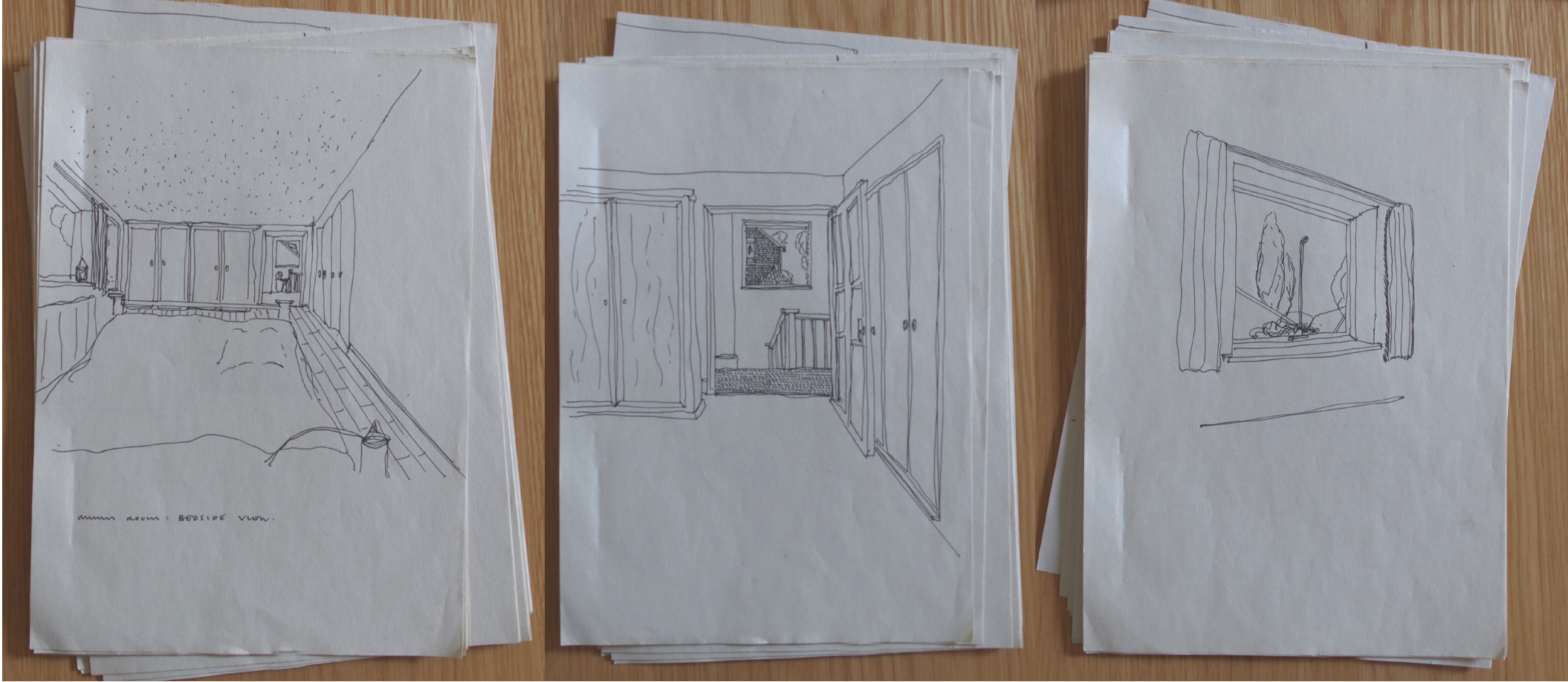
[at home]



[1] These drawings with only a slight difference, highlights a creeping clinical influence to the domestic environment of the researcher’s childhood home as outside healthcare professionals needed access to the home. Small changes could have considerable impact on the sub-conscious atmosphere and experience of the ‘home’.

FOLD HERE

[at home]

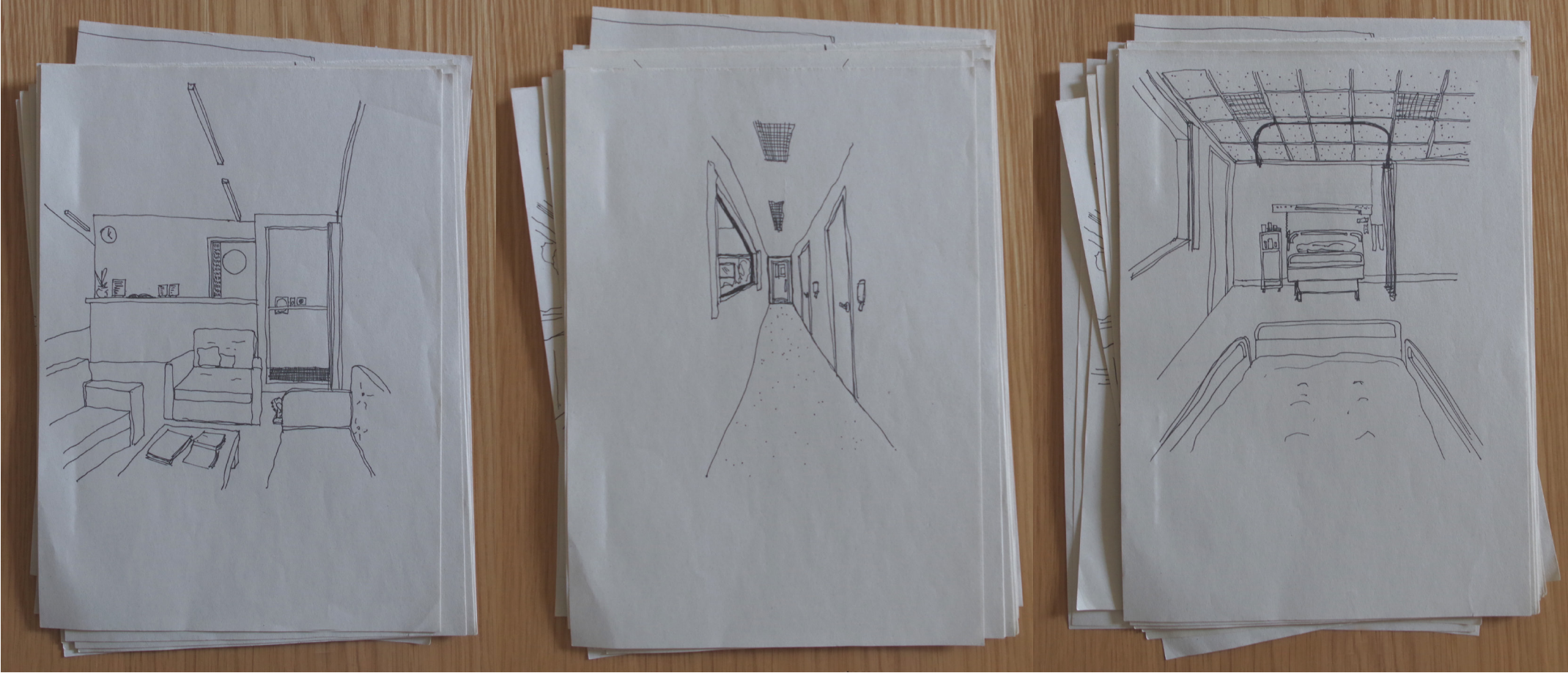


[2] The view from Jen’s bed, with two visible windows provided a choice of view, short and long distance. The drawing above tries to capture the textural quality of the materiality of the room, the timber floor and swirling Artex ceiling.

[3] Jen’s connection to the rest of the home was enabled by the threshold of the room that opened up to the double height void over the staircase that connected to the dining room below. The threshold additionally framed a long distance view out over the neighbours house and garden beyond.

FOLD HERE

[at the hospice]



[5] The threshold of the entrance to the hospice doubled as the reception space and a communal sitting area. Adjacent to the chaplains office and the quiet room - sitting here I felt like an imposter, often too close to other visitors or families in the space.

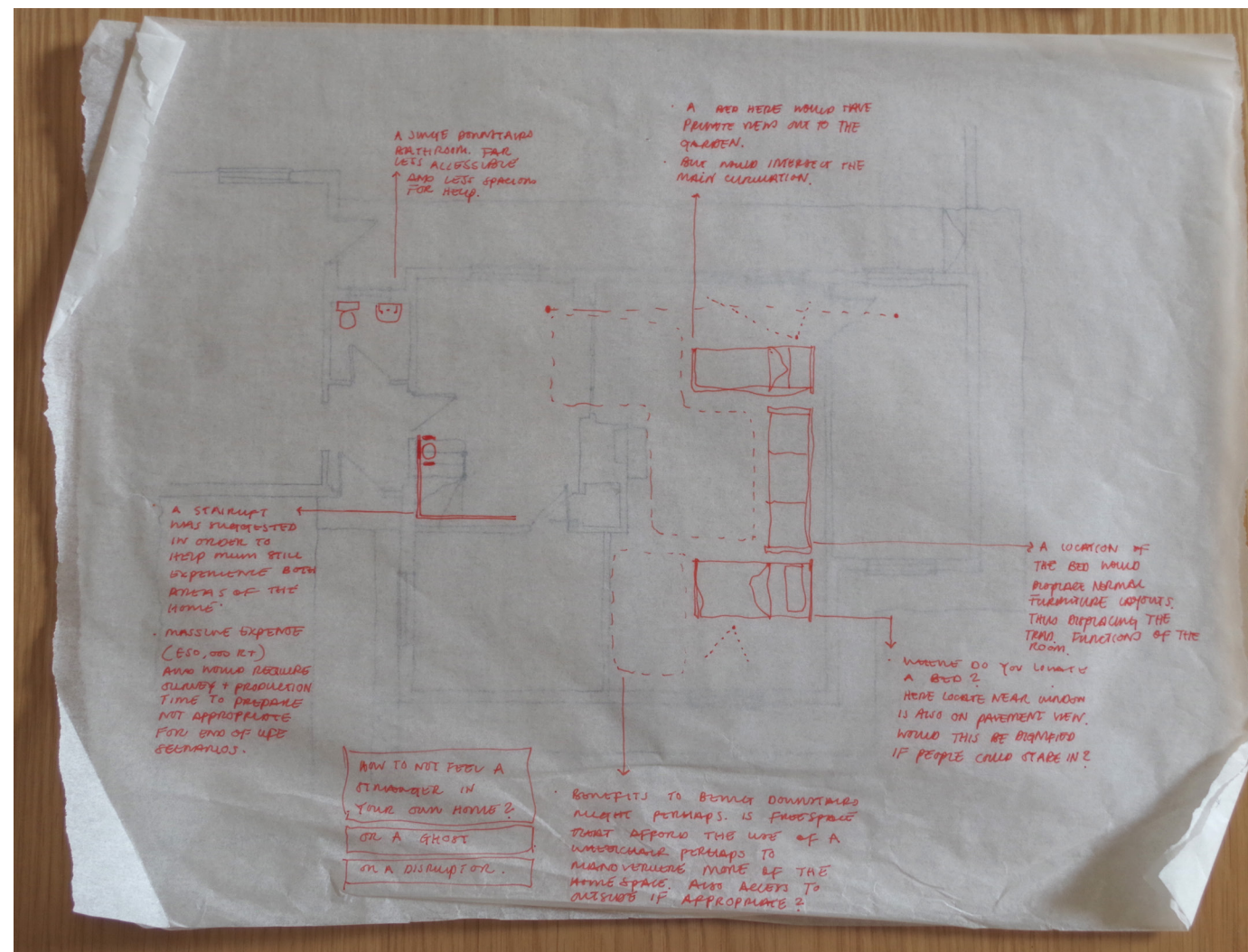
[6] One of the main corridors within the hospice, was a long horseshoe shape, tucking in around the edges of the courtyard. As I walked round and round, it stretched out in front of me with anonymous doors, and windows that I noted would be too high to see out of if in a bed or wheelchair.

[7] A contrasting tableau to that of the view from Jen’s bedroom at home, one of the pockmarked suspended ceiling, blue anti-bacterial curtain, and a direct view of the, luckily vacant, bed opposite. The almost full width window was low enough to see out of, and a bird table was quickly filled with bird feed to encourage birds to visit.

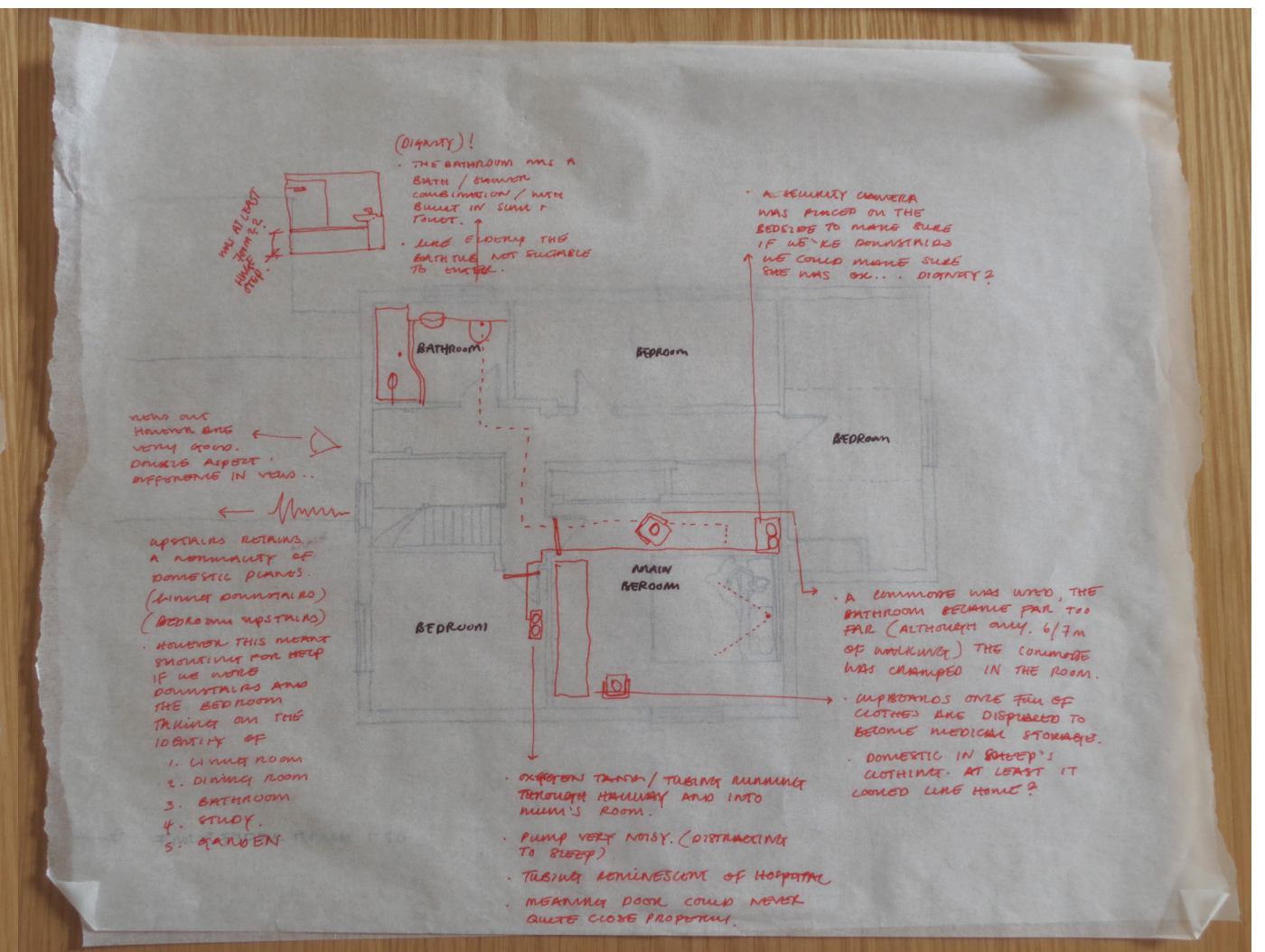
FOLD HERE



[ground floor at home]



[first floor at home]



Exploring the existing spatial arrangements of the ground floor and the potential implications of further clinical interventions that may have been necessary to facilitate staying at home as Jen's illness progressed. In order to maintain a connection to the rest of the home and to ensure that experience of the home isn't restricted to only the ground floor, a stairlift was discussed, though this still required a level of mobility.

On the first floor, various other factors came into play regarding dignity and access. A key aspect was easy access to the bathroom, and the use of a commode in the bedroom, reducing the domestic experience and atmosphere. Another change to the sleeping area was the introduction of an oxygen machine, kept in another bedroom to reduce disruption for Jen, though this caused disruption to the family member sleeping in that room.

Despite the collection of work on the previous pages appearing only in this practice note and not directly in the body of thesis - the process of auto-ethnography used in the formative stages of my research encouraged me to practice a reflexive sensibility moving forward. As the research focus moved away from a purely phenomenological investigation to an inquiry of the organisational experiences of the in-patient hospice the role of an auto-ethnographic approach became less relevant. That is not to say this early work contextualising my positionality was abortive; rather, consciously deciding to utilise my positionality afforded me positive opportunities to assist in gaining access to the in-patient hospice and establishing kinship with potential research participants.

Furthermore, it is hoped that my closeness to the subject provides an opportunity for 'enriching the understanding for other architectural practitioners of a building typology who few may have direct experience of'.<sup>[3]</sup> Tacit knowledge of environments plays a critical role in an architects design process, being able to quickly draw on their own experiences of space to assist in informing their design decisions. The more specialised the building type, the less scope there may be for architects to have held that personal connection in understanding the physicality and phenomenological experience.

It is important to note, however, that this form of tacit knowledge or personal connection certainly can be helpful to exploit, it is crucially not a 'silver bullet' procluding those without this experience in designing specific building types. The role of an architect is to be subjective, to make sense of and respond to the experience of end users - tacit knowledge should not be used to place singular personal experiences above anything else. Rather it could be seen as an additional tool that could help equip empathetic approaches by exchanging knowledge with others and opening honest channels of discussion to encourage collaboration and co-production.

## Endnotes

1 Ruth Behar, *The Vulnerable Observer : Anthropology That Breaks Your Heart*. ed. by Viet Nguyen-Gillham (Boston: Boston : Beacon Press, 1996), p.14

2 Michael Schwalbe, 'The Mirrors in Mens Faces', *Journal of Contemporary Ethnography*, 25.1 (1996), 58-82, p.58

3 Annie Bellamy, 'The Insider Vs the Outsider: Architectural Investigations of Palliative Care Environments as Both Researcher and Daughter', in *AHRA Young Researchers Symposium* (Newcastle University 2020)

## 2

### Hospice as a concept

This chapter outlines the complex and often misunderstood term of ‘hospice’, whether as a conceptual framework of care or the colloquial term for a building. Here we will explore the origins and evolution of the concept of hospice and before moving to consider the current landscape of death and dying, the influence of over-medicalisation and a discussion on who now uses hospice. This is followed by an investigation into the contextual background of EoLC and palliative care within the environmental, social, and political context of Wales, the focus of this study.



## Hospice

The use of 'hospice' can be first traced back historically as a linguistic term and concept originating from the times of the Roman empire. The word finds root in the Latin term 'hospes' meaning 'a friend, one bound by ties of hospitality'<sup>63</sup> and 'with a host's politeness'<sup>64</sup> – or more simply put 'guest' and 'host'. The term was used to describe the act and associated social rituals of hosting guests or strangers. It ascribes 'politeness' within the act itself suggesting an implicit act of caring and generosity; given by one, to the other. 'Hospes' is correspondingly the same root term for the contemporary word, hospital, which emerged from the Latin term 'hospitium'.<sup>65</sup> This term represents the common ancient shared Greco-Roman concept of 'hospitality', a notion that describes an ancient form of caregiving and care-receiving - which eventually grew to convey the explicit 'place' where this was experienced.<sup>66</sup> The etymological core of our contemporary understanding of the term 'hospice' can thus be seen as having grown out of a basic human act of providing shelter, food and entertainment – perhaps an early reference to contemporary concepts of holistic care.

Hospice as a place seeks to provide care for those with terminal and or life-limiting illnesses, looking after well-being and aiming to improve quality of life. It also lends its name to the colloquial term for the building type dedicated to providing this unique form of care. The contemporary concept of hospice is now understood as a broad programme of care. HospiceUK states that it:

can be provided at any stage of a person's condition, not just at the end of their lives. It can include symptom management, and social, practical, emotional and spiritual support. It helps people live as fully and as well as they can to the end of their lives, however long that may be.<sup>67</sup>

As a key term of reference, however, hospice has developed significantly since the modern movement found traction in the twentieth century, see Fig. 2-1 to explain this in more depth.

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63 T Charlton Lewis, *An Elementary Latin Dictionary: Hospes* (n.d) <<http://www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.04.0060%3Aentry%3Dhospes>> [accessed 9th July]

64 Ibid.

65 Collins Dictionary, *Hospitium* (Collins Dictionary, n.d) <<https://www.collinsdictionary.com/dictionary/english/hospitium>> [accessed 9th July]

66 Grace Goldin, 'A Protophospice at the Turn of the Century: St. Luke's House, London, from 1893 to 1921', *Journal of the History of Medicine and Allied Sciences*, XXXVI.4 (1981), 383-415, pg.386

67 HospiceUK, *What Is Hospice Care?* (HospiceUK, n.d) <<https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care>> [accessed 23rd August]

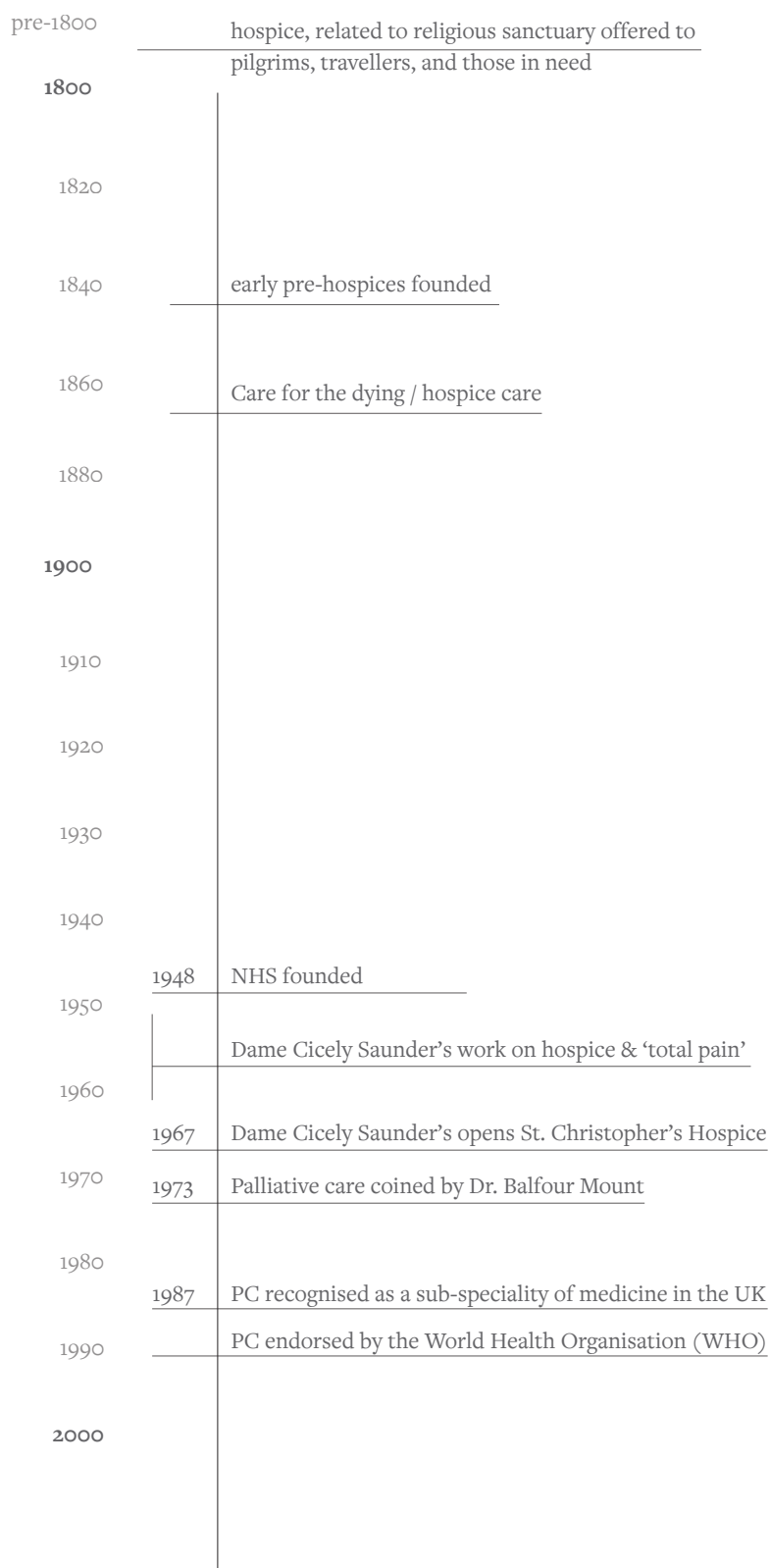


Fig. 2-1 Terms of reference timeline

The timeline above describes the evolution of critical terms of reference within the field of death and dying. The timeline describes how much of the language used by this sector is relatively young, and has only developed in the latter half of the 20th century. Missing from the time is the key term, end of life care, EoLC. There is no defined point as to when EoLC was first coined however it is now the preferred term of reference.



Before 1948, at which point the United Kingdom saw the birth of the National Health Service, most people died at home. The terminally ill were traditionally cared for by extended members of the family in the domestic home, with the living room acting as the 'final domestic resting place'.<sup>68</sup> We might trace the contemporary concept of hospice to the work of Dame Cicely Saunders in London, UK during the early 1950's. As will be discussed in the following chapter, some homes for the dying had already been established, but were the result of religious philanthropy. As medical knowledge was advancing, Dame Saunders was developing revolutionary ideas regarding the care of dying and pain relief. Though her work resulted in the founding of St. Christopher's Hospice as a physical embodiment of her ideas, it must be noted that 'even before St. Christopher's had begun operational life, it had already become a source of inspiration, not only to others elsewhere in Britain but also to individuals and groups overseas, particularly in the United States'.<sup>69</sup>

Shortly after St. Christopher's opened in 1967, the Swiss American psychiatrist Elisabeth Kübler-Ross published *On Death and Dying*<sup>70</sup> bringing the discourse of dignity in death and clinical perceptions of terminal illness to an international stage. It was this work that coined the 'five stages of grief' – originally an approach intended to describe and seek understanding of the feelings of those that are terminally ill, facing death and the bereaved, but is now used to portray grief more generally. With more hospices being built, it was observed in *Death, Society and Human Experience* first published in 1977, by Robert Kastenbaum that 'a hospice can be thought of more aptly as a process and as a spirit of mutual concern rather than as a place'.<sup>71</sup> In 1973 palliative care (PC) was first introduced as a new term of reference. Coined by Canadian physician Balfour Mount after a visit to St. Christopher's, as his colleagues had shunned use of the word 'hospice' due to adverse connotations in the French language that relayed negative perspectives of dignity and care for the impoverished. Bellamy and others reflect on the term:

In an interview about his work Mount describes 'palliative' as meaning 'improving the quality of'. Yet the very word 'palliative' originally derives from the Latin root, palliatus and later palliate, as meaning to 'cloak' or 'hide' instead supporting the contemporary view of the hiding of death and dying.<sup>72</sup>

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68 Edwin Heathcote, *The Meaning of Home*. (London: Frances Lincoln. 2012) pg. 34

69 David Clark, 'Originating a Movement: Cicely Saunders and the Development of St Christopher's Hospice, 1957-1967', *Mortality*, 3.1 (1998), 43-63

70 Elisabeth Kubler-Ross, *On Death and Dying*, 1969)

71 R.J. Kastenbaum, *Death, Society and Human Experience* Pearson Education, 2011), *ibid.* p.157

72 Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969, p.2

Upon returning to Canada, Mount used the term to name the unit and programme of care at the Royal Victoria Hospital in Montreal where he worked, with palliative used in reference to the cloaking of symptoms of those dying. The introduction of a specific term is critical to note, as it signals a turn away from the realities of death and dying, sounding more socially acceptable than 'care of the dying'. It should be noted that Mount's use of the term palliative care, was not fundamentally different to that of hospice care as being developed by Saunders in the UK. Though hospice is still a key term of reference, it might now be seen as much more of an umbrella term that captures the broad spectrum of care practices operating to support those with terminal and life-limiting illnesses. Despite the deeper etymological meaning of PC as described above, it was formally endorsed by the World Health Organisation in 1990, recognised as a 'major global health challenge'<sup>73</sup> and recognised as a sub-speciality of medicine in the UK in 1987. PC has evolved over the decades to describe a mode and approach to care as being person-centred, based on neither diagnosis nor prognosis but on the needs of patient and their respective carers.<sup>74</sup> However, Bellamy and others write that the holistic essence of this approach is unsustainable, and is not supported by the 'structural context of twenty-first century healthcare due to the influence of strategic, organisational, and operational factors'.<sup>75</sup> End of life care (EoLC) is another commonly used term, whose origins as a term of reference are unknown but it would be shrewd to speculate it is plainly descriptive. In contrast to the approach of PC, EoLC is used to 'refer to the care of people of any age with diagnoses of advanced, incurable, cancer and/or end-stage lung, heart, renal, liver failure or other life-threatening conditions and who are likely to die within the next 12 months'.<sup>76</sup>

We might observe that the ideology of hospice has remained relatively similar since the original work of Dame Saunders in the 1950's, with a focus on the holistic experience of those experiencing death and dying. However, the terms of reference used by the medical community such as EoLC, palliative care, care of the dying are considered by many practitioners as complicated. Though twenty years old, Lamer's labelling of this as having contributed to 'needless controversy'<sup>77</sup> is still an apposite critique with regards to not only the public but those working in conjunction with

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73 David Clark, 'Controversies in Palliative: A Matter of Definition', in *End of life studies* University of Glasgow, 2019)

74 K. Boyd and S. A. Murray, 'Recognising and Managing Key Transitions in End of Life Care', *Bmj*, 341 (2010), c4863

75 Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969

76 General Medical Council, 'Treatment and Care Towards the End of Life: Good Practice in Decision Making', General Medical Council 2010), p.8 cited in Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969

77 William M. Lamers, 'Defining Hospice and Palliative Care', *Journal of Pain & Palliative Care Pharmacotherapy*, 16.3 (2002), 65-71

healthcare professionals. Twenty years later, the Lancet Commission's 2022 'Value of Death' report provides contemporary evidence for continued complications, summarising Conrad that death and dying is still 'defined in medical terms, described using medical language'.<sup>78</sup>

### The contemporary death-scape

Despite the growing presence of the hospice movement, death and dying is still very much a taboo subject. There is a reluctance and hesitance to embracing an open attitude, and very often conversations on how and where a person may wish to spend their final moments happen too late, denying people a chance to exercise the control and dignity they would have had in their living life. As the Lancet's Commission into the Value of Death stated 'conversations about death and dying can be difficult. Doctors, patients, or family members may find it easier to avoid them altogether and continue treatment, leading to inappropriate treatment at the end of life.'<sup>79</sup> This has been reinforced, as Lamer's explains by a 'prevailing cultural reluctance to speak openly about dying and death prompt[ing] a number of health professionals to use [a] neutral term' such as PC.<sup>80</sup> Furthermore use of the word's hospice or EoLC may trigger sub-conscious negative connotations. Mol and others write that:

if care practices are not carefully attended to, there is a risk that they will be eroded. If they are only talked about in terms that are not appropriate to their specificities, they will be submitted to rules and regulations that are alien to them.<sup>81</sup>

An interview with a hospice staff member undertaken during the researcher's previous study revealed that they had had many conversations with terminally ill persons who refused to utilise hospice care services, and even enter a hospice building due to the preconception that they 'would not leave'.<sup>82</sup>

In the UK, in 2009 the National Council of Palliative Care (now HospiceUK) launched the Dying Matters Coalition supported by various sectors such as funeral care, charities, community organisations, trade unions etc. The aim of the project was to encourage people to have

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<sup>78</sup> Sallnow and others, 'Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life', *Lancet*, 399:10327 (2022), 837-84, p.863

<sup>79</sup> *Ibid.*, p.837

<sup>80</sup> Lamers, 'Defining Hospice and Palliative Care', *Journal of Pain & Palliative Care Pharmacotherapy*, 16.3 (2002), 65-71

<sup>81</sup> Annemarie Mol and others, *Care in Practice: On Tinkering in Clinics, Homes and Farms*. Vol. 8, Series: Care in Practice, (2010) p.7

<sup>82</sup> Annie Bellamy, 'A Place for Mortality', Cardiff University, (2017)

conversations with loved ones and friends surrounding their wishes towards the end of their life, hoping to demystify negative connotations around how we die. This is supported by the annual 'Dying Matters Awareness Week' held across the UK, with a variety of organisations such as schools, libraries, and theatre groups nurturing open conversation on the topic and offering learning resources for members of the public and those that are providing care at home.

The growing conversation around death and dying is not only due to the efforts of the third sector raising awareness, but in recent years has become a popular topic for authors, especially those from clinical backgrounds sharing their experiences as care-providers. American surgeon and public health leader, Atul Gawande published the seminal 2014 *Being Mortal*.<sup>83</sup> Motivated by his personal experiences of medicine, ageing and the death of his father this finds synergy with the researcher's own experience with Jen that uses personal experience to challenge architectural practice. Gawande writes that society should aspire to facilitating 'not a good death but a good life to the very end'<sup>84</sup> aligning with the contemporary principles of hospice. Furthermore, Gawande asserts that there must be a shift to recognise that contemporary society has become disconnected from the process of dying, and it is no longer seen as the natural progression of life.

Post *Being Mortal* there have been further emerging conversations that seek to bring to light the realities of death and dying, see Fig.2-2, such as 2016's *When Breath Becomes Air*<sup>85</sup> by American neurosurgeon Paul Kalanithi written in the last 22 months of his life following a terminal diagnosis, finished posthumously by his wife. Kathryn Mannix, a UK based consultant in palliative medicine published *With the End in Mind: How to Live and Die Well*<sup>86</sup> in 2017, and was nominated for the Wellcome Book Prize, a prestigious literary award for books that engage critically with topics on medicine, health, and illness. Having spent her professional career working within palliative care, Mannix, states that her literary work is part of 'a mission to reclaim public understanding of dying'.<sup>87</sup> Furthermore, in 2021 she published *Listen: How to Find the Words for Tender Conversations*<sup>88</sup> that more broadly focused on methods to approaching difficult topics within healthcare. We might also

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83 Atul Gawande, *Being Mortal : Medicine and What Matters in the End* First edition. New York : Metropolitan Books, Henry Holt and Company, 2014., 2014)

84 Gawande, A. (2015). *Being Mortal: Illness, Medicine and what matters in the end*. Profile Books Ltd.

85 Paul Verghese A. Kalanithi, *When Breath Becomes Air*, 2016)

86 Kathryn Mannix, *With the End in Mind*, 2019)

87 Dr Kathryn Mannix, About the Author (n.d) <<https://withtheendinmind.co.uk/about-the-author/>> [accessed 23rd January]

88 Kathryn Mannix, 'Listen : How to Find the Words for Tender Conversations', (2021)



Fig. 2-2 Taboo breaking literature

A selection of key works surrounding the topic of death and dying that have become popular contemporary best-sellers, these have begun to contribute to the normalisation of conversations around this area, so much so that 'Being Mortal' is currently being adapted into a major motion picture.

note that the advent of social media has also seen an impact on public discussions on death and dying, for example the #DyingWellDiary of Clair Fisher on Twitter and Deborah James 'Bowel Babe' blog, documenting their lives with terminal cancer.

Gawande states that the traditional nuclear family is steadily becoming more geographically dispersed and thus less able to support the older or ill family members at home. Subsequently our wider knowledge and awareness of death is not as it once was. It is not only geographic influences that can be observed as having contributed to this deterioration, but also as our elderly population rises, and co-morbidity becomes more common, the family unit and home are no longer appropriate environments for end-of-life care. As American journalist Karen Brown reflected on her experience with her terminally ill father, 'at the end of life, things can fall apart quickly, and neither medical specialist nor hospice worker can guarantee a painless exit.'<sup>89</sup> A detachment can also be observed in the portrayal of environments of death and dying within popular entertainment and media, that tend to consign death to anonymous hospital-like clinical spaces playing on tropes of medical environments, such as blue dividing curtains or in contrast, by over-romanticising the event away from the realities of the process thus removing it from the natural sphere of day-to-day life.<sup>90</sup> For many, the portrayal of death via the visual communication of the media is the only exposure to the process. In response to this cultural blindness, the Danish philanthropic organisation, RealDania, in the final report *Programme for The Good Hospice in Denmark* write that it is architects that must 'put death into a space – to become something natural, and not a taboo...the hospice [gives] a signal in the public sphere that death is here – death becomes visible.'<sup>91</sup> Therefore architectural design shares the responsibility as part of a broader societal approach to encourage and signal this change.

## Post COVID-19

The previous sections considered the contemporary state of hospice within the broader context of death and dying, prior to the outbreak of the COVID-19 pandemic. The immediate impact of the pandemic placed incredible strain on the NHS, and preventative measures to stop the spread of the virus meant that many third-sector healthcare providers, such as hospices, either shut or

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<sup>89</sup> Karen Brown, 'This Was Not the Good Death We Were Promised', The New York Times 2018

<sup>90</sup> We might think of UK based tv-shows such as 'Casualty' or 'Holby City', infamous films such as the 'The Notebook'

<sup>91</sup> Niels Peter Agger + SIGNAL Architects, Programme For The Good Hospice In Denmark, 2006

greatly reduced their services. Visitation was also impacted, with many healthcare environments placing strict limitations on visiting hours and rights, separating patients from their loved ones.<sup>92</sup> Furthermore the necessity of the requirements for personal protective equipment and the two-metre constraint of social distancing provided negative disruption to experiences of death and grieving. Reflecting on admissions of patients to hospital, the invisible nature of the virus created a sense of fear, as it was observed that 'many patients were reluctant to go into hospital at the height of the COVID-19 crisis, when visiting restrictions were so tight and there were fears of contracting the virus'.<sup>93</sup> This reluctance to enter healthcare settings, in turn saw an increase in the number of people dying at home, with research funded by the King's Trust speculating that 'more people dying at home may, like many other changes induced by this pandemic, be here to stay'.<sup>94</sup>

However, it was not only hospitals and large medical centres that were affected by the pandemic; hospice and community care providers also saw immeasurable impact on their services, needing to 'respond rapidly, adopting new ways of working as resources are suddenly stretched beyond their normal bounds'.<sup>95</sup> With a rise in people dying at home, and perhaps a heightened awareness of the services of EoLC and palliative care in the community, the pandemic prompted a 'reframing of contemporary society's approach and attitude toward death and dying'.<sup>96</sup> However, this reframing did not only affect humanist perspectives on the concept of death and dying, with many design professionals recognising that the impact of COVID-19 offered a potential turning point for healthcare typologies. Large scale change to the existing frameworks of procurement is not quickly implemented and may take many years for the delivery of such potential changes. However, there are emerging threads of change to the perspective of the design of healthcare buildings, typically previously seen as only the domain of highly specialist architecture firms. As KiHyun noted 'recent interest in hospital design by premier architectural firms is a new and interesting phenomenon'.<sup>97</sup> Furthermore Reiner de Graaf, partner at OMA, described how, the studio, 'were

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92 Sarah Yardley and Martin Rolph, 'Death and Dying During the Pandemic', *BMJ*, 369 (2020), m1472

93 Sarah Neville, 'Rise in Uk Deaths at Home During Pandemic Raises Questions About Support and Treatment', *The Financial Times*, August 31st 2021

94 Veena Raleigh, 'Invisible Deaths: Understanding Why Deaths at Home Increased During the Covid-19 Pandemic', (The King's Fund, 2021)

95 Simon N. Etkind and others, 'The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the Covid-19 Pandemic', *Journal of Pain and Symptom Management*, 60.1 (2020), e31-e40

96 Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969

97 Park Jeffrey KiHyun, 'Rethinking Modern Hospital Architecture through Covid-19', *McGill Journal of Medicine*, 20.1 (2022)

selected precisely because we had never done a hospital. And that therefore, we were unburdened by a lot of baggage.<sup>98</sup> Whilst the pandemic has the potential to influence the design of large-scale healthcare infrastructure, it might be observed that this change has not trickled down to smaller, more specialised environments such as hospices. Rather, many hospices post-pandemic are vulnerable - 'covid stress-tested a struggling system; palliative care was compromised because it is not recognised as essential.'<sup>99</sup> Further suffering from the financial implications of the pandemic, this financial insecurity has further prohibited their ability to implement change.

## Who uses hospice

The contemporary hospice is witnessing a significant shift in the care and services they offer, reflecting not only the medical changes of dying patients, but the broader societal attitudes outlined previously. Historically hospices found much of their funding from cancer focused charities, with cancer being the dominant illness and remit of hospice care. As Bellamy and others describe we can observe that there has been:

a disproportionate concentration of care on those suffering from cancer, due to its common association as a 'tragic' or 'untimely' death. Such focus on cancer-related illnesses may play a role in the 'glamorisation' of dying, thus confusing the physical and architectural requirements of what a hospice building should provide.<sup>100</sup>

However there has now been a shift away from the dominance of cancer as the primary remit of hospices to include to those with other life-threatening and limiting conditions. As such, the types of people using, and occupying hospice buildings is changing too. Níall McLaughlin, principal of Níall McLaughlin Architects responsible for an award-winning respite centre for those with Alzheimer's, describes that a key challenge for architects working in healthcare today is how 'with limited resources, to develop a caring environment that recognises the special sensitivities of people'<sup>101</sup>. As such, architects and designers must undertake an 'activity of conceiving futures...look[ing]

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98 Tom Ravenscroft, "Hospitals in Drastic, Drastic Need of Innovation" Says Reinier De Graaf (Dezeen, 2021) <<https://www.dezeen.com/2021/03/03/hospitals-of-the-future-reinier-de-graaf/>> [accessed 1st February]

99 Olszowski, 'Hospice Care Is a Right, Not a Luxury', The Guardian, 20th February 2022

100 Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', Medical Humanities (2020), medhum-2020-011969, p.4

101 Níall McLaughlin Architects, 2016, 15



towards “what might be”<sup>102</sup> and remain informed about the changing needs and characteristics of those using the hospice, resisting an impulse to rely on historic or out of date profiles of needs.

At a high-level, the users of the hospice could be broadly divided into two main population groups - those receiving care and those giving care, see Fig 2-3. The implications of these two sets of populations with regards to the built environment demand distinct categories of space and function within the hospice environment that are suitable for their specific requirements. We can observe that a key group defined as those that are receiving care are primarily patients, but also family and friends. With regards to patients, their specific needs upon entering a hospice will vary upon their diagnosis and illness trajectory. They may be admitted for a variety of reasons, such as a home environment unable to support their care needs, to relieve pressure on their caregivers or support network or for active symptom control – all of which contribute to the more medicalised nature of the hospice. However, as Lawton discusses the over-medicalisation of death and dying:

hospices are progressively able only to cater for those patients who cannot be looked after within the community, because the community cannot accommodate them either practically or symbolically. Consequently, it is not dying as such but, rather, certain kinds of deaths which are to be found within contemporary hospices.<sup>103</sup>

Unlike many other healthcare environments, for example, wards in major hospitals that are separated by nature of their specialism or patient diagnosis, the hospice in contrast must be an environment that offers care safely and comfortably to any patient regardless of their medical context. Unlike other residential care facilities, a stay in a hospice is typically for a ‘relatively short space of time, measured in days and weeks’<sup>104</sup>.

Worpole writes ‘the one-way door has become a revolving door’<sup>105</sup> with those using hospices no longer solely those receiving EoLC. Many hospices additionally offer respite care; short-term bedded care to those also suffering from terminal or life-limiting illnesses or receiving palliative

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102 Jack Breen, ‘11 Designerly Enquiry’, in *Ways to Study: Design Research and Typology* (OpenCourseWare: TU Delft, 2020) pg.97

103 Julia Lawton, ‘Contemporary Hospice Care: The Sequestration of the Unbounded Body and ‘Dirty Dying’’, *Sociology of Health & Illness*, 20.2 (1998), 121-43

104 Ken Worpole, *Modern Hospice Design : The Architecture of Palliative Care* (London, New York: Routledge, 2009), pg.8

105 Ibid. pg.12

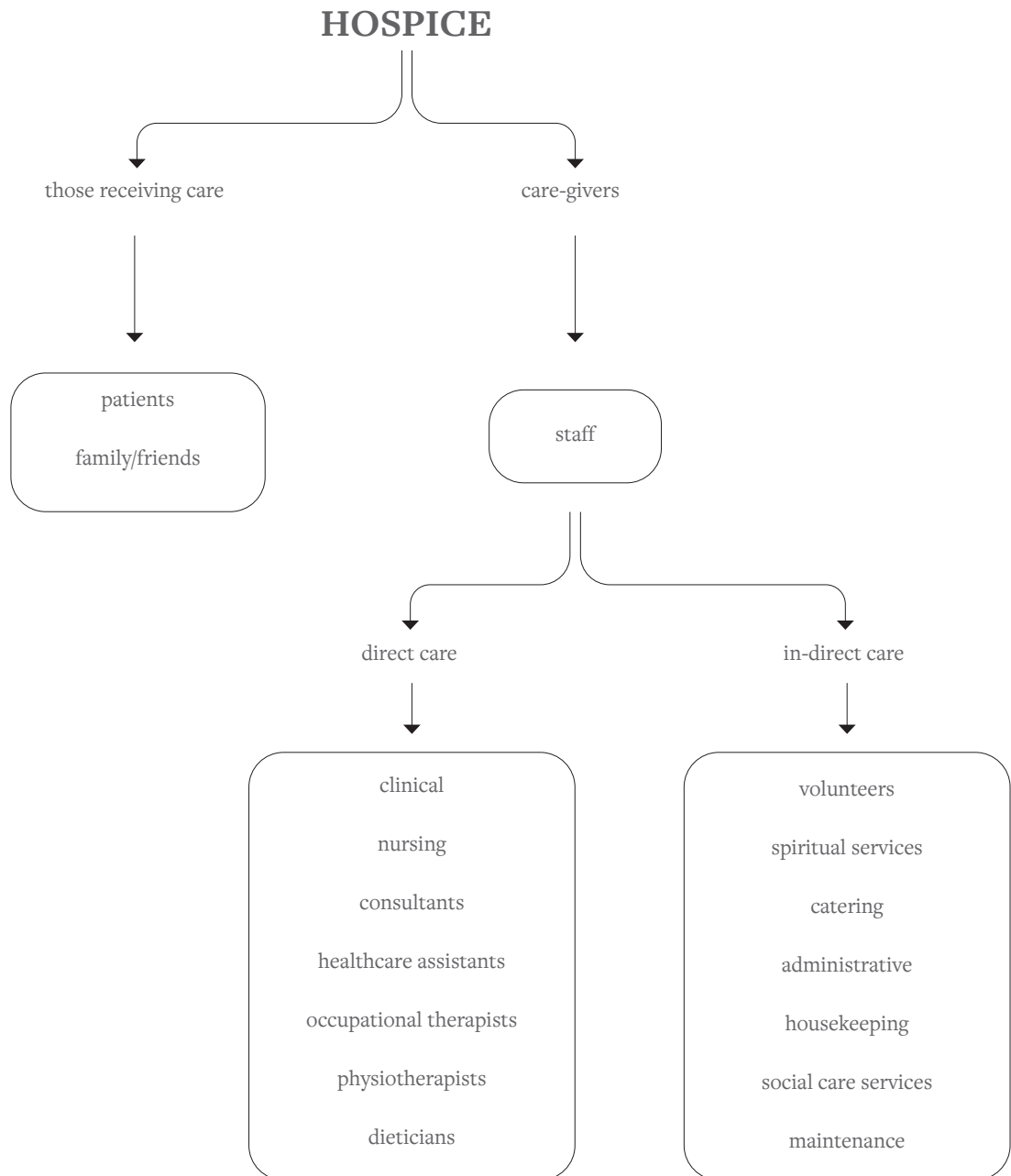


Fig. 2-3 Inhabitants of hospice buildings

This diagram outlines the typical organisational structure of those who inhabit the in-patient hospice, but is not an exhaustive list. Some hospices may have more roles that use the hospice depending on the exact services that they provide. More and more hospices are subsuming more services into their buildings as a central hub for EoLC and its supporting networks of community care. There is an obvious majority of care-givers in comparison to those receiving care, however what is interesting is the split between those who provide direct and in-direct care.

care to facilitate a break for those with caring responsibilities or to further manage symptoms or complications of illness. Though respite care in a hospice is temporary, it is nevertheless residential and potentially as clinically demanding depending on the patient and their needs. Previously, as a place for EoLC, the architecture of the hospice was conceptualised as a place for the end of the 'journey'. The introduction of respite care is problematic to this concept – architecture designed to respond to a narrative of a final place may be subconsciously inappropriate for those patients on a different trajectory. This marks a fundamental re-shaping of the design brief. Those receiving care includes associated visitors, such as family and friends. HospiceUK write that the approach of hospice also includes 'family members and others close to the person who is receiving hospice care. This support is offered during a person's illness and into bereavement'.<sup>106</sup> Whilst this occupant group does not require the physical care offered by the hospice, they are nonetheless recognised as needing elements of holistic care offered by the hospice, such as emotional, psychological, or spiritual support.

Renowned journalist Joan Kron wrote over forty years ago that 'a good building can make a difference to the backs and feet of the staff'.<sup>107</sup> Hospices, as a place of care, are also predominantly a workplace for those who provide not only care for the patients, but for the building in support of care. Direct patient care is managed by those with various levels of clinical training, the most senior clinical roles being consultants in palliative care and junior doctors, before moving to the nursing team who manage patient care day to day, with the most junior being healthcare assistants. As patient needs have become more complex and there is a growing focus on rehabilitation some hospices employ other clinical specialities, including but not limited to physiotherapists, occupational therapists, and dieticians. It is no longer necessary to stay at a hospice to receive their care as community outreach is becoming an engrained aspect, as Neale writes, 'care in the community is care by the community'.<sup>108</sup> This has meant that hospices as workplaces have expanded to become hubs for other critical community services and roles, such as social workers.

Those who work within the hospice environment but do not provide care for patients, will be referred to as indirect carers. These include roles that may seem 'hidden' considering the clinical focus of the hospice and are those that encompass the running and management of the building in support

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<sup>106</sup> HospiceUK, What Is Hospice Care? (HospiceUK, n.d) <<https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care>> [accessed 23rd August]

<sup>107</sup> Joan Kron, 'Designing a Better Place to Die', 1978

<sup>108</sup> Brenda Neale, *Informal Care and Community Care*. ed. by David Clark, Series: The Future for Palliative Care : Issues of Policy and Practice (Buckingham: Buckingham : Open University Press, 1993) p.56

of direct care given to patients, families, and carers. These behind-the-scenes roles we might consider contributing to challenging the view that 'architecture is mute'<sup>109</sup> in the context of care and play a vital role in ensuring the environment of the hospice is aligned with the principles of care. Such roles include those employed to maintain the building fabric, housekeeping, and the catering team. We might observe that these roles have been overlooked in favour of clinical narratives with regards to experiences of the hospice building. This co-produced work will talk to those providing indirect care and direct carers - as this is representative of the professional approach of architects that seeks to understand the requirements of a spread of end users, not solely one group - in search of a synergy between architecture and healthcare.

## Landscape of EoLC in Wales

A report commissioned by Hospice UK in 2018 wrote that 11,400 individuals accessed and benefitted from the services of charitable hospice care in Wales,<sup>110</sup> with 1,400 adults receiving in-patient care.<sup>111</sup> The care of this population group in Wales is not overseen or delivered by a single entity but is rather a co-operative effort between statutory and voluntary organisations, characteristic of EoLC across the United Kingdom. However, the direction of EoLC in Wales is guided by strategic national policies that aim to 'drive forward change'<sup>112</sup>, one of only two nations from the United Kingdom to do so. Though EoLC has been a concern within the healthcare sector since the emergence of the contemporary hospice movement; the 2007 report *One Wales – A Progressive Agenda for The Government of Wales* commissioned by the Welsh Assembly Government cemented the need to address previously highlighted inequalities in the provision of palliative care in Wales. In response to 'One Wales' the Minister for Health and Social Services established the Palliative Care Planning Group Wales, whose 2008 Sugar Report outlined recommendations for how NHS Wales and the third sector could positively improve the experience of dying people. These reports were instrumental in the development of the Welsh Palliative Care Implementation Board in 2008. This has since been superseded and replaced by the End of Life Care Implementation Board established in 2014 in a joint initiative by NHS Wales and the Welsh Assembly Government. The *Palliative and End of Life Care Delivery Plan* written in March 2017 states that the impact of previous reports has

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109 Annmarie Adams, *Medicine by Design: The Architect and the Modern Hospital, 1893–1943* University of Minnesota Press, (2008)

110 HospiceUK, 'Hospice Care in Wales 2018', (2018) pg.8

111 Ibid. pg.9

112 NHS Wales, 'Palliative and End of Life Care Delivery Plan', Welsh Government, (2017), pg.4

placed Wales as a nation 'ahead of the game'<sup>113</sup> with regards to EoLC. In addition to the above, reports published by NICE (National Institute for Clinical Excellence) and the Welsh Assembly's update to the National Cancer Standards<sup>114</sup> offered further guidance on the provision of specialist palliative care. In March 2022 however, the *Palliative and End of Life Care Delivery Plan* came to an end, with the Policy & Public Affairs Manager of Marie Curie Wales, Bethan Edwards stressing that 'without a national plan to take its place, we risk losing the strategic focus and decade of progress that has been made'<sup>115</sup> similar to the UK government's Health and Care act that made no mention of EoLC and palliative care provision moving forward. HospiceUK's Future Vision plan for Wales, *Seamless and Sustainable*, published in 2022 states that 'current approaches – or doing the same thing – isn't sustainable. This calls for a transformative approach.'<sup>116</sup>

The role of the End of Life Care Implementation Board is to support each of the seven university health boards (UHB, LHB) within Wales in their commissioning and delivery, and outcomes of national policies concerning specialist palliative care across the twenty-two principal areas to ensure that 'good end of life and palliative care should be available, universally across Wales'.<sup>117</sup> The board aims to provide national leadership that promotes 'genuine co-production'<sup>118</sup> between healthcare professionals and the public regarding the variety of services at end of life available in Wales. Some critical clinical roles in hospice care are directly funded by local health boards and NHS Wales,<sup>119</sup> however it has been critically recognised that third sector organisations are fundamental in funding and supporting EoLC services vital to ensuring a positive experience of dying. Palliative care services offered by third sector organisations in Wales encompasses a breadth of services to alleviate the stress on acute hospital beds including hospice at home, day hospice and in-patient services, their roles 'cannot be overstated'.<sup>120</sup> It was revealed in previous research undertaken by the author that hospice is often misconceived as meaning a building where someone goes to die. However, as shown in Fig.2-4, the most common place of death is the hospital, followed by homes and care homes, with hospice at the lower spectrum.

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113 Ibid. pg.3

114 Kathryn Potter, 'Palliative Care', in *Members' Research Service: Topic Brief National Assembly for Wales*, (2007) pg.1

115 Bethan Edwards, 'Don't Let the Plan Run out for Dying People in Wales', *Bevan Foundation*, (2022)

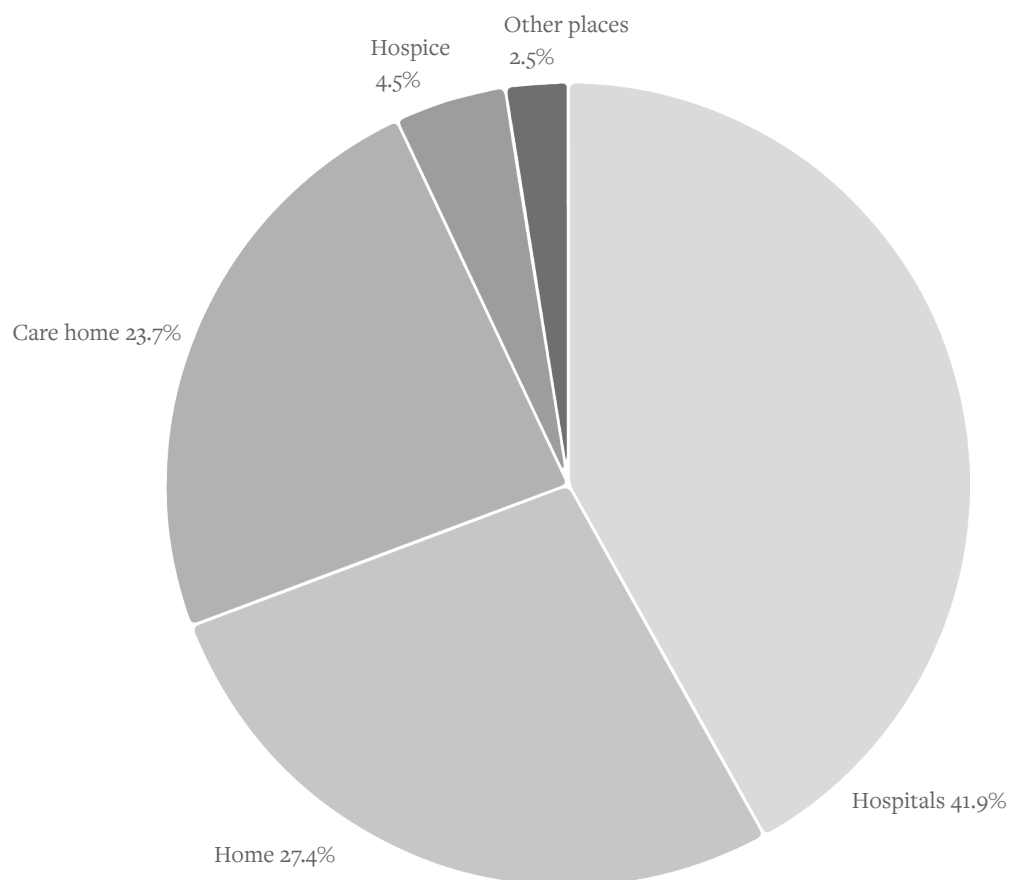
116 HospiceUK, 'Future Vision Cymru: Seamless and Sustainable: Report on Engagement Discussions and Ways Forward', (London: HospiceUK, 2021) p.6

117 Wales Palliative Care Implementation Board, 'Dying Well Matters One Wales: 3 Years on (2008 – 2011)', (2011) pg.4

118 Wales, 'Palliative and End of Life Care Delivery Plan', *Welsh Government*, (2017) pg.1

119 HospiceUK, 'Hospice Care in Wales 2018', (2018) pg.17

120 Wales, 'Palliative and End of Life Care Delivery Plan', *Welsh Government*, (2017) pg.4  
Board, 'Dying Well Matters One Wales: 3 Years on (2008 – 2011)', (2011) pg.2



Places of death in the UK, all ages, in 2020

Fig. 2-4 Places of death

The chart above outlines the percentage of places of death in 2020 for all ages, using the 'Palliative and End of Life Care Profiles' available from the HM Government's Office for Health Disparities and Improvements, Office for National Statistics. It is critical to note that hospice is the second lowest entry, with only 4.5% of the population dying in hospices overall - a very low figure in comparison to the other values in the chart. Furthermore, as this latest information is from 2020, during the peak of the pandemic it is worth acknowledging that this data may have changed as a consequence - and especially in light of the latest directives of palliative care for all.

## Structure of care in Wales

As is commonly found across the United Kingdom, most in-patient hospices in Wales are run by third sector organisations, such as local or national charities who deliver specialist palliative care. Each of these charities appear to have identified gaps in the specific palliative care and EoLC needs of their local communities. For many rural communities in Wales this is particularly pertinent. Trystan Pritchard, Chair of Hospices Cymru, an organisation representing the independent hospices within Wales, states that 'hospices are their communities'.<sup>121</sup> As third-sector organisations, this additionally means that the communities they serve are those with whom they collaborate for outreach and engagement purposes, but also for the funding needed to sustain their services.<sup>122</sup> Following the 2007 Sugar report, the Welsh Assembly Government provided funding to hospices using the Welsh Funding Formula that aims to allow local health boards to cover the cost of core clinical roles as part of a national strategy to provide equitable services across the country.<sup>123</sup> However, a 2018 report by Hospice UK states that government funding contributes approximately only £5 million of the estimated £36 million that is required to fully cover the running costs of the hospices. This leaves a combined annual shortfall of £28 million in running costs<sup>124</sup>; historically covered by charitable activities and donations including wills and legacy gifts. However, this shortfall is likely to have been exacerbated by the COVID-19 pandemic and its consequent negative impact and reduction in charitable giving and fundraising, with typical income streams such as events and retail shops forced to shut down during spring 2020 following the mandated lockdown.<sup>125</sup> In the Welsh Government's 2020-21 report on health board funding, just over £5 million was allocated to the support of palliative care services and a further £9.3 million was allocated as emergency funding to cover the aforementioned shortfall.<sup>126</sup>

The consequence of partial financial independence has historically resulted in hospices being solely responsible for the commissioning and development of their buildings and environments. Therefore, any proposed projects - whether refurbishments, extensions and alterations or new-

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<sup>121</sup> Ibid. pg.1

<sup>122</sup> Board, 'Dying Well Matters One Wales: 3 Years on (2008 – 2011)', (2011) pg.2

<sup>123</sup> HospiceUK, 'Hospice Care in Wales 2018', (2018) pg.17

<sup>124</sup> Ibid. pg.17

<sup>125</sup> BBC, 'Coronavirus: Hospices in Wales to Share £6.3m Funding', BBC News (2020), <<https://www.bbc.co.uk/news/uk-wales-52340135>>

<sup>126</sup> Finance Directorate Welsh Government, '2020-21 Health Board Allocations', (Welsh Government, 2019) p.20 & Vaughan Gething, 'Written Statement: Update on Palliative and End of Life Care', (gov.uk: Welsh Government 2021)

build elements - would have typically relied upon charitable donations and fundraising to generate adequate funds to cover construction costs (including any associated professional and statutory fees, such as the cost of a planning application) on top of annual running costs. Whilst there are environmental requirements of the previously mentioned regulatory institutions, such as Care Inspectorate Wales, this relative financial independence has afforded hospices opportunities to individually develop their approaches to the built environment within the limitations of traditional building work such as planning and building regulations. Construction projects, regardless of scale, have been able to respond in a more direct manner to contextual characteristics such as identifying the specialist palliative needs of the local community or local architectural character.

It can be observed however, that this comparative independence offers both advantages and disadvantages for hospices undertaking a design project and their subsequent commissioning of architectural services. A financial balance that is reliant on charitable sources poses potential instability with regards to preserving quality and value for money. For example, the phasing of works to break up the overall financial burden to smaller packages and potential value-engineering exercises that impacts upon the aspiration of architectural features and qualities. Development processes may uncover hidden or unexpected costs that arise during design, planning or construction that could threaten the integrity of the hospice's original plans or vision. Conversely, the absence of other involved parties, who may have otherwise placed certain governance restrictions or requirements on the built outcome offers potential freedom for hospices to have full control over the determination of their buildings, and in a broader sense, their care.

Hospices' early independence from the NHS, however, might be seen to be converging. Palliative and EoLC services are forming closer relationships and becoming increasingly integrated with University Health Board's (UHB's) with regards to both financial and clinical aspects of their management. As described previously, the NHS - via UHB's - contribute a defined portion towards the cost of running a hospice (usually per bed) and provide certain clinical roles. Anecdotal information from the hospice community revealed that the NHS and the Welsh Assembly Government recommended new-build hospices to be built in the grounds of the closest acute major hospital for purposes of efficiency – though this did not transpire for the most recent new-build hospice in Wales, St David's Hospice in Newport.



The above describes a tension between the public and third sector in the direction and delivery of hospice environments in Wales. The further involvement of public sector funding and management (though tying in with national strategic plans for palliative and EoLC care) has the potential for diluting decision making and generating stricter control on the parameters of future hospice design. Multiple factors, such as the 2020 recession and the ongoing impact of COVID-19 resulted in loss of income for the charitable sector. It is inevitable that ongoing further involvement of the public sector will be necessary to maintain the services of hospices. Subsequently, twice in 2020 the UK Government announced emergency funding packages for hospices across the four nations totalling £325 million.<sup>127</sup>

## Summary and reflection

Considering hospice as a broad concept, we have seen that it found its etymology is predicated on care as an abstracted form of human interaction. This did not specify acts or constraints on the type of care, but rather found meaning in social frameworks, especially relating to hospitality, such as basic shelter and food and drink. Where originally hospice was not considered a place - but a broader philosophy or approach - it has now evolved to be a specific place. The modern hospice movement championed by Dame Saunders in the early twentieth century, taking on board advancements in medical care, echoed the core principles of hospice care from its early definitions. As this developing field of hospice care became more prevalent and conversations on death and dying were beginning to emerge into contemporary society, further key terms of reference were introduced to capture the specificities of contemporary approaches. However, it has been noted that there remains a general anxiety toward the topic of death and dying, and that this may have been exacerbated by the language that has developed around the subject. Within the healthcare profession there is a recognised confusion between the overlapping nature of the terms.<sup>128</sup>

Though we might observe that the overall ideology of hospice as a concept has remained mostly like its early origins, it is now subject to a much more complex context. Where hospice care found its foundations in cancer care, with much of its funding from cancer care related charities, hospice now caters for a much broader spectrum of patients suffering from other life-limiting

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<sup>127</sup> Hospice UK, Hospice UK Responds to the Government Announcement of Additional Funding for Hospices (2020) <<https://www.hospiceuk.org/about-hospice-care/media-centre/press-releases/details/2020/11/24/hospice-uk-responds-to-the-government-announcement-of-additional-funding-for-hospices>> [accessed 28th November]

<sup>128</sup> Lamers, 'Defining Hospice and Palliative Care', *Journal of Pain & Palliative Care Pharmacotherapy*, 16.3 (2002), 65-71

conditions. The projected changes in demographics and increase in complex co-morbidities has seen hospice care become far more medicalised than ever before. This has required additional infrastructure, with regards to both the number of professions involved in hospice care, but also the buildings themselves providing the environment necessary for those with complex health issues and different types of care, for example respite, EoLC.

The COVID-19 pandemic has had a demonstrable impact on the way in which death and dying is viewed. The introduction of social distancing measures and stringent use of PPE has perhaps contributed to development of an underlying fear of healthcare environments, that overall saw deaths at home rise during the initial lockdowns in the UK. The pandemic has also seen the beginnings of a new shift in thinking toward the approach to design of many healthcare settings – and what the impetus of care means for architectural design. Considering those who now use hospice, though we might split the inhabitants into two umbrella groups, receiving and giving care, this is not a definitive split, especially as we look to the future direction of hospice care. Those who might receive care in an in-patient setting may not necessarily be someone at the end of life. Those giving care, staff members of all levels and disciplines, need a different type of care to ensure that they can perform their job to required standards. However, the care for those providing care must go beyond pragmatic requirements for their day-to-day job, but also mentally and emotionally, for which the architectural environment can also assist. Wales, through its development of the End-of-Life Care Implementation Board, has demonstrated that at a strategic and national level it is prioritising the provision of specialist palliative care. However, an interest in providing high standard care does not necessarily translate into a high standard of the built environment for accommodating care services. Many, if not all in-patient hospice providers in Wales rely on charitable funding to meet most of their running costs. Any refurbishment, renovation or new-build project require large financial investment to cover the necessary consultant fees and cost of construction works and as such the constraint of charitable funding means that these costs will be tightly controlled to ensure that the projects are delivered efficiently.

This chapter furthermore has contributed to the researcher's shared understanding of hospice as a concept from a healthcare perspective. As highlighted in the prologue of the thesis the researcher's previous insider experience of the hospice environment was an intensely personal one, witnessing Jen's death in a hospice. The process of exploring its origins, evolution and current context supported the development of a more rigorous insider perspective for the researcher.

Engagement with the process of investigating hospice enabled a move away from the personal experience of family to one predicated on a professional understanding of the focus of study, reducing risk of personal bias. It has moreover supported the researcher in achieving several of the study objectives listed on pg 25-26. Overall, this chapter generated greater awareness of practical knowledge of the hospice and therefore strengthens subsequent consideration of architectural design within hospice in future chapters of the thesis.

# 3

## Hospice as a typology

The previous chapter set out to explore the context and history of end-of-life care (EoLC) within broader care contexts, addressing both the historical development of hospice care but also contemporary issues facing the movement today. This chapter, completing the first part of the thesis presents a similar structure, but instead moves the discussion into the centre ground of architectural design. Here, we will examine and re-evaluate the building typology of the in-patient hospice as uniquely distinct from other medical environments. This chapter will present a typological study of the hospice tracing the history and origins of hospice buildings and an overview of the functions of the hospice in practice today. It will close with a literature review of available design guidance and standards, and a discussion on existing architectural precedent.

## A note on architectural typology

In architectural praxis typology has 'become conventional, hence an easily recognizable and transmittable password'<sup>129</sup>. Adrian Forty describes that architectural typology commonly occur in two distinct groups - typologies of form, such as pyramids, and typologies of function, such as churches.<sup>130</sup> Thus, the term typology acts as a shortcut in defining a general image of buildings through either the form or function. The design process may traditionally use typology as a starting point, which Braham denotes as a 'dominant model of an architectural method'<sup>131</sup>. It provides a set of rules and approximations that are 'not prescriptive in a formal sense'<sup>132</sup> but consolidate many years of development of conceptual and diagrammatic organisation, including but not limited to spatial hierarchies, adjacencies, and size appropriate for the function.

The French architectural theorist Antoine-Chrysostome Quatremère de Quincy was one of the first to define architectural type in 1825 in the *Dictionnaire historique de l'Architecture*. Noble cites Vidler's translation of the entry as:

less the image of a thing to copy or imitate completely than the idea of an element which itself ought to serve as a rule for the model...the type is an object after which each artist can conceive works that bear no resemblance to each other.<sup>133</sup>

These attributes, highlight, albeit vaguely that the early understanding of architectural type may be a framework that contains conceptual and aesthetic ideologies that designers can respond to rather than explicitly follow. The discussion notably re-emerged with the publication of Nikolaus Pevsner's seminal 1976 *A History of Building Types*.<sup>134</sup> In this he stated that typology defined by functional categorisation 'allows for a demonstration of development both by style and by function, style being a matter of architectural history, function of social history'.<sup>135</sup> The catalogue explored how the architectural style of each group has developed in a coherent way throughout history but

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<sup>129</sup> Micha Bandini, 'Typology as a Form of Convention', *AA Files*.6 (1984), 73-82, pg.73

<sup>130</sup> Adrian Forty, *Words and Buildings: A Vocabulary of Modern Architecture* (London: Thames & Hudson, 2000) p.304

<sup>131</sup> William Braham, 'After Typology: The Suffering of Diagrams', 70 (2000) pg.1

<sup>132</sup> Sam Jacoby, 'Type Versus Typology Introduction', *The Journal of Architecture*, 20.6 (2015) pg.5

<sup>133</sup> Jonathan Noble, 'The Architectural Typology of Antoine Chrysostome Quatremere De Quincy (1755-1849)', (2000) pg.155

<sup>134</sup> Nikolaus Pevsner, *A History of Building Types* (Princeton, N.J.: Princeton University Press, 1976)

<sup>135</sup> Ibid. pg.6

that are inextricably linked to 'particular conventions, cultures, and forms of practice'.<sup>136</sup> Following this in 1978 Spanish architect Raphael Moneo wrote *On Typology*<sup>137</sup> suggesting that type is also linked to architectural production. The design process, using a typology as the model, brings together the unique elements of a particular group into existence within the constraints of individual context, as Moneo states, it is:

intimately connected with reality – a vast hierarchy of concerns running from social activity to building construction. Ultimately, the group defining a type must be rooted in this reality as well as in an abstract geometry. This means, for example, that buildings also have a precise position in history.<sup>138</sup>

Moneo acknowledges that the grouping of a building type must go beyond simple similarities and are instead defined by the complex circumstances from the current context of a building.<sup>139</sup> Whilst typology offers a way to catalogue historical iterations and explorations, Jacoby states that typologies as objects 'do not require continuity'<sup>140</sup> and 'have to be adapted to a contemporary context'<sup>141</sup>. Thus, a typology cannot be described as either a fixed or stable architectural notion but rather an evolving definition and synthesis of architecture and its context curated around a particular group.

If typology, therefore, is not a fixed, but a shifting concept that responds to social, cultural, and political factors each influencing the way in which designers respond appropriately to the grouping - we can observe that this act may have unintentionally led to an oversimplification and careless stereotyping of the nuances and requirements of a building. Bandini argues that the responsive nature of architectural typologies has been somewhat lost, declaring that:

instead of being a 'progressive programme' of research, typology has become a 'degenerative one' which no longer possesses those regenerative features which could redirect it towards a more fruitful, non-tautological search for knowledge.<sup>142</sup>

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<sup>136</sup> Braham, 'After Typology: The Suffering of Diagrams', 70 (2000) pg.1

<sup>137</sup> Raphael Moneo, 'On Typology', *Journal for Ideas and Criticism in Architecture*, 13 (1978), 22-44

<sup>138</sup> Ibid., pg.24

<sup>139</sup> Jacoby, 'Type Versus Typology Introduction', *The Journal of Architecture*, 20.6 (2015) pg.25

<sup>140</sup> Ibid. pg.25

<sup>141</sup> Ibid., pg.4

<sup>142</sup> Bandini, 'Typology as a Form of Convention', *AA Files*.6 (1984), 73-82, pg.81

As typology has passed into contemporary architectural terminology as a shortcut, it can be considered to have reduced the architectural translation of specific forms and functions to generic terms and visual tropes. In this sense typology, if not fully embraced may become a passive descriptor that requires only the application of design elements or patterns.

In considering the hospice as a typology, we must consider issues that obscure a contemporary understanding of the type pertinent to this thesis. The hospice, as a form of healthcare environment has been derived from the broader 'hospital' typology and is often catalogued under this type, sharing many elements of architectural language found in clinical environments. Yet, the hospice is born of a distinct function - to facilitate EoLC, in direct contrast to the hospital's focus on curative medicine and recovery – and is also the culmination of a specific socio-historic factors that saw the emergence of specialist and holistic palliative care. With divergent aims, the hospice building and the hospital building, have differing requirements and expectations of the built environment to best support the care needed. Without relevant explorations of the hospice typology as a 'generative tool' it could therefore be said that a lack of necessary architectural and contextual adaptation is a complicating factor in hospice's unsettled identity.

## Hospice in history

### Ancient histories

To understand and evaluate the position of the contemporary hospice as its own typology we must look back to the architectural genealogy of the 'hospice' building and understand how it has sat within the history of more common healthcare environments, most notably the hospital. The following hopes to provide the setting to understand where the 'hospice' evolved; or devolved from. Saliu et al state that there is no agreeable established date that healing, and care environments became 'organized and structured for the first time in accord with sets of rules and functions of a certain society'.<sup>143</sup> There is evidence that spaces used, for, and of healing have existed since the times of ancient civilisations in Mesopotamia, India, China, and Southeast Asia. It must be noted however, that the concept of medicine and care existing during these periods would be unrecognisable with regards to our contemporary understanding; illness and treatments being perceived more as consequences of religious and social beliefs. Primitive hospital-esque environments may

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<sup>143</sup> Nuran Saliu and others, 'From Asclepius to Ospedale - the Evolution of Space for Healing from Antiquity to the Age of Enlightenment', in UBT International Conference (Kosovo, UBT Knowledge Center 2016) pg.143

have been in existence prior, however, to maintain a particular focus on the origins of 'hospice' the following historic account begins with the Greco-Roman period, where emerging suggestions of 'hospice' can be identified.

Temples originally built and devoted to the Greek god of medicine, Asclepius, in mountainous and coastal locations steadily evolved into vast complexes of 'highly standardised'<sup>144</sup> buildings that were able to support a wide range of interconnected activities and rituals devoted to emerging notions around the science of medicine. Of particular interest is the 'abaton' a temple building that was explicitly designed to fulfil a quasi-residential function within the complexes; offering a place for long- or short-term rest to the ailing who had travelled to the asklepiion's in search of treatment, see Fig.3-1. The 'abaton' was typically a simple and common Greek architectural form, the stoa<sup>145</sup>, that was enclosed on three sides, with an open portico orientated south toward the sun providing direct access to the outside and thus the fresh air.<sup>146</sup> Those seeking treatment at the asklepiion, it is thought would rest alongside the back wall with views facing out. Medical historian Guenter B. Risse states that the asklepiion's 'fulfilled the criteria of establishments created for healing purpose. These temples provided carefully controlled spaces conducive to healing.'<sup>147</sup> There may be no direct historical connection between asklepiion's and the hospice as an explicit place of care for the dying, we can observe that these healing complexes formed the foundation of architectural exploration of the consideration of what Kestenbaum describes as the 'whole person'<sup>148</sup>, with marked similarities to contemporary principles of hospice care.

### Monastic hospices

The initial 'hospice' movement was principally shaped in the early Medieval period owing to the growth and spread of Christianity. It is important to clarify, however, that tracing the history of the hospice back to this era is problematic, in Grace Goldin's seminal discussion on early hospice care she recounts historian Dr. Charles Talbot's warning that these historical references to hospices do not offer 'care of the dying as such [and] in general, the idea of a hospice had nothing to do

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<sup>144</sup> Ibid. (Saliu and others, pg.143)

<sup>145</sup> John D. Thompson and Grace Goldin, *The Hospital : A Social and Architectural History*. ed. by Grace Goldin (New Haven, London: New Haven, London, Yale University Press, 1976) pg.5

<sup>146</sup> Guenter B. Risse, *Mending Bodies, Saving Souls : A History of Hospitals* (New York: New York : Oxford University Press, 1999) pg.23

<sup>147</sup> Ibid. pg.56

<sup>148</sup> Kastenbaum, *Death, Society and Human Experience* (Pearson Education, 2011) pg.151



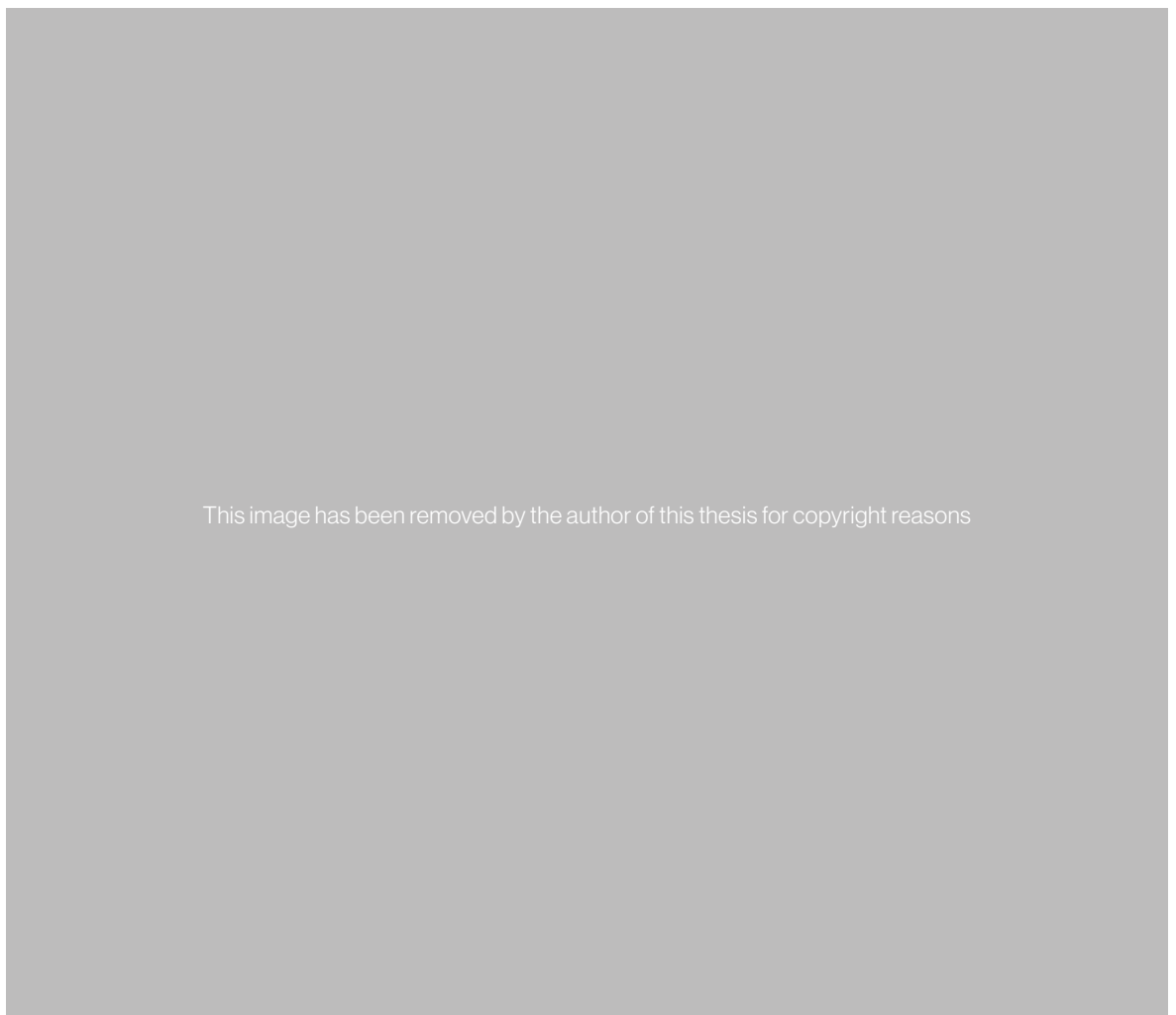


Fig. 3-1 Site plan of Epidaurus

Note that the abaton, the area of building used for short and long term rest is semi-open, with a portico on one side, allowing for natural ventilation. Orientated almost due south, this area would have also benefit from maximum sunlight during the day. The plan of Epidaurus above also serves to highlight, that despite a rudimentary understanding of health - environments of care were assembled as a more holistic landscape of care.

with death'.<sup>149</sup> The characterisation of a 'hospice' at this point was instead intrinsically linked with religious sanctuary and the act of 'mercy' by Christian charity.<sup>150</sup> It is also here at an undefined point during this period that the term 'hospice' is first used; the Latin root, *hospitium*, discussed earlier as describing a generic place of care, mutated from the original Latin word to the French vernacular 'hospice'.<sup>151</sup>

The earliest explicit references to hospice buildings were the monastic hospices of the early 11th century, notably constructed in the area surrounding the 'Holy Land' - such as Jerusalem. These hospices were unlike the contemporary hospice we know today and would be more akin to the contemporary 'hostel', providing shelter and food for religious travellers. One of the earliest documented indications of a distinct hospice building was about the work and mission of the Order of the Hospital of St. John of Jerusalem, known more commonly as the 'The Knights Hospitallers'. The Order's original purpose centred around providing care for ailing and dying pilgrims and religious soldiers taking part in the Crusades. However, as many illnesses and injuries in those times were incurable, the care they offered began to be expanded to additionally provide care for members of the local community who were ailing or dying, regardless of their spiritual faith.

The act of caring irrespective of belief and the nature of ailment, reflects a core element of the contemporary hospice movement, stemming from its religious origins. Whilst the exact date of the Order's establishment is unknown, it is thought that a hospice was built in Jerusalem between approximately 1070-1080 A.D as a permanent place to provide care.<sup>152</sup> The site of this hospice lies beneath the grounds of the Church of St. John the Baptist in the Muristan complex in the Christian Quarter of the Old City of Jerusalem. Though the Church still exists and is a protected holy site (it is thought to be the birthplace of St. John the Baptist) there are very few remnants of the original buildings. In Fig.3-2, a 1472 map of Jerusalem, the hospice is shown as a courtyard complex to the West of the Church of the Holy Sepulchre. The courtyard and its buildings were most likely in existence before the hospice was formed, as a complex of religious buildings.

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149 Goldin, 'A Protohospice at the Turn of the Century: St. Luke's House, London, from 1893 to 1921', *Journal of the History of Medicine and Allied Sciences*, XXXVI.4 (1981), 383-415, pg.389

150 Thompson and Goldin, *The Hospital : A Social and Architectural History*. ed. by Goldin (New Haven, London: New Haven, London, Yale University Press, 1976) (Thompson & Goldin, pg.6)

151 Goldin, 'A Protohospice at the Turn of the Century: St. Luke's House, London, from 1893 to 1921', *Journal of the History of Medicine and Allied Sciences*, XXXVI.4 (1981), 383-415, pg.387

152 St John's England, *History of the Order of St John* (n.d) <<http://www.stjohnengland.org.uk/about-us/history/>> [accessed 9th July]

This image has been removed by the author of this thesis for copyright reasons

Fig. 3-2 Town plan of Jerusalem

The image above is dated from 1472. The hospice - Hospital of St. John - is the courtyard complex to the West of the Church of the Holy Sepulchre, taking a central place in the layout of the city.

This hospice, therefore, though perhaps one of the first built and documented forms of its type is an example of what Thompson and Goldin refer to as 'derived plans, plans originally evolved for other purposes and adapted to nursing'<sup>153</sup> Little is known about the precise spatial programme and layout of the building. However, in Edgar Erskine Hume's account on the medical work of the Knights Hospitallers, he includes a brief description of the hospice written by John of Würzburg - a German priest who documented Christian holy sites whilst on a pilgrimage to the Holy Land in the 1130's:

...towards the south, is a beautiful church built in honour of John the Baptist, annexed to which is a hospital...an edifice of vast dimensions – accommodating 2000 patients. It covered an area of 150 square metres. The walls enclosed three beautiful churches, the hospital proper, a palace for the Knights, and a convent for the nursing sisters. The ruins of the massive walls still remain, with several rows of stone pillars, and the lovely gateway, the main entrance of the ancient hospital.<sup>154</sup>

The above description, though brief in nature, provides a glimpse into the architecture of the site as visited some one hundred years after its construction. The account outlines the key built elements to be found within the courtyard complex, which include not only the hospice building itself but the auxiliary buildings for the Knights and nursing sisters. Whilst perhaps an inheritance from the complexes 'derived plan' of a religious compound, it's siting, however, within this location of an enclosed space nevertheless demonstrates that the hospice even then was operating as a holistic environment, able to provide all the elements needed for caregiving within one shared location. Assuming the spatial layout of a traditional Church of that time, the aforementioned 'several rows of stone pillars' portray a large open-plan internal space, that perhaps once would have been the nave of a church building. A second account documented by Hume, written by Thomas Wright upon visiting the site in the mid nineteenth century supports John of Würzburg' account, describing the hospice as having 'one hundred and twenty-four pillars of stone: and in the walls of the house, beside the number aforesaid. There are fifty-four pillars that support the house.'<sup>155</sup>

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<sup>153</sup> Thompson and Goldin, *The Hospital : A Social and Architectural History*. ed. by Goldin (New Haven, London: New Haven, London, Yale University Press, 1976) pg.5

<sup>154</sup> Edgar Erskine Hume, 'Medical Work of the Knights Hospitallers of Saint John of Jerusalem', *Bulletin of the Institute of the History of Medicine*, 6.5 (1938), 399-466, pg.406

<sup>155</sup> Ibid. pg.414 (Hume)

Depicted in the engraving of Fig.3-3, we can begin to see the volume and size of the infirmary space offered by the large spans of columns; resulting in a high-density dormitory like arrangement with beds lined in rows between the columns. Saliu et al posit that this would also have been to ensure that 'the sick should see and hear religious ceremonies from their beds.'<sup>156</sup> This would be in part due to the derived plan of the monastery, but also a considered spatial reflection of the importance of religion in the healing process. Though the approximation of 150 square meters implies very little space per person (roughly 0.75 sq.m) the engraving suggests the space was distributed between single beds with some space between for circulation. What can also be seen in this engraving is the human scale engagement of the hospice. The image depicts scenes of relative comfort and luxury in comparison to the perhaps usual experience of poverty the patients may experience in day-to-day medieval life. The beds are individual and look to have soft furnishings such as cushions and blankets to provide comfort. We can also observe that there is space in-between each bed, allowing access to provide different types of care. For instance, in the bottom right corner there is an image of an attendant at a patients bedside, offering food or drink, a monk to the right sitting directly at the patients side perhaps offering spiritual comfort, and finally two people in the foreground attending to the body of a deceased person in a care ritual emphasising post-death dignity.

An additional observation to be recorded from the engraving are the large openings shown in the background of the image, suggesting that the space not only received natural daylight but benefitted from direct fresh ventilation as this would have pre-dated glazing technology. Thompson and Goldin infer that healing temples of ancient Greece, asklepion's<sup>157</sup> 'may have played their part in determining the layout of large medieval wards.'<sup>158</sup> Much like the description of the hospice in Muristan. The details described above of the hospice showcases an emerging attention to individualistic care for the pilgrims/patients, and what today could be 'called a holistic approach to care'.<sup>159</sup>

Moving forward to the later Middle Ages hospices begun to be seen in many wider locations across Europe owing in part to the expulsion of Christians from Jerusalem. It is believed that at one point

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<sup>156</sup> Saliu and others, 'From Asclepius to Ospedale - the Evolution of Space for Healing from Antiquity to the Age of Enlightenment', in UBT International Conference (Kosovo, UBT Knowledge Center 2016) pg.148

<sup>157</sup> Thompson and Goldin, *The Hospital : A Social and Architectural History*. ed. by Goldin (New Haven, London: New Haven, London, Yale University Press, 1976) pg.3

<sup>158</sup> Thompson & Goldin, pg.4

<sup>159</sup> Janet Moscrop and Joy Robbins, *Caring for the Dying Patient and the Family* (Springer, 1995) pg.246

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Fig. 3-3 Ancient rituals

This image, an engraving of the hospice - Hospital of St. John - in Jerusalem established in 1080, depicts a multitude of activities. We can see in the foreground, a deceased person being attended to with post-death rituals, and in the mid-ground we see a religious figure attending to a bedridden person and another offering what appears to be a drink. This image captures the holistic care offered even in this era.

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Fig. 3-4 The Hospitium

Built in the grounds of the St. Marys Abbey, York, circa the fourteenth century. The area on the ground floor would have been used as a stable, to accommodate travellers horses, with the larger volume of the first floor used for accommodation.

there were over 750 medieval hospices in the country of England alone<sup>160</sup> most likely due to the proliferation of monasteries as self-sustaining communities and physical complexes. During this period, though, we can see the language of hospice shift once again and begin to be more closely aligned with the Roman term 'hospitium'. The Hospitium in York, pictured in Fig.3-4, a fourteenth-century building in the grounds of the St. Mary's Abbey in York is an example of such a building; a type of guesthouse offering dormitory style accommodation, but not necessarily care as had been seen in the earlier monastic hospices. Yet despite the early flourishing effort the prevalence of the original hospice was short-lived. The dissolution of monasteries in sixteenth-century England meant that many religious facilities that contained hospices were destroyed. Replaced by crude 'hospitals' that were places to be 'avoided at all costs'<sup>161</sup> due to lack of medical knowledge and poor sanitary standards – the hospice's 'mission of mercy for the dying faded away'<sup>162</sup> for several centuries.

## Post nineteenth century

### The hospice revival

Following a long period of dormancy, it was in the early nineteenth-century that we can observe the 'hospice' beginning to take on the attributes and functions of care for the dying that we see today. This resurgence, mirrors that of the medieval hospices, in part due to the religious culture and context of the time. David Clark describes how the movement gained traction due to Christianity's 'emphasis on service, and its propensity to organise through religious order's, charitable groups and associations.'<sup>163</sup> The revival of the hospice at this time can be traced to a small number of people, notably women, and organisations across numerous countries, that came to develop similar positions independently, through shared religious beliefs of compassion and care for the less fortunate. Where we see that ancient and medieval interpretations of hospices have occupied the 'derived plans' of religious building typologies such as churches and monasteries owing to care being a predominantly religious endeavour – the nineteenth-century hospice revival instead finds a building typology to draw from, the domestic home.

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<sup>160</sup> Ibid. (Moscrop & Robbins, pg.246)

<sup>161</sup> Ibid. (Moscrop) pg.246

<sup>162</sup> Kastenbaum, Death, Society and Human Experience (Pearson Education, 2011) pg.152

<sup>163</sup> David Clark, 'Women Pioneers in 19th Century Hospice Care', in End of life studies (University of Glasgow, 2014)



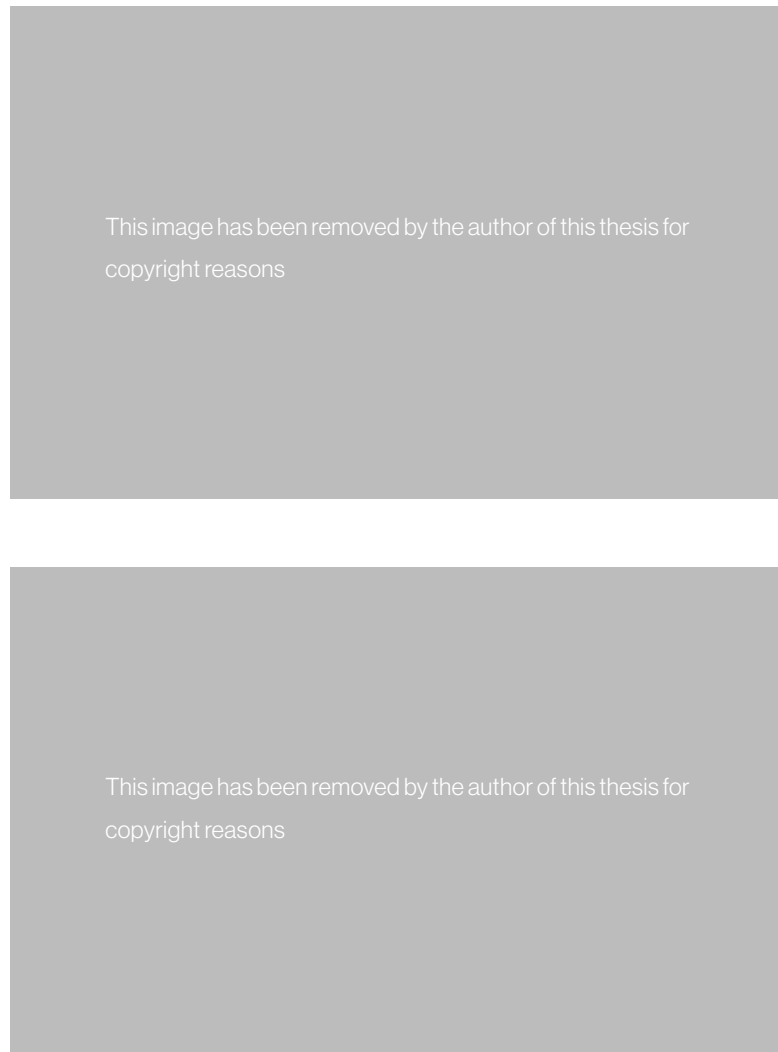


Fig. 3-5 The hospice at Harold's Cross, Dublin, Ireland

The religious inspiration is evident in the buildings and their adjacency to places of worship.

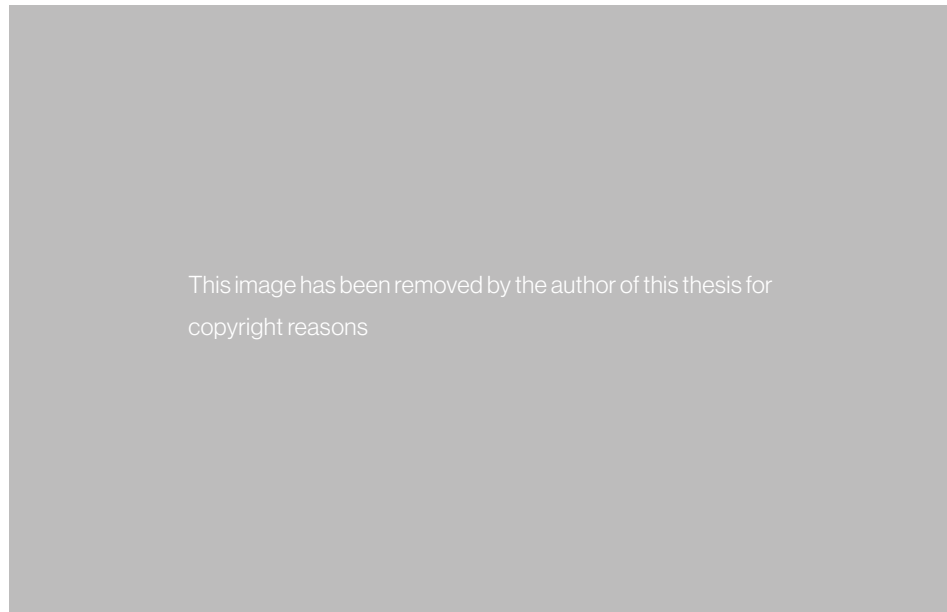


Fig. 3-6 The estate, Hospice des Dames Du Calvaire, Lyon, France

Though supported financially by prominent religious figures, the complex founded by Dame Jeanne Garnier was perhaps one of the first environments of care for the dying to re-purpose a residential building.

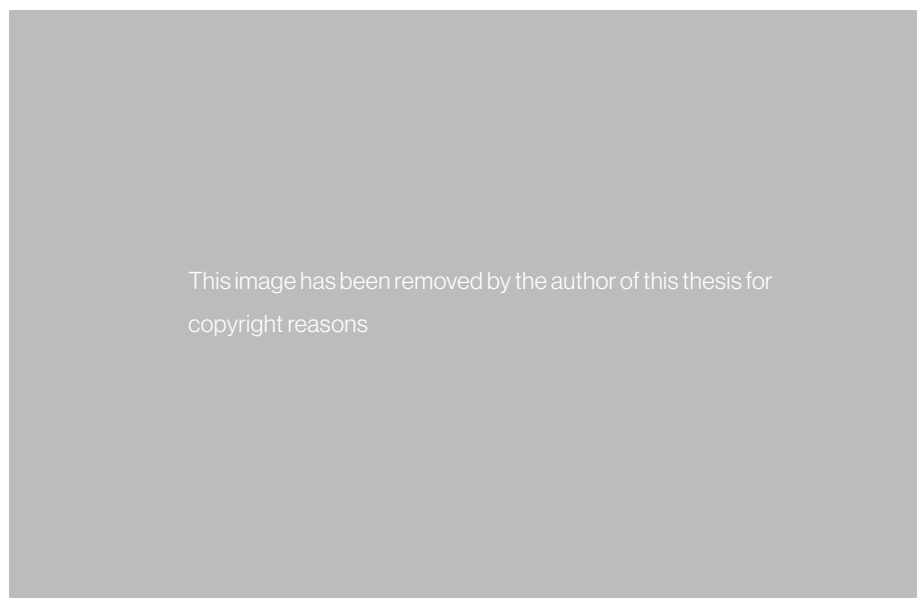


Fig. 3-7 The day-room at the Hospice des Dames, Du Calvaire, Marseilles, France

Visible is the overtly residential feel of the interior, with plenty of furniture and soft furnishings.

Two of the first iterations of the concept of a hospice-like environment (pre-hospices) were established in France and Ireland. The Frenchwoman Dame Jeanne Garnier formed the 'L'Association des Dames du Calvaire'<sup>164</sup> in 1842. The association, only open to women who were both bereaved and widowed, were supported by the Archbishop of Lyon in order to purchase a large house in the historic Saint-Irenee district in the heart of Lyon's old city dedicated to the ongoing care of incurable women, most likely suffering from cancer.<sup>165</sup> The term hospice used here has two meanings, related to both the emerging care of the dying but also the French word derived from the medieval word 'hospice'.

Similarly, The Religious Sisters of Charity, an uncloistered order founded by Mother Mary Aikenhead, established 'Our Lady's Hospice for the Dying' within accommodation they had previously owned in Harold's Cross, Dublin, Ireland, between 1860-1870, see Fig.3-5. Having previously run St. Vincent's Hospital in Dublin, the sisters later recognised a need for the care of those with incurable illnesses but who were not expected to survive long term. Goldin refers to the 'Our Lady's Hospice' as the earliest iteration of a building 'conforming in most respects to what we now know as a hospice'.<sup>166</sup> A description of the hospice states that 'this was obviously a converted house, with low, red-tiled passages and corridors, a broad-beamed roof, and pleasantly coloured wards and rooms'.<sup>167</sup> Fig.3-6 depicts the typical environment of this new iteration of hospices, retrofitted to exist within the domestic scale and settings of large houses. This is supported by Fig.3-7 of the Hospice's Dame du Calvaire taken from postcards that show scenes of domestic environments with very little evidence of a medical atmosphere. This is in part due to the religious concerns and a 'strong emphasis on the cure of the soul'<sup>168</sup> but would have been further emphasised by the nature of the pre-existing setting divided by function. Subsequently 'Our Lady's Hospice' commissioned a new wing for the hospice building designed by architect Mr. WM Byrne<sup>169</sup> circa 1890 to alleviate the demand for beds, making it possibly the first building constructed with a primary function of care for the dying.

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<sup>164</sup> Calvaire in French translates to English with the dual meaning of 'calvary' and 'suffering'.

<sup>165</sup> Marianna Karamanou and others, 'Treating the Incurables: Cancer Asylums in 18 Th and 19 Th Century', *Journal of B.U.ON.*, 22 (2017), 1367-71, pg.1369

<sup>166</sup> Goldin, 'A Protohospice at the Turn of the Century: St. Luke's House, London, from 1893 to 1921', *Journal of the History of Medicine and Allied Sciences*, XXXVI.4 (1981), 383-415, pg.390

<sup>167</sup> Ibid., pg.391

<sup>168</sup> Clark, 'Women Pioneers in 19th Century Hospice Care', in *End of life studies* (University of Glasgow, 2014)

<sup>169</sup> Katherine Butler, 'Our Lady's Hospice, Harold's Cross', *Dublin Historical Record*, 34.4 (1981), 122-35, pg.132

## The proto hospices of London

During, and shortly after the 1890s, several hospices were also founded in London, England. These select institutions were far more specific in their function than those of the earlier half of the nineteenth century and aspired to more holistic principles of care that can be ascribed as direct pre-cursors to Dame Cicely Saunders modern 'hospice movement'. The hospices discussed here are as Goldin describe - 'proto-hospices' - the initial experiments into the organisation and development of dedicated places of care for the dying in response to the contemporary meaning of hospice, rather than pre-hospices examined earlier in this chapter.<sup>170</sup> Similarly the result of religious motivations of individuals to help care for the dying, these proto-hospices were charitable societies, much like contemporary hospices today, thus affording a freedom from the larger hospitals of the time.

The very first was established by Frances Davidson in London in 1885. The Friedenheim, a crude moniker meaning 'home of peace' in German was given its name to set it apart from other spiritually led institutions of the time. From 1885 it occupied 133 Mildmay Road, Islington, London and had accommodation for eight beds, and was described as a small house with windows allowing private views out for patients and as having dedicated space for the staff.<sup>171</sup> In 1892, demand on the Friedenheim meant that the original premises were too small and the organisation moved to a larger house on Upper Avenue Road, Hampstead, that eventually housed fifty patients. Unfortunately, there is scant documentation on the Friedenheim, despite it being the first in London, however information uncovered by Broome for her doctoral research on the hospice documents the extent of building works that were undertaken to make the building 'fit for purpose' for its change of use from a home to hospice. This marks a crucial point where we can observe that the built environment was actively considered in light of the function of the hospice, for example the billiard room (an unnecessary function for those bed-bound) being sub-divided to provide space for a staff lounge and a chemist's dispensary.<sup>172</sup> Many other alterations took place in order to make the house an appropriate place of care, including such work as the installation of a lift for ease of access. Broome also describes additional major works to the house, that involved the construction

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<sup>170</sup> Goldin, 'A Protohospice at the Turn of the Century: St. Luke's House, London, from 1893 to 1921', *Journal of the History of Medicine and Allied Sciences*, XXXVI.4 (1981), 383-415, pg.385

<sup>171</sup> Helen Isobel Broome, 'Neither Curable nor Incurable but Actually Dying': The History of Care at the Friedenheim/St. Columba's Hospital, Home of Peace for the Dying (1885-1981)' (Doctoral, University of Southampton, 2011) pg.94

<sup>172</sup> Ibid. pg.101



Fig. 3-8. The Friedenheim, London

One of the first proto-hospices of London that sought to move away from religious connotations of care of the dying. Just visible at the far back right is the additional wing built for staff and the external corridor allowing patients to access the outdoor air.

of a wide balcony<sup>173</sup> so that bedridden patients could enjoy fresh air externally, landscaping of the grounds to ensure each patient had a favourable view, and the construction of a separate Nurses accommodation building, see Fig.3-8.<sup>174</sup> Ongoing works were also documented, which we may interpret as highlighting the hospice's need for the constant renewal of internal decorating and maintenance works in order to maintain its environment.

Shortly after the Friedenheim opened, in 1894, St. Luke's Home for the Dying Poor was opened. St. Luke's is one of the most notable proto hospices, primarily owing to its influence on Dame Cicely Saunders. Prior to her development of St. Christopher's (which will be discussed later) she had worked at St. Luke's during the 1950s as a volunteer nurse, providing her with 'a model: not by any means her only source, but a major one'<sup>175</sup> where she was able to observe and learn more about the emerging care practices and environment suitable for the dying. Secondly, St. Luke's was established by Dr Howard Barrett, making St. Luke's the first hospice to be founded and managed by a medical professional in collaboration with the West London Mission, a Methodist denomination. St. Luke's was first located at 50 Osnaburgh Street, Regent's Park, where it remained for seven years. An account of the building from their annual reports that 'we do not profess that it fulfils our ideal in many respects, but ideals are not much upon the market'.<sup>176</sup> The description of the house, see Fig.3-9, place it favourably alongside the environment that the Friedenheim offered, with 'little cosy corners with palms and ferns and easy-chairs'<sup>177</sup> and words such as 'cheerful, comfortable, neat' used as descriptors of the internal experience of the environment.

Recognised also however, were the difficulties of working within the constraints of an existing building, with it being noted, that amongst the defects of 50 Osnaburgh Street, the accommodation they were able to offer the nursing staff was deemed unsatisfactory due to spatial constraints.<sup>178</sup> In 1901, the organisation moved to new premises on Lawn Road, Hampstead, a pair of terraced houses, see Fig.3-10. This building was refurbished and redecorated to the needs of the patients, however they moved a year later, as the lease on Lawn Road forbid the house to be used for

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173 Though there are no records that document the physical width of this balcony, the suggestion that bedridden patients were able to use this space infer that it would have been wide enough to accommodate a bed or wheelchair.

174 Broome, "Neither Curable nor Incurable but Actually Dying": The History of Care at the Friedenheim/St. Columba's Hospital, Home of Peace for the Dying (1885-1981)' (Doctoral, University of Southampton, 2011) pg.105

175 Goldin, 'A Protohospice at the Turn of the Century: St. Luke's House, London, from 1893 to 1921', *Journal of the History of Medicine and Allied Sciences*, XXXVI.4 (1981), 383-415, pg.385

176 Ibid. pg.400

177 Ibid.pg. 401

178 Ibid.

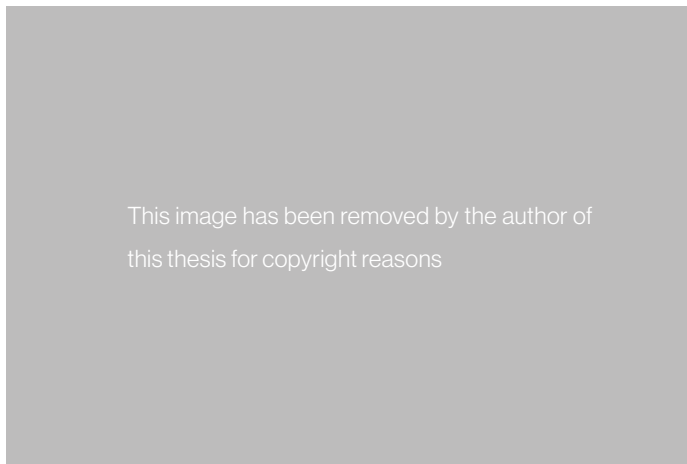


Fig. 3-9. 50 Osnaburgh Street, St Luke's

The interior environments of the original premises of St. Luke's at 50 Osnaburgh Street, much like the images of Lawn Road, the 'homely' decor is evident, also note that the rooms accommodate multiple persons, with no single rooms on offer.

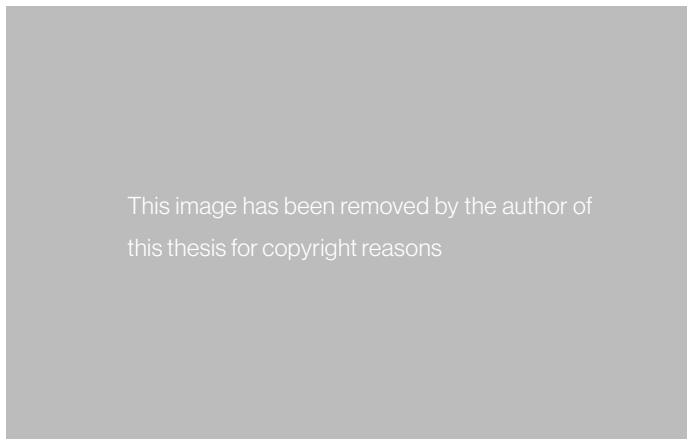
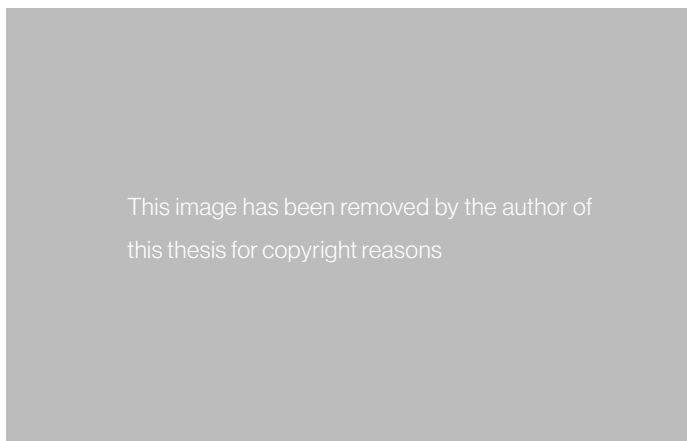


Fig. 3-10. Lawn Road, St. Luke's

The exterior and interior of the mansion at Lawn Road, Hampstead, a short lived home of St. Luke's. Both the interior and exterior show the unchanged nature of the formerly residential building in use as a proto-hospice.



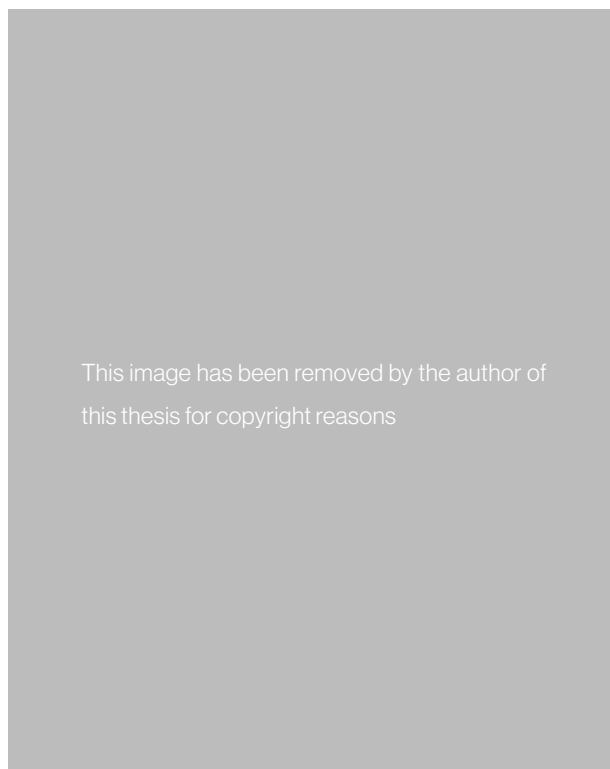
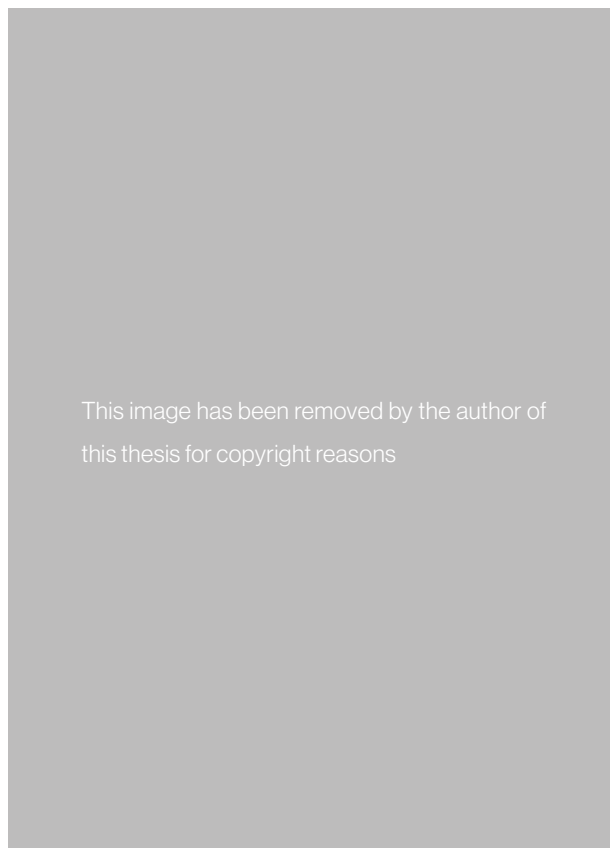


Fig. 3-11. Pembroke Square, St. Luke's

Another residential building occupied by St. Luke's, the images above show the exterior and interior of Pembroke Square. Note the close proximity of the patient beds in the room/ward area.



anything other than domestic purposes and was challenged by a local property developer claiming the presence of the hospice would prevent the letting of his properties. Regardless of their status of occupying outwardly domestic buildings, these proto hospices were nonetheless victims of the emerging taboo surrounding death and dying.

At this time, the philanthropic ideologies of a home for the dying were maintained by the charitable donations from the higher and richer classes, yet the notion of the hospice being physically amongst the affluent neighbourhoods was received negatively by many residents of the hospices. In 1903, the hospice moved to Pembroke Square, shown in Fig.3-11, another large domestic house before in 1923 moving a short distance to Hereford Road where a purpose-built facility was reportedly built. The hospice, named Hereford Lodge remained unscathed throughout the two world wars, yet there is little surviving information regarding this building apart from archival records of its address and purpose. The building was demolished in the mid 1980s following its services being taken over by two local NHS hospitals.

Running in parallel with the development of St. Luke's – another influential proto-hospice was being set up in Hackney - St Joseph's. Following on from their work in at Harold's Cross in Dublin, the Religious Sisters of Charity were invited by Cardinal Vaughan, then Archbishop of Westminster and Father Peter Gallwey, a Jesuit Priest<sup>179</sup> at the turn of the century to the borough of Hackney, which at the time suffered from extreme poverty and inadequate housing conditions. It was originally intended that the Sister's would move into rented accommodation, No.6 Cambridge Lodge on Mare Street. However, before this was finalised, the entire Cambridge Lodge estate consisting of six villas, a house and a substantial garden became available, expanding greatly the original ambitions of the Sisters allowing the provision of 25 beds, see Fig.3-12 & 13. In 1905, the site was gifted anonymously to the Sisters, and the hospice opened to the public; it operates on the same site today.

St. Joseph's played a pivotal role in the bridging the proto-hospices and the early iterations of modern hospices, unlike other proto-hospices at the time that favoured 'home-care' with a focus on replicating traditional domestic environments, the Sister's recognised that there needed to be 'an affiliation with a hospital for the sake of an antiseptic environment and ready source of medications

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179 St Joseph's Hospice, Our History (n.d) <<https://www.stjh.org.uk/about-us/our-history>> [accessed 19th Sep]

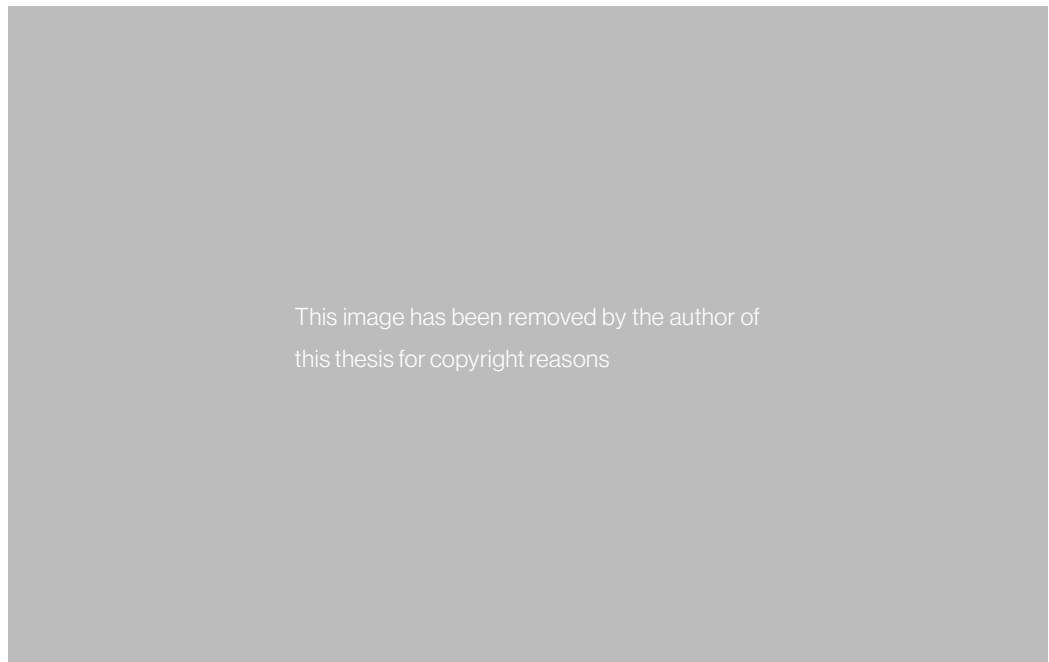


Fig. 3-12. Bedroom at St.Joseph's, Hackney

As with the interior of the earlier proto-hospices, the decorations and furniture are reminiscent of domestic interiors, with a timber unit acting as clinical storage. However, in contrast to the earlier proto-hospices, the layout and textiles of the beds are beginning to resemble that of a more institutional hospital environment - rather than a domestic atmosphere. Despite this shift, there is a cross visible on the back wall, indicating the ongoing influence of religion in care of the dying.

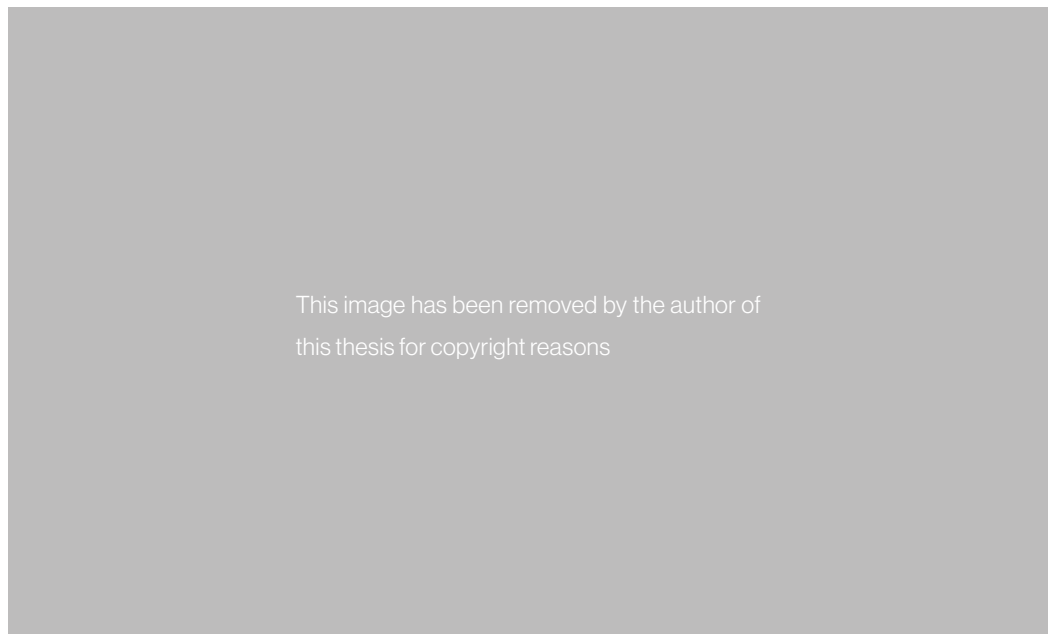


Fig. 3-13. Entrance to St.Joseph's, Hackney

Note the nearby park and residential neighbours with its grand architecture.

– but it ought not be an acute hospital.’<sup>180</sup> The latter part of this statement signifies a significant point in the development of the hospice as a building typology. The Sisters recognised that to provide the most appropriate and up to date care, hospices needed to align themselves to benefit from institutional principles of hospital care, – for example the word antiseptic in the previous quote most likely referred to what we would call sterile – but not at the expense of losing their unique identity and character. This was perhaps the first recognition that hospices required individual buildings that were designed and tailored to the specific needs of the dying. The influence of St. Joseph’s continued long after its establishment – as a newly qualified doctor, Dame Cicely Saunders spent several years researching pain control at the hospice formulating her plans for an entirely new purpose-built hospice. It is important to note that these early proto hospices of the nineteenth and early twentieth-century symbolised the architectural antithesis of hospitals at the time. The influence of the work of Florence Nightingale and her seminal *Notes on Hospitals*, in combination with increasing knowledge of medical science resulted in hospital environments that were ‘cold, naked and clean’<sup>181</sup> as can be seen in the previous images of St. Joseph’s. The growing knowledge on the classification and transfer of disease transformed the early nineteenth-century hospital as a place of convalescence into a place of examination and observation, where the architectural design of ventilation, lighting and hygiene overtook the experience of the patient. The progression of the hospital offering treatment to previously untreatable ailments served to generate a fear of death and dying, as a failure of the new medical era. Death had previously been in the domestic realm, with the living room as ‘a final domestic resting place’<sup>182</sup> for viewing of the body. Hospice’s charitable nature allowed them to focus on details of the environment, considering the person in response to the scale of the domestic house, rather than the hospitals of the time who were dealing with larger numbers of patients.

At the forefront of medical practices for the terminally ill and dying, the previously mentioned proto-hospices could be seen as unintentional architectural explorations of the home as hospice model, looking at the benefits of a domestic-like environment not only physically but spiritually and psychologically in terms of home-comfort and familiarity. The proto hospices led by those mostly outside the medical profession and in retrofitted environments ‘created some of the pre-conditions

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180 Goldin, ‘A Prothospice at the Turn of the Century: St. Luke’s House, London, from 1893 to 1921’, *Journal of the History of Medicine and Allied Sciences*, XXXVI.4 (1981), 383-415, 392

181 Ibid., pg.392

182 Edwin Heathcote, *The Meaning of Home* (London: Frances Lincoln, 2012) Pg. 34

1840	1842	L'Association Dame du Calvaire, Lyon, France
1850		Our Lady's Hospice for the Dying, Dublin, Ireland
1860		
1870	1872	St. Thomas's Hospital re-opens in London, incorporating 'Nightingale wards' influenced by the work of Florence Nightingale
1880	1885	The Friedenheim, Islington, London
1890	1895	St. Luke's Home, Islington, London
	1896	St. Rose's Home for Incurables, Manhattan, New York, USA
1900	1905	St Joseph's, Hackney, London
1910		
1920		
1930	1929	Marie Curie Hospital opens, marking the origins of the Marie Curie charity
1940		
1950	1948	Birth of the NHS
	1952	Marie Curie begins their programme of building purpose-built cancer homes
1960		
1970	1967	St Christopher's, Sydenham, London
		Coppercliff Hospice, Brighton

Fig. 3-14. Timeline of the hospice evolution from the 19th C

The evolution of early proto-hospices and other notable healthcare environments, it is worth noting that the early proto-hospices were fairly close to the shift in attitude toward health and medicine as championed by Florence Nightingale.

for wider developments in modern hospice and palliative care'.<sup>183</sup> The nature of their emergence in existing dwellings, especially, channelled the concept of home as having beneficial qualities. Most critically, the idea of a nurturing environment was not limited to the patients, but rather as noted in each of the proto hospices discussed, was extended to the care team and staff, with many renovating or re-building their staff accommodation.

## The modern hospice movement

The proto hospices undoubtedly paved the way for the emerging modern hospice movement, providing spaces where healthcare professionals could develop methods and approaches specific to the process of dying away from the institutional settings of the NHS.<sup>184</sup> Though the growth of the hospice movement was interrupted by the impact of the two World Wars, the movement again found traction in the post War years. In 1948, following the destruction of their first hospital premises in the blitz, the Marie Curie Memorial Foundation was established. In the ensuing years the Marie Curie Foundation undertook a nationwide investigation into the needs of those suffering with cancer with a focus on environmental and domestic needs. In 1952, on the first floors of a National Trust property in Cupar, Fife<sup>185</sup>, the first of ten Marie Curie run residential care homes for cancer patients was opened, see Fig.3-15 & 16.<sup>186</sup> These ten homes built between 1950-60 were established in existing properties that included a 'prep school, a railwaymen's convalescent home, [and] a police orphanage'<sup>187</sup> and were each adapted for their use for the care of critically ill patients. However, post-occupancy, Marie Curie recognised the retrofitted buildings as inappropriate for the needs of the patients and in 1965 the first purpose built home opened in Belfast, Ireland, shortly followed in 1966 by another in Edinburgh, Scotland. Unfortunately, there is little surviving record of these ground-breaking purpose-built homes meaning that we cannot examine how the architectural design considered and responded to the requirements of the patients. Nonetheless, Marie Curie's identification of adapted buildings generally being unfit for purpose signalled one of the first major shifts for the hospice typology.

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<sup>183</sup> Clark, 'Women Pioneers in 19th Century Hospice Care', in *End of life studies* University of Glasgow, 2014)

<sup>184</sup> The United Kingdom's National Health Service (NHS) was founded in 1948, transforming the fragmented pre-war health services of the nation into a comprehensive service with two over-arching principles of free healthcare and that care would be based on need rather than income.

<sup>185</sup> Marie Curie, Our History (n.d) <<https://www.mariecurie.org.uk/who/our-history>> [accessed 19th September]

<sup>186</sup> It is interesting to point out that Holme Tower, the subject case study for this thesis was one of the ten, this will be explored in further detail in a subsequent chapter

<sup>187</sup> Curie, Our History (n.d) <<https://www.mariecurie.org.uk/who/our-history>> [accessed 19th September]

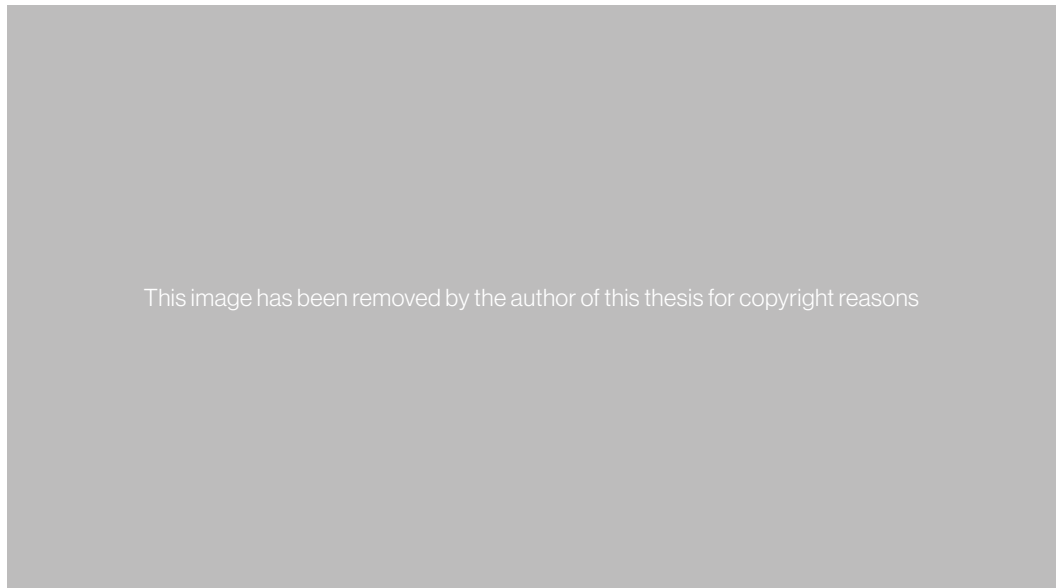


Fig. 3-15. Hill of Tarvit, Cupar, Fife, Scotland

Marie Curie's first purpose - built home for cancer patients. The manicured gardens in the foreground of the photo suggest a potential recognition of the importance of outside space.

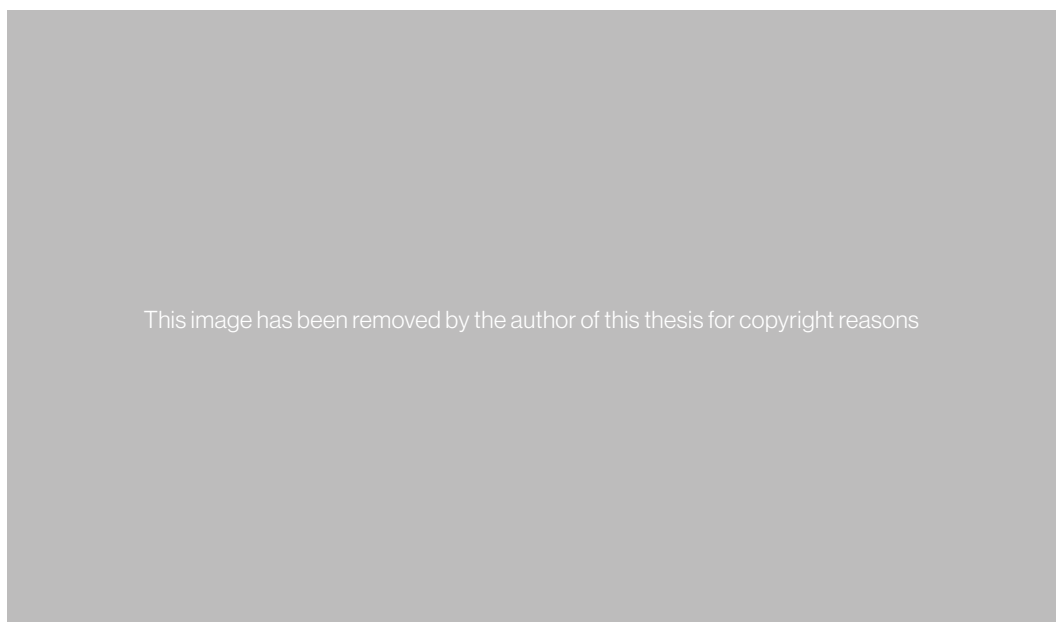


Fig. 3-16. Interior of the Hill of Tarvit

The domestic interior of the day lounge of the Marie Curie home, as the external photograph shows above, though this was the purpose built home for cancer care, the architectural design is one that speaks to domesticity rather than medicinal. We might consider that this type of patient-centric environment is one similar now to the approach of institutional places of healthcare in emulating the 'hotel' or 'home' experience.

## Co-production

St. Christopher's in Sydenham, London, is arguably, one of the most famous hospice buildings and the first research and teaching hospice. One of the first purpose-built hospices, it opened in 1967 and was the work of palliative care pioneer Dame Cicely Saunders. Though other purpose-built hospices, such as those built by Marie Curie, were opened before St. Christopher's, Saunder's desire to exploit the relationship between our environment and well-being is fundamental to the hospice typology today. During her time working at St. Joseph's, Saunder's worked in an extension to one of the wings designed by the architects Stewart, Hendry, and Smith, see Fig.3-17, whom she contacted to assist with her vision for St. Christopher's. The hospice as planned by Saunders and her architects, was arranged over five floors, with each offering three four-bed bays and two private double rooms for those at the very end stages of life, see Fig.3-18. The building facilitated the residential care of up to sixty in-patients with supporting ancillary spaces that were central to Saunder's vision for a holistic environment that could improve both patients and staff well-being. These spaces included a patient lounge, beauty salon, complementary treatment rooms and a spiritual room. Generous staff amenities, such as a lounge, canteen and dining room were designed to be separate to the spaces provided for the patients and their visitors offering a place for the members of staff to rest. It was not only the patient facing side of the hospice that had been meticulously planned, but also the clinical, with a mortuary also included in the programme of the hospice. The inclusion of this allowed the hospice to play an active role in the wider medical community of palliative care research, contributing to the developing field and innovations in care.

In line with the vision that Saunders was attempting to achieve, that of an atmosphere of home 'one may have expected [it to] have leaned towards a more residential design'<sup>188</sup> however it was the prevailing architectural style at the time, modernism (or the 'International Style') that Saunder's and Peter Smith, the project architect, adopted in order to provide an environment that respected both the medical needs and comfort and dignity of the patients. An example of this is the cantilevered 'balconies' that dominate the main west elevation of the hospice building, seen in Fig.3-19. Utilising features of the modernist movement, the balconies are canted at each four-bed bay, projecting out from the main building on an angle to create an informal additional 'lounge' space for both patients and visitors to inhabit. Designed with large openings, the internal 'balcony' sought to connect the internal spaces with the outside and benefitted from warm evening sunlight that Saunders

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<sup>188</sup> Dr Avnita Amin, 'St.Christopher's Hospice: A Space for Dying', in Archives of Dame Cicely Saunders (1918-2005): Cataloguing the papers of the modern hospice pioneer 2015)

This image has been removed by the author of this thesis for copyright reasons

Fig. 3-17. The extension to St. Joseph's Hospice, Hackney

Our Lady's Wing, the 1957 extension to St. Joseph's designed by architects, Stewart, Hendry and Smith, drawing inspiration from the Peckham Health Centre, a seminal example of modernist architecture at the time. Dame Cicely Saunder's worked here whilst developing her vision for St. Christopher's. This was demolished to make way for a new building circa 1994/5



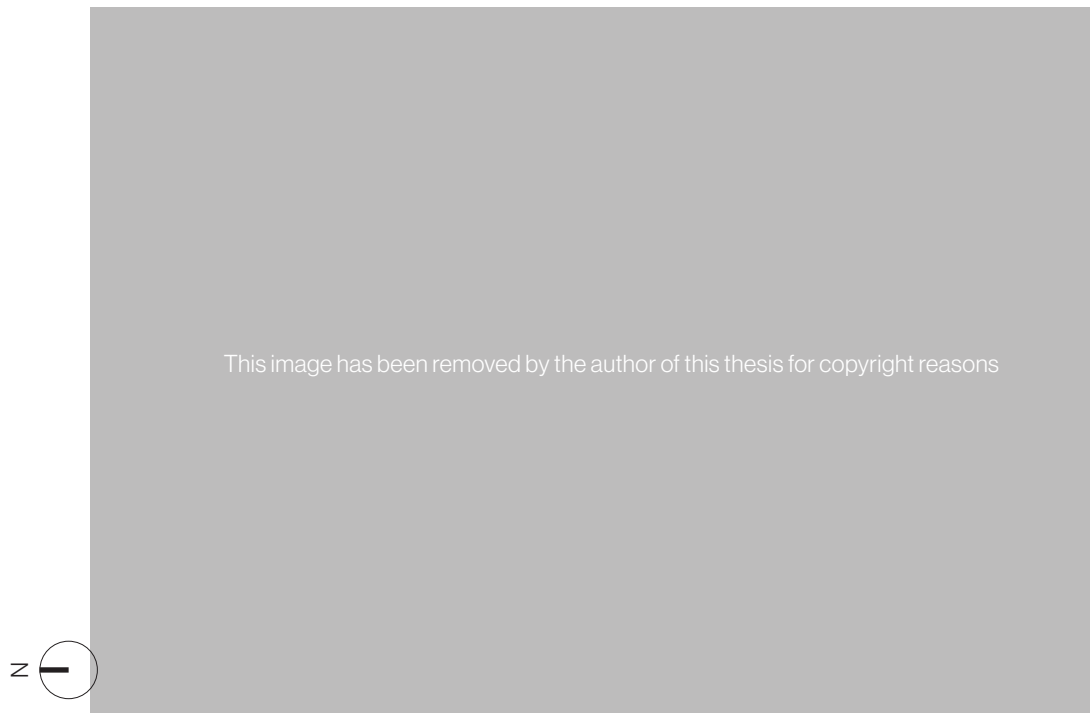


Fig. 3-18. Plan of St.Christopher's Hospice, Sydenham

A plan of the first floor of St. Christopher's Hospice, believed to be as existing in 1975, though the drawing block is dated to 1995. Visible clearly on this plan drawing is the canted windows that connect through to the patient bedrooms via a sunlit corridor space. This could be used by patients or their visitors as more private spaces with the curtains drawn across.

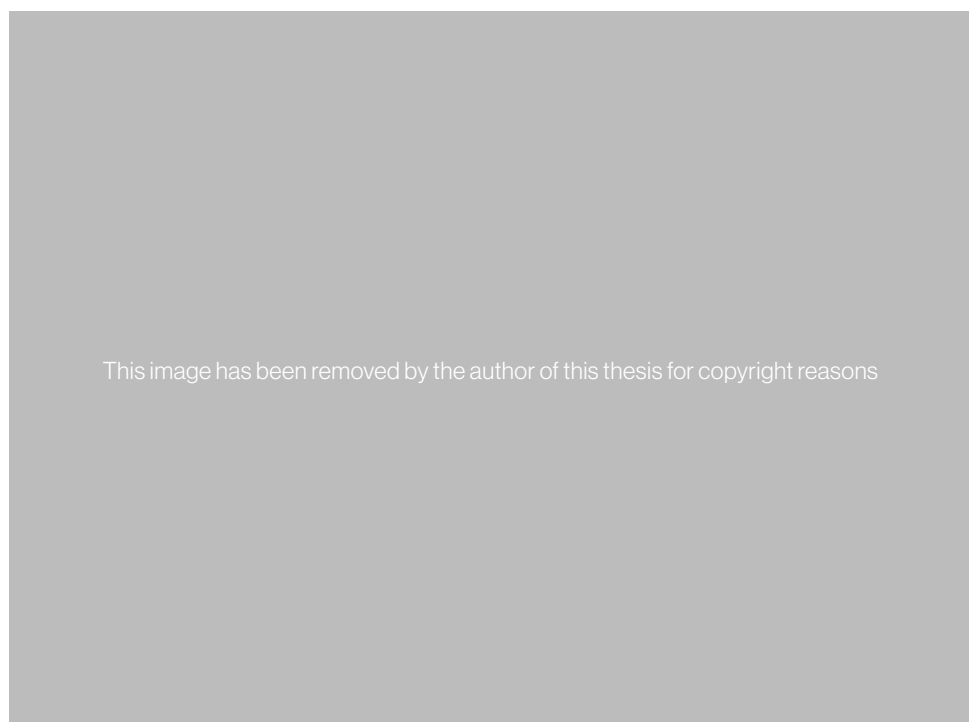


Fig. 3-19. Exterior facade of St.Christopher's Hospice, Sydenham

The photograph above shows the canted balconies that span the patient bedrooms. Note that the rooms have been renovated to close off the previously open corridor in favour of privacy for each bedroom.

hoped would enhance a feeling of spaciousness, intimacy, and comfort, akin to the contemporary architectural concept of winter gardens, see Fig.3-20 & 21. Key to Saunder's concept for the hospice was her first-hand experience of caring for the dying from her time working St. Luke's and St. Joseph's. Her knowledge of emerging palliative care, as nurse, doctor, and social worker, was able to inform the design of the hospice to positively improve not only patient, but staff experience. For example, ample storage closets and sluices were placed adjacent to patient rooms to reduce walking times and oversized bathrooms were designed to accommodate beds for those with limited mobility.<sup>189</sup> These insights documented by Saunders were then translated into a series of spatial underpinnings developed by Smith.

Saunder's and Smith's combined vision sought to create an atmosphere that was person-centric and supportive of the everyday life of the hospice, arguably preceding the approach of contemporary architect Peter Zumthor, who describes of architecture overall being 'an envelope and background for life which goes on in and around it'.<sup>190</sup> The significance of St. Christopher's to the hospice typology as Amin argues is not the design of the building itself 'which had minimal architectural value, but on the place created, the atmosphere it fostered'.<sup>191</sup> We know that St. Christopher's was among one of the first purpose-built environments for the requirements of palliative care though anecdotally it is referred to as the 'first' hospice, perhaps due to Saunder's persistent dissemination of the emerging hospice movement and model. It's legacy, however, this thesis argues, much like Amin, stems not from the architecture itself but from the design process. Together, the multi-disciplinary team of Saunder's and Smith were able to 'focus on the design of St. Christopher's in more detail than ha[d] been previously done'<sup>192</sup> – an approach that is posited here as only possible due to the co-productive nature of the design process between clinician and architect. Clark, author of Saunder's biography highlights that co-production was central to the development of the hospice, stating that 'it was not always clear where the ideas of each of them begun and ended. It was a remarkable partnership not always found between architect and client.'<sup>193</sup> The building at St. Christopher's operates as a hospice today though it has been refurbished several times to modernise the facilities, most notably the four bed bays have been turned into single

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189 Amin, 'St.Christopher's Hospice: A Space for Dying', in Archives of Dame Cicely Saunders (1918-2005): Cataloguing the papers of the modern hospice pioneer 2015)

190 Peter Zumthor, *Thinking Architecture* (Basel; Boston, Mass.: Birkhäuser, 1999)

191 Amin, 'St.Christopher's Hospice: A Space for Dying', in Archives of Dame Cicely Saunders (1918-2005): Cataloguing the papers of the modern hospice pioneer 2015)

192 Ibid.

193 David Clark, *Cicely Saunders : A Life and Legacy*, 2018)

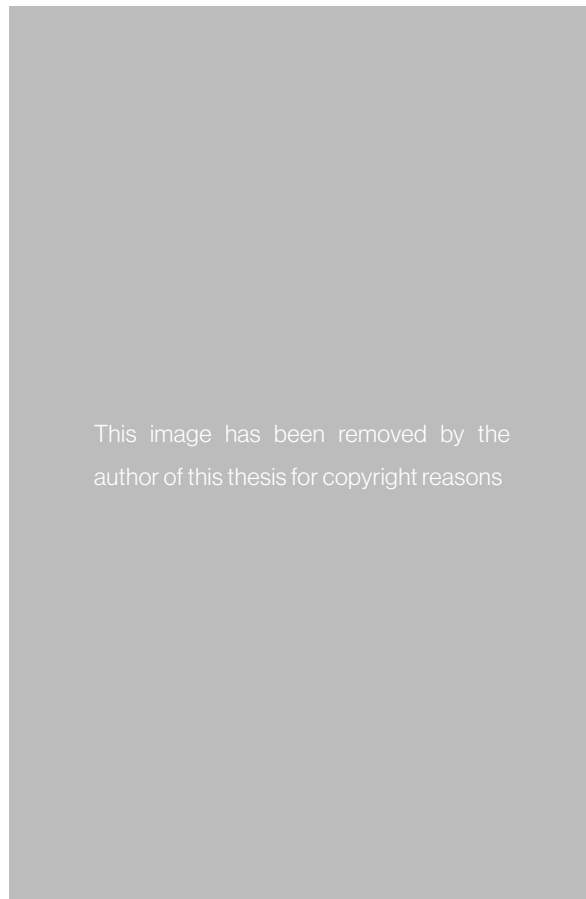


Fig. 3-20. Internal balcony at St.Christopher's Hospice, Sydenham

Adjacent to the bays, the curtain that separates them is possible to be seen in the background. The canted design it is presumed allowed for a patient bed to be easily wheeled into position next to the windows, whilst simultaneously allowing for clear circulation.

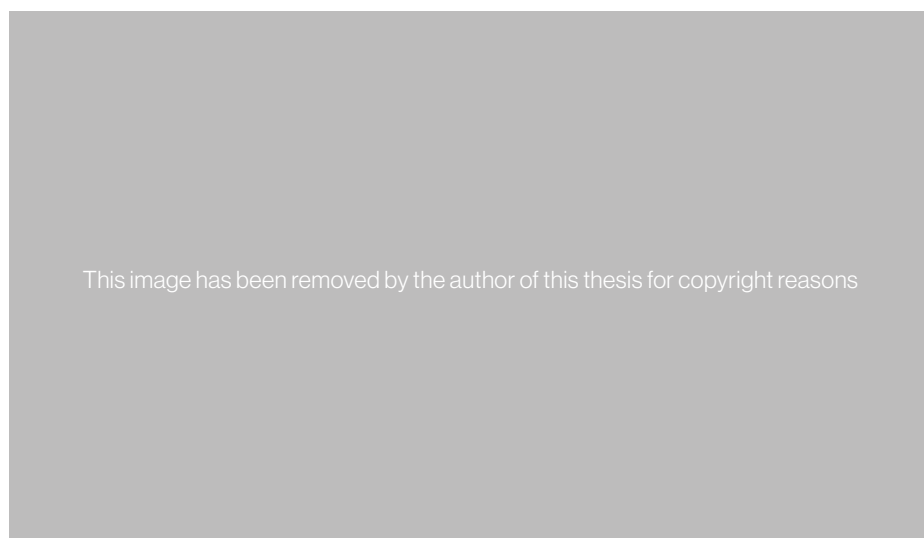


Fig. 3-21. Looking toward the bays, St.Christopher's Hospice, Sydenham

The 'internal' balcony is seen in the background with a visitor sat in it reading, note how close this is to the bed next to it

patient rooms that subsequently subsumed the internal 'balcony'. Yet, St. Christopher's remains an aspiration for many hospice providers today when faced with the opportunity to refurbish or build new accommodation, not in physical form but as a phenomenological model. The building was the outcome of Saunder's concept for a sense of community between patients, staff and local area that would translate to positive experiences and well-being.

## The contemporary hospice

### Hospice in the twentieth century

As they currently exist, contemporary in-patient hospices in the UK provide residential twenty-four hour care to patients recognised as being what the General Medical Council define as 'approaching end of life' - those likely to die imminently and within the next 12 months irrespective of diagnosis.<sup>194</sup> Care provided by in-patient hospices typically falls under two types of stay, end of life, for those likely to die imminently, or respite, providing a short stay to provide relief to either the patient or their carer's or for active symptom control. Prior to 2020 there were over two hundred recognised hospice providers in the United Kingdom offering palliative care to adults and children.<sup>195</sup> Since the modern hospice movement gained traction in the late 1960s, due to the success of St. Christopher's and the tireless publishing and campaigning of Saunders, the decades following saw a large growth in the construction of dedicated hospice buildings. It was Saunders:

active choice to build the Hospice outside the bureaucracy and constrictions of the National Health Service [which] allowed for a flexibility in design and building which were important in creating the philosophy of hospice care that evolved from St. Christopher's.<sup>196</sup>

As such hospice today remains as organisational bodies predominantly independent from but complementary to the NHS, both physically and strategically, in part owing to the proto-hospices

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194 "Guidance", General Medical Council, 2019, <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/guidance#targetText=Patients%20who%20are%20approaching%20the, and%20to%20die%20with%20dignity.&targetText=For%20the%20purposes%20of%20this, within%20the%20next%2012%20months>.

195 Melanie Hodson, Request for Information - PhD Project Email received 22nd October Melanie</author></authors></contributors><titles><title>Request for information - PhD project</title></titles><dates><year>2019</year><pub-dates><date>22nd October</date></pub-dates></dates><work-type>Email</work-type><urls></urls></record></Cite></EndNote>

196 Amin, 'St. Christopher's Hospice: A Space for Dying', in Archives of Dame Cicely Saunders (1918-2005): Cataloguing the papers of the modern hospice pioneer (2015)

original religious and philanthropic missions and Saunder's work at St. Christopher's. Negatively however, this indicates that many were built in affluent areas rather than based on community need. Yet contemporary hospices are required to operate within extremely different contexts (both medically and socially as discussed in the previous chapter) but also architecturally, facing the constraints and complex climate of building regulation and the construction industry.

It is undeniable that the construction of St. Christopher's was a seminal turning point for the hospice typology, however, since the 1960s an impeding factor in the evolution of the typology may be comparable to those facing the design of broader healthcare settings, most notably hospitals, during the same period. As the National Health Service experienced a period of extreme expansion, Amin describes that 'restrictions of finance, the multiplicity of needs and limited physical space in urban areas led to continual setbacks in design, planning and building'.<sup>197</sup> Design in the context of the NHS is bound by strict regulations and procurement frameworks necessitating pre-qualification. Specialised knowledge of medical equipment, familiarity with authorised standards and processes has led to healthcare architecture, in broad terms, to be regarded as an exclusive architectural specialism; with a proliferation of practices who focus solely on medical environments. Such as the aptly named Medical Architecture and LSI Architects, amongst many others. During a conference regarding the sociological exploration of architecture in the context of health and care, architect Stephen Witherford, principal of award-winning architects Witherford Watson Mann Architects described the nature of labelling architectural practices as 'specialists' may be regarded as a threat to creative practice and design innovation by potentially encouraging those in charge of particular building typologies to follow 'one-size-fits-all' approaches.<sup>198</sup> The hospice remains outside the immediate constraints of the NHS, but still responsive to required contracts and outcomes for care. As we witness the process of death and dying becoming further over-medicalised, so too can we observe that the environment and design is shifting to reflect this with 50% of UK deaths taking place within acute hospitals.<sup>199</sup>

Alongside the institutional and industry difficulties described above, architects and designers today also face the further challenge of grappling with the social and cultural phenomenon of the taboo of death and dying. Valin's et al assert that the creative industry suffers from 'ineptitude

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<sup>197</sup> Ibid.

<sup>198</sup> Stephen Witherford, 'Plenary Speaker', in 'Buildings in the Making': A Sociological Exploration of Architectural Design for Care (York, 2018)

<sup>199</sup> Office for National Statistics, 'National Survey of Bereaved People (Voices): England, 2015', 2016)

and embarrassment when designing for places for people who are dying.<sup>200</sup> Whilst we have seen that the hospice typology is opening itself up to a broader range of patient needs as opposed to solely EoLC, death and dying remains a pertinent part of the hospice programme. Emphasised in architectural education, architects and designers faced with a design brief are actively encouraged to seek cues from first-hand experience to form contextual, responsive, and sensitive creation of space that is fit for both function and users.<sup>201</sup> First-hand, or tacit knowledge of a particular building type or function can highlight nuances of lived experience that designers can respond to – as we saw with Dame Cicely Saunder's contributions to the design of St. Christopher's with regards to the efficiency of spaces for staff members. However, Saunder's was but one voice within the hospice organisation - this thesis seeks to uncover a hierarchy of voices to generate a broader understanding of the requirements of the hospice building.

Architects, as the 'carers' of the built environments have a duty to design buildings that are sympathetic and appropriate for the intended function and those that are using it – a duty perhaps even more pertinent in environments for care and well-being. However, in the case of the hospice, Worpole writes:

few contemporary architects and designers are able to bring extensive historical reference, let alone direct experience. This is new territory for many, and because it has death – that most mysterious and irreducible human fact – at its centre, it is territory that requires sensitive, reflexive kinds of thinking. Indeed it requires a certain piety and humility – not always qualities associated with architects.<sup>202</sup>

The statement may be pessimistic in nature in relation to the architectural profession but highlights additional issues facing those responsible the development of the hospice typology. Worpole draws attention to the probable lack of direct experience in contrast to other common building typologies, such as libraries or schools. We might argue that this cannot be remedied in a direct way by architectural education or practice and relies instead on the personal experience of architects or designers. Yet this positionality can be said to be true of many building types, intended occupants

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200 Martin, S. Valins and others, 'The in-Patient Hospice - Theory and Case Study', in *Futurecare : New Directions in Planning Health and Care Environments*. ed. by Martin Valins and Derek Salter (Oxford: Blackwell Science, 1996), pp. 104-13, pg 109

201 Bellamy, 'The Insider Vs the Outsider: Architectural Investigations of Palliative Care Environments as Both Researcher and Daughter', in *AHRA Young Researchers Symposium* (Newcastle University 2020) pg.4

202 Worpole, *Modern Hospice Design : The Architecture of Palliative Care* (London, New York: Routledge, 2009) pg.9

or population demographics – there are innumerable realities that architects and designers may not have lived experience of - and this should not be considered an automatic impediment to the ability to design for others. As architect Níall McLaughlin summarised we must 'strive to imagine what it is to be someone else experiencing a place. This intuition is the cornerstone of an architect's role.'<sup>203</sup> Part of this intuition, correspondingly is, the ability to recognise when additional expertise is required to develop respectful and creative architectural strategies for the requirements of the brief and programme. For example when designing a religious building that must respect certain rituals. It is an empathetic and collaborative outlook that the author believes is vital to the development of the hospice typology – architects and designers who can critically imagine themselves within a new other context. A more detailed discussion regarding empathy as a distinct architectural skill will take place in Chapter 7.

### Functions of the hospice today

The model developed by Dame Cicely Saunders and her architects Stewart, Hendry, and Smith in 1967 offered a modest range of services for those receiving palliative care and facilitated the definition that 'the principle architectural feature of the hospice was patient accommodation'<sup>204</sup>. A key development within St. Christopher's, however, was the additional inclusion of space dedicated to complementary care such as treatment rooms, a hairdresser, and a beauty salon, that offered differing types of care under the holistic principles of palliative care at the time. The majority of the two hundred hospice providers in the UK now are individual organisations,<sup>205</sup> with an increasing number of hospices for children and young people. It should be noted that the scope of this study does not include a discussion on hospices for children and young people. This is a throwback to their proto-hospice origins - and as such hospices have seemingly developed their functionality idiosyncratically.

Despite the history of the hospices demonstrating a physical distance away from hospitals, this is now shifting to hospice's inclusion within hospital grounds to access other services and personnel. The capacities of individual hospices have been added and expanded to include functions that

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203 Níall McLaughlin Architects, p.15

204 Ken Worpole, 'A Home at the End of Life: Changing Definitions of 'Homeliness' in the Hospice Movement and End-of-Life Care in the UK', in *Ways of Home Making in Care for Later Life*. ed. by Bernike Pasveer and others (Singapore: Springer Singapore, 2020), pp. 135-58, pg 148

205 There are several larger organisations, such as Marie Curie, Macmillan and Sue Ryder who are responsible for multiple hospice facilities.

are responsive to local and contextual demands and requirements. It may be owing to the nature or size of a local hospital or other medical provisions – or lack thereof – that these hospices, collectively, begun to adapt to offer a wider range of functions than solely in-patient care to their local community. Alongside, bedded in-patient care, hospices, as explained by HospiceUK now also provide a wide range of critical additional services such as:

pain and symptom control; community-based services, such as Hospice at Home; psychological and social support; rehabilitation, such as physiotherapy and occupational therapy. Such services aim to help people remain independent and improve their quality of life; complementary therapies, such as massage and aromatherapy; spiritual care; family care; companionship and practical support services to help people living at home; practical and financial advice; bereavement care.<sup>206</sup>

The above services may be provided holistically during in-patient stays but also as part of out-patient services offered at day hospice units that are increasingly being situated within the footprint of in-patient hospices. This has marked a slow shift from the hospice as a facility dedicated to residential patient care to what Worpole describes as a ‘therapeutic community or “home from home”’.<sup>207</sup> Day hospice accommodation may house lymphoedema and other clinics, complementary care, and meeting spaces and whilst the day hospice is not within the scope of this thesis, it is important to note that they provide an integral aspect of EoLC within local communities.

Practically, there are fundamental spaces that the in-patient hospice must accommodate to provide not only the care described above but clinical care for those receiving EoLC or respite care. It must be noted that the functions outlined in Fig.3-22 is not an exhaustive list of the requirements that might be needed to facilitate in-patient care – as mentioned previously hospices might provide a selection of these functions or many more. However, there are those that provide the basic and necessary infrastructure for specialist aspects such as ambulance access, the provision of oxygen and other piped gases, rooms for the secure storage of drugs, and care of deceased persons. Historically, the distinction between these two groups - those receiving care and the caregivers – can be informally observed in the architectural articulation of spaces and functions in the hospice

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206 HospiceUK, What Services Are on Offer? (HospiceUK, n.d) <<https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care/what-services-are-on-offer>> [accessed 23rd August]

207 Worpole, ‘A Home at the End of Life: Changing Definitions of ‘Homeliness’ in the Hospice Movement and End-of-Life Care in the UK’, in *Ways of Home Making in Care for Later Life*. ed. by Pasveer and others (Singapore: Springer Singapore, 2020), pp. 135-58, p.149



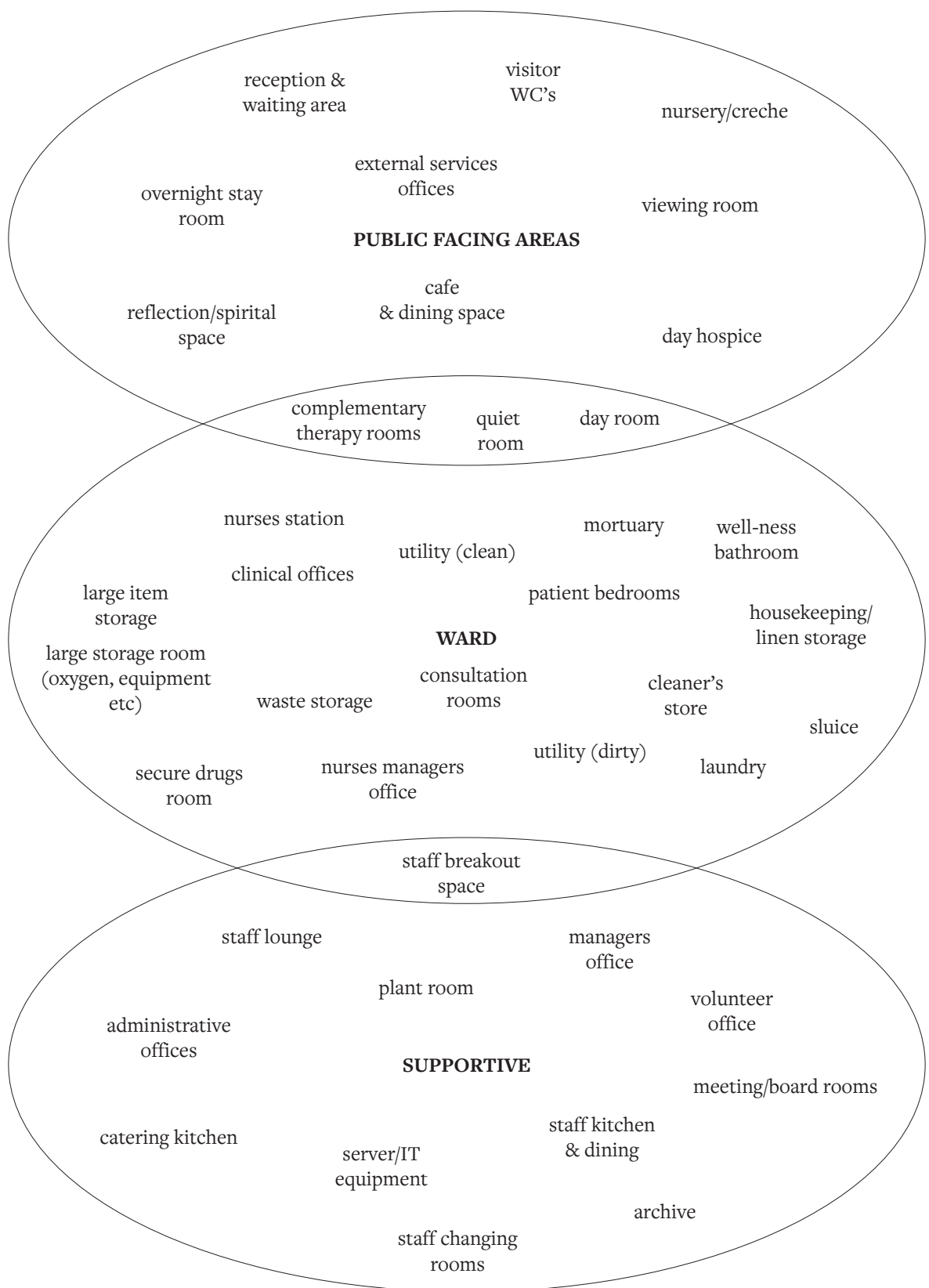


Fig. 3-22. Common functions of contemporary hospices

The diagram above illustrates some of the typical functions and spaces needed in the hospice, arranged between public, ward and supportive areas - visible are rooms that occupy spaces of overlap and are accessed by multiple user groups.

building with a division between what might be colloquially referred to as 'front' and 'back' of house.<sup>208</sup> This division of function is often marked by a visual change of material or volume of space, for example the public-facing reception areas may use softer textures and larger volumes of space to characterise a welcoming threshold – where ward environments are materially closer to clinical spaces, for example hospitals.

## Designing for care

### Design aspirations

Hospices today are responding to a far more complex context and system of social and medical requirements and standards than the proto hospices that first emerged in the early nineteenth-century. These proto hospices originated from a pragmatic response to the lack of appropriate psychical environments for the terminally ill at the time given the poor standards of hospital care. Yet it is evident that there was also a clear aspiration from their founders that they would offer a completely unique phenomenological atmosphere in direct contrast to the institutional atmospheres of healthcare buildings of the time. The proto hospices as discussed found themselves in the refurbished accommodation of large domestic dwellings, often villas or mansions in more affluent urban locations that had access to private gardens. These environments by their very nature presented patients (and staff) with an atmosphere of the 'home', of intimate spaces, comfort, and nostalgia. Yet, the image presented by these buildings would have most likely been at odds with the typical lived experience of 'home' by the demographic of patients at the time, usually amongst the poorer citizens, as the richer classes would have had access to private medical care. Hospices, offering shelter and care remains a concept that encompasses more than the 'bricks and mortar' of a building. The hospice, some argue must also comprise phenomenological qualities. Worpole writes on the emergence of the hospice typology that there is a 'poetics of space as much as there is a volume and a shape of space, and a spirit to a building as much as there is a schedule of works and accommodation'.<sup>209</sup>

In the years following St. Christopher's construction the architectural response to the spirit of hospice care was to emphasise the homeliness and identity of the hospice as a 'home away from

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208 These two terms are typically used in reference to spaces in the hospitality sector, with front of house referring to customer-facing spaces and back of house as being the spaces of preparation.

209 Worpole, *Modern Hospice Design: The Architecture of Palliative Care* (London, New York: Routledge, 2009) pg.10

home'. A common form of health anxiety suffered by terminally ill people, is that of the domestic home becoming a 'site of struggle'<sup>210</sup> - it may be observed therefore that the replication of the comforts of a domestic-like environment may go some way to alleviate contentions between the principles of hospice care and clinical atmospheres. As a result of the desire for a homely environment, hospices can be observed to have developed an 'overly domestic look...which is calm and serene but distinctly middlebrow in its colours and materials'.<sup>211</sup> In conversation with a consultant psychologist who often worked in hospice environments at a UK conference concerning the sociology of architecture of care, they described their perception of contemporary hospices as now 'looking a little John Lewis if you know what I mean, you know that middle class plush interior you see in hotels and things'.<sup>212</sup> Despite this in-patient hospices remain determined to provide an atmosphere of place that defies societal attitudes to morbidity and death, described by one respondent to a BBC article on 'How hospices care for the dying?' as an 'incredibly uplifting experience'.<sup>213</sup> Yet this raises considerable difficulties regarding the subjective nature of this aspiration; home is a vague term that means many different things to everyone and the 'rooms that soothe one person may alienate another'.<sup>214</sup> We might observe that the prevalence of the term 'homely' has perhaps become an easy buzzword that exonerates a critical engagement with the typology.

### Architectural precedent

Kenneth Frampton quotes Alexander Tzonis and Liane Lefaivre in stating that 'no new architecture can emerge without a new kind of relation between designer and user, without new kinds of programs'.<sup>215</sup> Galen Cranz suggests that 'architecture also communicates through form rather than language'.<sup>216</sup> Whilst written guidance for architecture and the built environment can be valuable with regards to understanding practical information of spatial layouts and design efficiencies – the analysis of built architectural precedent is able to bring a visual and physical aspect to the

210 Andrew Moore, Bernie Carter, Anne Hunt, Kay Sheikh, 'I am closer to this place'—Space, place and notions of home in lived experiences of hospice day care, *Health & Place*, Volume 19, 2013, Pages 151-158,

211 Worpole, 'A Home at the End of Life: Changing Definitions of 'Homeliness' in the Hospice Movement and End-of-Life Care in the UK', in *Ways of Home Making in Care for Later Life*. ed. by Pasveer and others (Singapore: Springer Singapore, 2020), pp. 135-58, pg 150

212 anonymous, 'Buildings in the Making Conference Discussion', ed. by Annie Bellamy, 2018)

213 BBC, "How hospices care for the dying" < <https://www.bbc.co.uk/news/magazine-34452836> > [Accessed on 1st June 2018].

214 Nitin Ahuja, 'End Stages', *Places Journal* (2018)

215 Kenneth Frampton, 'Towards a Critical Regionalism: Six Points for an Architecture of Resistance', *OASE* 103 (2019) p.20

216 Cranz, *Ethnography for Designers*, 2016) p.13

design process. During a pre-arranged structured phone interview with an architect working for a practice that specialises in hospice design it was discussed that a typical component of the early design process was using the internet to identify projects they felt relevant. A limitation of this is the potential of architects exploring others' folios as presented for marketing purposes, for example popular websites such as *ArchDaily*<sup>217</sup> and *Dezeen*<sup>218</sup> privileging visual imagery in easily accessible look-books. A reliance on imagery may be because, as Annemans and others describe, because architects 'like information to be presented graphically, or that they often feel mistrust towards data that have already been interpreted. They prefer raw data in a format that is condensed down to be design-relevant'.<sup>219</sup> There is a danger that a focus on purely visual sources reduces exposure to beneficial evidence based or scientific research.

Architectural precedent for the in-patient hospice is fairly limited within the United Kingdom owing to the historical stock of hospice buildings and relatively low number of new-build hospices. Therefore, architects may look to other building types such as care homes for the elderly that might offer architectural 'best practice' from which design cues might be taken. However, there are a growing number of architectural practices that specialise in the design of hospice care and completed many projects for hospice organisations. JDDK and KKE Architects are two such practices and have between them worked on over twenty-five hospice projects, including both in-patient and day hospices ranging from small extensions to existing hospices to new-build projects. Though JDDK and KKE are seemingly dominant in the industry, there are many other architectural practices that have been involved in the design of hospice buildings. Of these projects, we might consider that there are several that have been recognised by the architectural community as exemplars or models of best practice measured by their success in established architectural awards. Notably, St Michael's Hospice, Hereford by Architype won a RIBA West Midlands Regional Award in 2017; the in-patient building for St. David's Hospice care in Newport, Wales by KKE Architects which has won a RIBA National Award, a RSAW<sup>220</sup> Welsh Architectural Award 2018 and the Eisteddfod Gold Medal for Architecture 2018, as well as being awarded a Commendation at the Civic Trust Awards; the Prince and Princess of Wales Hospice, Glasgow by Ryder Architecture<sup>221</sup> was highly commended

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<sup>217</sup> n.a, (n.d) <[www.dezeen.com](http://www.dezeen.com)>

<sup>218</sup> Ibid.

<sup>219</sup> Margo Annemans and others, 'Informing Hospital Design through Research on Patient Experience', *The Design Journal*, 20.sup1 (2017), S2389-S96

<sup>220</sup> Royal Society of Architects in Wales

<sup>221</sup> The original design was produced by NORD Architects, the practice was disbanded during the design process and was taken on by Ryder with the appointment of a former employee.

at the Scottish Design Awards in 2019, won the Supreme Award from the Glasgow Institute of Architects in 2019 and shortlisted for a RIAS<sup>222</sup> Award in 2020. However, it is worth noting that the few examples listed above have won awards for their architecture judged by architects and does not represent a judgement from the clients or end users who may have differing interpretations of the everyday experience of occupying these buildings.

We might look globally for further architectural precedent and innovative best practice - but whilst these may highlight potentially exemplar architectural interpretations of care environments, they are the reflections of different cultural approaches to death and dying and national strategies for EoLC and palliative care. One such precedent that has gained critical acclaim within the architectural community is the Urban Hospice located in Copenhagen, Denmark, designed by NORD Architects and was the first hospice built in Denmark in an urban setting, and is explored in more depth in Practice Note 3. The building gained considerable coverage in architectural media owing to its use of highly reflective golden bronze-zinc alloy cladding that stood out amongst the relatively muted neighbourhood palette of timber and brick. Furthermore, it was a hospice, not an acute hospital or cancer centre – and the materiality celebrated this, with the architectural community perhaps perceiving this function to be ‘exotic’ and/or radical. The intent of creating a ‘unique place for the final journey’<sup>223</sup> was reflected in the architecture, see Fig.3-23. With a relative lack of precedent of new-build hospices – in contrast to more common healthcare environment such as hospitals – we might consider few appear as designerly as the Urban Hospice.

The context of geographic location is key, with Danish culture having a more open approach to death and dying but also a rich history of design that exemplifies a humanist approach to architecture and the built environment that has evolved to ‘express a concern for human well-being that includes both psychological and physical comfort, an intense respect for craftsmanship that is also a sign of respect for the occupants, a subtle understanding of tradition, and an adoration of nature.’<sup>224</sup> The architects, NORD, recognised that the built environment can have a substantial influence on the occupants but that close collaboration with the client could also have a positive impact on the outcome. NORD define this dialogue as ‘co-creation’ – much like the definition of co-production used in this thesis. Mia Baarup Tofte, a project manager at NORD Architects who worked on the

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222 Royal Institution of Architects in Scotland

223 Benjamin Wells, The Urban Hospice: Institutions (Danish Architecture Center, n.d) <<https://dac.dk/en/knowledgebase/architecture/the-urban-hospice/>> [accessed 29th August]

224 Michael Sheridan and others, Landmarks : The Modern House in Denmark (Ostfildern: Hatje Cantz, 2014) p.75

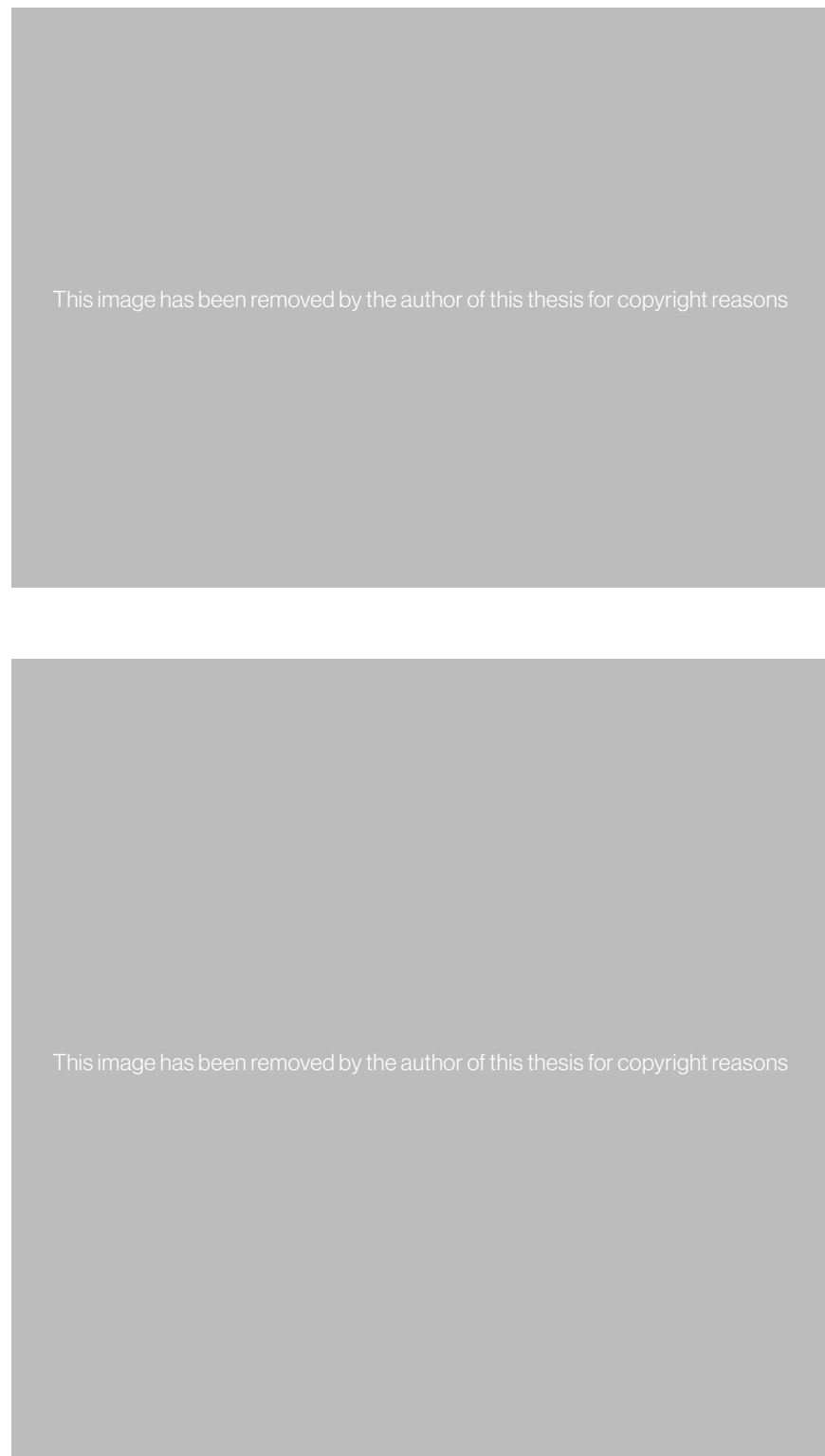


Fig. 3–23. Proposed and as-built communal area, Urban Hospice, Copenhagen

The top image shows a rendered illustration of the proposed Urban Hospice internal environment, the image below demonstrates the as-built space. It is clear from comparing these two images that the architectural intent and aspiration for quality of space has been successfully retained from conception to completion.

project described that the process 'based on architecture's best tools and the client's expertise, we have created a house where one can part with life in a safe environment'.<sup>225</sup> As a hospice, the building itself personifies cultural attitudes towards death and dying as meaningful architectural gestures that can enrich the lived experience of those dying.

### Maggie's Centre's

A contemporary discussion of hospice care architecture would be incomplete without Maggie's Centres. Anecdotally, within the architectural field, Maggie's Centre's have steadily become the 'go-to' reference for designers involved with places for death and dying. This is despite the fact that Maggie's Centre's do not provide clinical care but instead focus on the provision of social and community led care,<sup>226</sup> and act as support centres with less technical and medicalised requirements. The charity founded by the architectural critic Charles Jencks in honour of his late wife Maggie Keswick Jencks, who wrote the seminal manifesto *A View from the Front Line* before her death from cancer musing on the holistic care of those living with terminal illnesses. The Maggie's Centre charity have since 1996, commissioned, built, and continue to run, thirty international centres that 'are places to find practical advice about benefits and eating; places where qualified experts provide emotional support' places to meet other' places where you can simply sit quietly with a cup of tea'.<sup>227</sup> These centres are typically found in the grounds of NHS hospitals as community assets for the support and social care of those living with not only cancer but other life-limiting illnesses. The centres are individually designed by 'starchitects'<sup>228</sup> such as Zaha Hadid, Frank Gehry and Norman Foster 'that put architectural flair at the heart of their vision'.<sup>229</sup> Testament to their admiration from the architectural community, Maggie's Edinburgh by Richard Murphy Architects, Maggie's Glasgow by OMA, Maggie's Lanarkshire by Reiach + Hall (see Fig.3-24) have all been

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225 Wells, The Urban Hospice: Institutions (Danish Architecture Center, n.d) <<https://dac.dk/en/knowledgebase/architecture/the-urban-hospice/>> [accessed 29th August]

226 Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969

227 Maggie's Centres. (2018). About Maggie's. [online] Available at: <https://www.maggiescentres.org/about-maggies/> [Accessed 6 Nov. 2018].

228 This is a portmanteau term of 'star' and 'architect' used to refer to celebrity architects who may be regarded so highly that they are public figures to the general public.

229 Worpole, 'A Home at the End of Life: Changing Definitions of 'Homeliness' in the Hospice Movement and End-of-Life Care in the UK', in *Ways of Home Making in Care for Later Life*. ed. by Pasveer and others (Singapore: Springer Singapore, 2020), pp. 135-58, pg 150

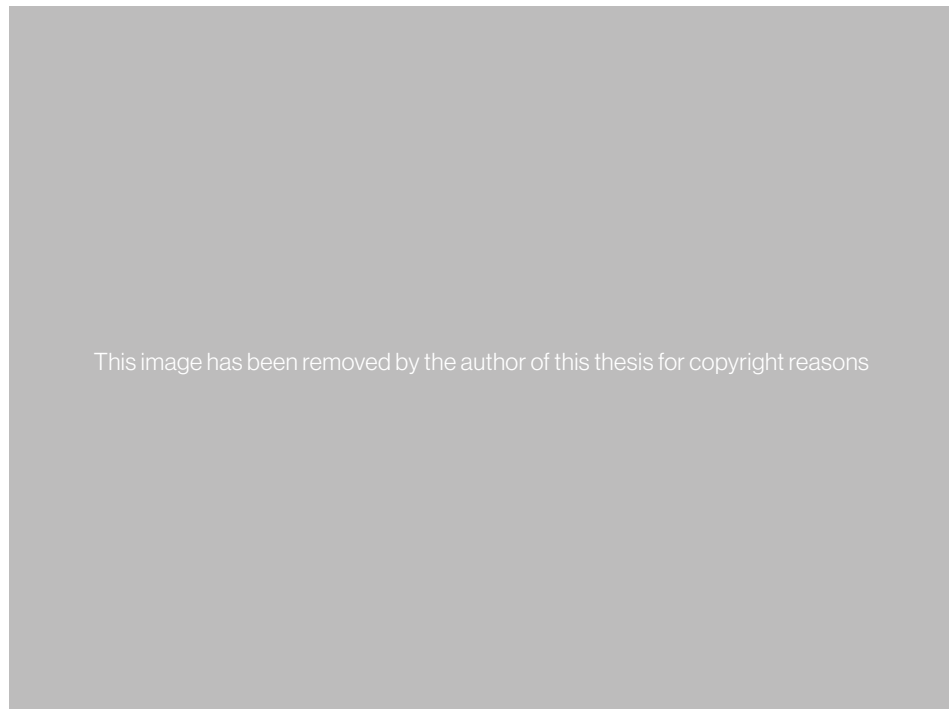


Fig. 3–24. Maggie's Lanarkshire, Reiach and Hall Architects

The courtyard garden and kitchen table at Maggie's Lanarkshire. Built in the grounds of the local acute hospital, the architects developed a concept of a walled garden to promote a sense of disconnect from the institutional grounds it is situated in. The interior environment uses a very simple palette of light washed timber to invoke a sense of calm and peace. Maggie's, being non-clinical spaces are afforded the freedom to use these natural materials, however hospices, like hospitals would need specific sign-off from the associated Infection Control team.



shortlisted for the prestigious Stirling Prize<sup>230</sup> - with Maggie's London by Rogers Stirk Harbour + Partners winning in 2009, see Fig.3-25.

The non-medical environments of Maggie's Centre's acknowledge the correlation between the well-being and environment and aim to counteract the institutional experience of acute hospital settings:

Maggie's scale is deliberately a domestic one, the antithesis of the hospital's.

The concern is for you as a person; the focus is on you, not the disease. We need to think of all the aspects about a hospital layout which are so demoralising: the closed doors implying secrets withheld, the endless corridors, the signposting, the artificial light, and then unpick and unravel these<sup>231</sup>

The architectural brief defined by Maggie's is purposively succinct and consists of recognisable and mostly domestic elements: entrance, welcome area, office, kitchen, computer desk, notice board, library, three sitting rooms of varying scales, consultation rooms, toilets, retreat, views out and in, and parking. Of these spaces the brief elaborates on the intangible qualities of space that the architecture of these spaces should generate, for example:

Maggie's Centres can and should look (and feel) bold and self-confident, as well as inviting and safe. They must look and feel joyous, they must have zest as well as calm. The impression they must give is 'I can imagine feeling different here'<sup>232</sup>

Maggie's Centre's desire to create a space away from the institution offers architects and designers the chance to experiment with 'spatial and material concepts of the 'home' as well as expressive building forms relating to the local built environment and community'.<sup>233</sup> However, as Maggie's overarching aim is one of social support – and not medical care – their buildings are afforded a freedom that the in-patient hospice is not able to offer. Hospices, though run mostly by third-sector organisations are to some extent bound by the requirements of infection control and other medical regulations to ensure standards of care. They are therefore, constrained by the way materials and products, such as timber floors or soft furnishings such as rugs and curtains may be used to create

230 This prize is awarded annually by RIBA to the designers of a building judged to have made the greatest contribution to architecture that year, it is judged against a variety of criterion.

231 Maggie's Keswick Jencks Cancer Caring Trust, 'Maggie's Architecture and Landscape Brief', n.d) p.6

232 Maggie's Centre's, 'Maggie's Architecture and Landcape Brief', Maggie's Keswick Jencks Cancer Caring Trust, 2015) pg.4

233 Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', Medical Humanities (2020), medhum-2020-011969, p.4

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Fig. 3–25. Maggie's London, Rogers Stirk Harbour +Partners

The exterior and interior kitchen area of the Stirling Prize winning Maggie's London by Rogers Stirk Harbour + Partners. There is material and spatial freedom to the design of Maggie's. The internal image above shows a seamless connection from communal space to the outside courtyard, emphasising the relationship between building and landscape.

an atmosphere that Bloomer and Moore describe as being architecture that is a 'a sympathetic extension of our sense of ourselves'.<sup>234</sup> This materiality is difficult to specify in a healthcare setting such as the hospice if they are not pre-approved or pose potential infection control concerns. The challenges presented to a design team for designing an in-patient hospice are far more complex than that of a Maggie's Centre and need to consider not only the dying person and their immediate environment but also the wider infrastructure required by the clinical setting. Yet, despite the non-clinical comparison, it is arguable that the over-arching attitude of Maggie's is playing a significant role in revolutionising an approach to care environments - providing a 'springboard' for which hospice as a typology might begin to draw and extract key elements from. As we have seen the functional programmes of hospices now go beyond the provision of traditional patient accommodation with many incorporating spaces for community and complementary care like that offered by Maggie's Centre's. The open brief and engagement of new architects for each centre provides a benchmark aspiration for reflection and variety with regards to the design of hospices not as micro-hospitals, but individual settings with distinctive characteristics that can provide care and dignity for those with cancer and other life-limiting diagnoses inherently linked to the local community. However, despite this positivity, an opposing perspective to the approach of Maggie's is that the overwhelming domesticity of the buildings are not always easily accessible to those less able, and certainly do not offer space for those closer to the end of life.

We might consider that Maggie's Centre's form the basis of a 'pattern book', back catalogue or built design guide for areas that are shared between the hospice and Maggie's, in particular the interior atmosphere and communal living/dining areas. In comparison to evidence-based design, the research of 'whether there are measurable (and by implication, causal) relationships between the quality of design...and wellbeing, if not measurable improvements in their health'<sup>235</sup> that often remains in the realm of academia, Maggie's signals a tangible framework for a practical relationship between architecture, well-being, and medicine that champions interdisciplinary collaboration between inhabitants, designers, and clinicians. This approach may furthermore contribute to the breakdown of death and dying as a taboo subject by demonstrating a rejection of the institutional environment and the benefit of architecture that aims to 'salute the magnitude of the challenge'<sup>236</sup> that faces the inhabitants regardless of diagnosis.

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234. Kent C Bloomer and Charles Willard Moore, *Body, Memory, And Architecture*, (New Haven: Yale University Press, 1977) pg. 78

235. Worpole, *Modern Hospice Design : The Architecture of Palliative Care* (London, New York: Routledge, 2009) pg.12

236 Centre's, 'Maggie's Architecture and Landcape Brief', Maggie's Keswick Jencks Cancer Caring Trust, 2015) pg.3

## Available guidance

It is well recognised that the experience of environment is inextricably linked to care,<sup>237</sup> yet this connection is one that very few architects and architectural researchers have engaged with in the context of EoLC and as such there are few sources of research that may be referenced in contrast to other institutional healthcare settings, such as hospitals. The following titles represent the sum of literature over the past 17 years regarding specifically hospice (of which most cover both in-patient and day centre) design:

- *Innovations in Hospice Architecture*<sup>238</sup>, Stephen Verderber and Ben Refuerzo in 2005,
- *Modern Hospice Design: The Architecture of Palliative Care*<sup>239</sup> by Ken Worpole in 2009
- and most recently *The Production of Hospice Space: Conceptualising the Space of Caring and Dying*<sup>240</sup> by Sarah McGann in 2013.

The advice that is available is usually presented as a set of principles – which as Ann Heylighen writes ‘reduce the human body to a source of an abstracted system of proportions’<sup>241</sup> that very often are removed from the emotional human experience of places. In summarising the work of Verderber and Refuerzo, Nitin Ahuja writes despite their claim there is no silver bullet for hospice design:

they don't hesitate to offer surprisingly specific guidelines for color (“Above all, avoid yellow and dull, bland hues in the hospice setting”), dimensions (“Private bedrooms should be 20-25 percent larger in size than the typical hospital room. ... Provide interesting ceilings with recesses, barrel vaults, and indirect lighting”), and material (“Wood is of the earth, a tree grows with time, and its age rings are visible, symbolizing the change of season. ... Wood therefore possesses therapeutic value in the palliative care experience”)<sup>242</sup>

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237 As a wider reference the book ‘Healing Spaces: The Science of Well-being and Place’ by Esther M. Sternberg; documents numerous scientific studies on the impact of environment on sensory experiences within medical contexts. One of the most famous is the impact of a view of green space that requires patients to need less analgesic (pain relief) medication, eventually leading to faster recovery times.

238 Stephen Verderber, *Innovations in Hospice Architecture*. ed. by Ben J. Refuerzo (London: Routledge, 2005)

239 Worpole, *Modern Hospice Design: The Architecture of Palliative Care* (London, New York: Routledge, 2009)

240 Sarah McGann, *The Production of Hospice Space: Conceptualising the Space of Caring and Dying* (Ashgate, 2013)

241 Heylighen, A., Van-Doren, C. and Vermeersch, P. (2013). Enriching our understanding of Architecture through disability experience. *Open House International*, 38(1), p.17.

242 Ahuja, ‘End Stages’, *Places Journal* (2018)

It is vital that design led research moves away from the rigid literary proposals of 'design principles'<sup>243</sup> – and moves into the practice itself, constantly asking questions of how we may best 'design' for people in this extreme and evocative situation. As noted by Bellamy, Clark and Anstey, the apparent lack of reference literature for architects, is not despite a

lack of a thriving research community for PC that includes architects, for example, the international European Network Architecture for Health annual conference, the European Healthcare Design annual conference run by Architects for Health and more recently the inaugural Palliative Care, Architecture and Design symposium in 2018 exploring interdisciplinary practice. Yet, despite this, the literature has unfortunately seemed to remain very much in the realm of academia—and has done little to influence broader architectural practice and attention.<sup>244</sup>

We may look to the small handful of design guides that have been commissioned by bodies such as:

- *Design Guidelines for Specialist Palliative Care Settings*<sup>245</sup>, Irish Department of Health and Children, 2004
- *Improving Environments for Care at End of Life*<sup>246</sup>, The King's Fund, 2008
- *Design & Dignity Style Book*<sup>247</sup>, The Irish Hospice Foundation, 2014

These short reports tend to have a particular stance with regards to the topic area, for example predominantly technical and operational perspectives, discussing adjacencies and space requirements for medical equipment or the discussion of several pilot study projects that focused on mortuary viewing facilities. Despite their stand-alone nature, these reports are a valuable resource as they provide advice direct to hospice organisations as opposed to architectural research that may only be accessible to designers or academics. It is worth noting that the literature is dominated either by considerations of hospice from the perspective of someone receiving care

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<sup>243</sup> It is worth noting, many architecture practises who undertake an in-patient hospice as a project, proclaim to have engaged in very in-depth consultation periods with the client regarding the needs of the spaces, and the needs of staff etc though it is hard to distinguish this from the traditional consultation needed to define a brief for the project.

<sup>244</sup> Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969, p.5

<sup>245</sup> Department of Health and Children, 'Design Guidelines for Specialist Palliative Care Settings', Government of Ireland, 2004)

<sup>246</sup> The Kings Fund, 'Improving Environments for Care at End of Life', (London: The Kings Fund, 2008)

<sup>247</sup> The Irish Hospice Foundation, 'Design and Dignity Style Book', 2014)

or more ergonomic aspects of spatial layouts and design. There is little that focuses on the type and form of accommodation for members of staff that supports wellbeing and might reduce the potential for burnout. There is brief mention of this type of space discussed by architect Lo-Yi Chan in 1978 regarding his design of the New Haven Hospice that was described as 'an improvement' on Saunder's St. Christopher's Hospice.<sup>248</sup> An illustration, seen in Fig.3-26, describes a sensorial blank slate for staff members to retreat to counteract the potential stresses of working within palliative care.

The discussion would not be complete without a note regarding guidance published by the NHS - health building notes (HBN's) and health technical memoranda's (HTM's), see Fig.3-27 & 28. Since they were first published in the early 1980's, these collections aimed to 'ensure good relatively standardised working conditions' within new and existing NHS environments, specifically hospitals.<sup>249</sup> The Department of Health and Social Care define HBN's as giving:

best practice guidance on the design and planning of new healthcare buildings and on the adaptation or extension of existing facilities. They provide information to support the briefing and design processes for individual projects in the NHS building programme.<sup>250</sup>

A 2009 study by Hignett and Lu that investigated the role of HBN's in the delivery of healthcare environments, concluded that, despite the guidance available there is a fluctuating scale within which architects employ the notes – noting that some used it literally and others saw it as reference information.<sup>251</sup> Whilst there might be specialist information regarding spatial layouts for environments of care within the HBN's – as noted previously this collection is managed by NHS Estates and as such in-patient hospices are not mandated to abide by this. Though it is worth noting that outside influences, such as infection control teams from the LHB may refer to this guidance when conducting audits of in-patient hospices.

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248 Kron, 'Designing a Better Place to Die', 1978, p.3

249 Sue Hignett and Jun Lu, 'An Investigation of the Use of Health Building Notes by Uk Healthcare Building Designers', *Applied Ergonomics*, 40.4 (2009), 608-16, p.608

250 Department of Health and Social Care, Dh Health Building Notes (gov.uk: HM Government, 2017) <<https://www.gov.uk/government/collections/health-building-notes-core-elements>> [accessed 27th August]

251 Hignett and Lu, 'An Investigation of the Use of Health Building Notes by Uk Healthcare Building Designers', *Applied Ergonomics*, 40.4 (2009), 608-16, p.615

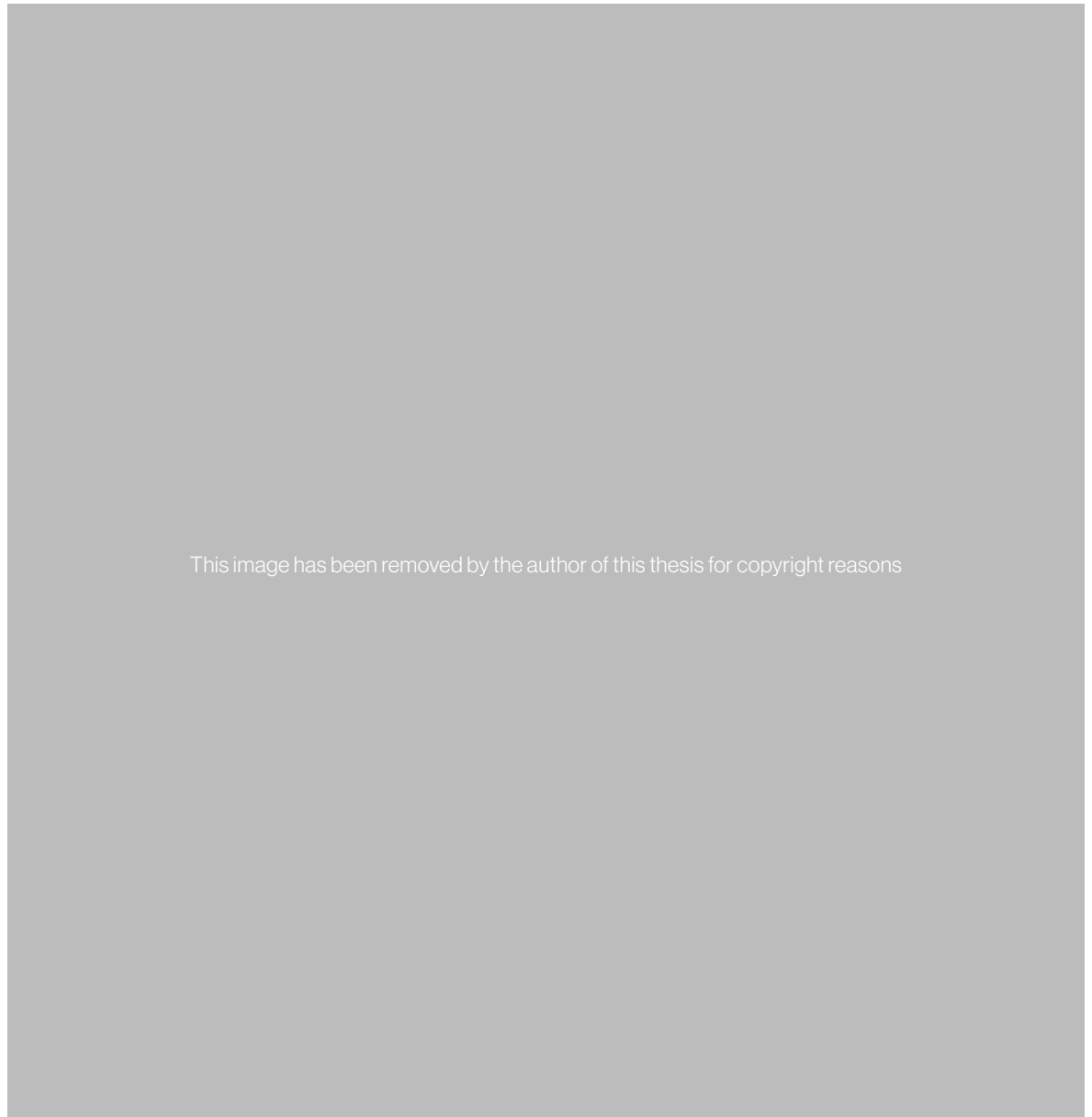


Fig. 3-26. The 'escape hatch'

An excerpt from Joan Kron's article 'Designing a Better Place to Die' and the design of the New Haven Hospice in America - shown here is the design of an 'escape hatch' specifically designed as a place for members of staff to have space away from the pressures of the ward environment. Note the description that describes a very different sensory experience to that of the ward and patient bedrooms that aimed to provide a 'blank slate'.

There is also emerging international literature surrounding the focus of architecture and palliative care, most notably the *Programme for the Good Hospice in Denmark* commissioned by the Danish philanthropical think-tank RealDania and authored by SIGNAL Architects. The report came about following the 2004 Danish 'hospice law' that outlined all counties must work toward providing twelve hospice beds with a local hospice provider.<sup>252</sup> Denmark, prior to this, had a relatively young model of palliative care, with their first hospice only opening in 1992 and with far fewer hospices than the UK relative to population size.<sup>253</sup> This report is unique having found real-world impact, as the resulting principles of design have been used as the basis for four new-build hospices in Denmark. Subsequently the project was additionally used as the basis for a further research initiative regarding architecture and palliative care undertaken by REHPA, Denmark's national knowledge centre for rehabilitation and palliation. The project 'Architecture and Relief' was driven by a desire to strengthen the architecture and the framework around the alleviation efforts for patients affected by life-threatening illness, their relatives and staff.<sup>254</sup> The uptake from the findings of the report by architects commissioned with hospice design contrasts with the engagement of architects with the respective information available in the United Kingdom.

## Chapter reflections

We have seen that the etymological assessment of the origins of the word 'hospice' itself raises a crucial issue facing the contemporary interpretation of 'hospice' as a unique typology. In historical accounts, hospice and hospital have appeared to be interchangeable, for example where some sources use the term hospice, others may reference hospital. This can be contributed to the history of medicine - illness inevitably meaning death or dying due to a lack of medical knowledge at the time. It is evident that historic hospice's have been inextricably linked to the development of other building types owing to their common accommodation in the derived plans, for example, religious building typologies such as churches as well as domestic buildings. We might observe that there is, however, a vital concept that has perhaps been lost from the early roots of ancient and mediaeval times, that of a holistic 'landscape of care'. That care is not constrained to a singular environment that contains everything but that the hospice might act as part of a broader network of caring environments.

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<sup>252</sup> SIGNAL Architects, 'Programme for the Good Hospice in Denmark', 2006) p.5

<sup>253</sup> Ibid. p.5

<sup>254</sup> REHPA, About Architecture and Relief (n.d) <<https://arkitektur-lindring.dk/9-2/om-arkitektur-og-lindring/>> [accessed 27th August]





Fig. 3-27. NHS Health Technical Memorandum's

Developed by the NHS, HTM's are technical schedules of knowledge for aspects such as ventilation, waste etc.

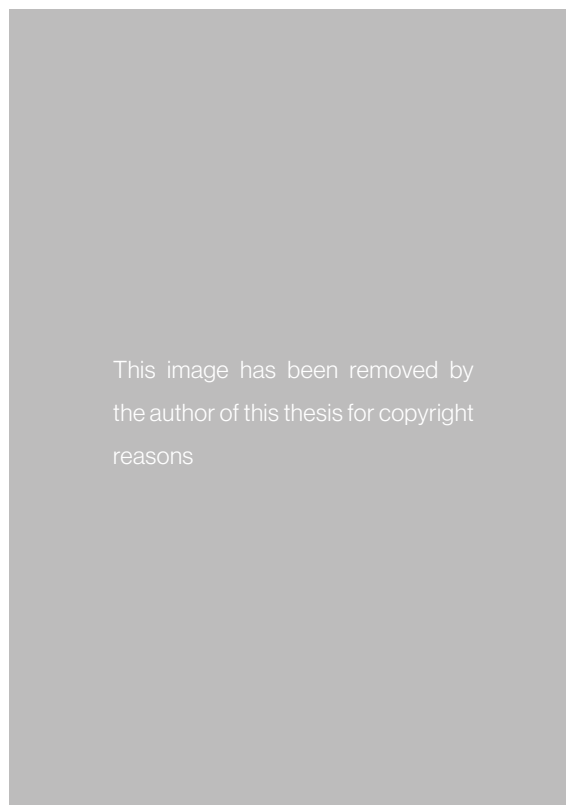


Fig. 3-28. NHS Health Building Notes

Also developed by the NHS in collaboration with architects and designers aim to help provide critical knowledge of space alongside ergonomic diagrams much like Part M of the Building Regulations.

As previously discussed, the contemporary hospice finds its origins in the domestic environments of the proto hospices of late nineteenth and earlier twentieth-century, that were shaped by the charitable activities of the organisations. These domestic interiors were not intended to be medical environments but were instead inspired by the religious and philanthropic ideologies of the volunteers and staff who wished to help those live a good life until the end. St Christopher's on the other hand was explicitly designed as medical environment and its adoption of modernist principles of architecture, reflected the notorious aphorism 'form ever follows function'<sup>255</sup> by renowned architect Louis H. Sullivan. Both the proto-hospices and perhaps more so, St. Christopher's, demonstrated critical turning points in the history of the hospice typology with regards to the intended end inhabitants. Each reflected accumulated knowledge of care for the dying that enabled a context for an architecture to emerge that reflected the updated and new needs of death and dying at the time. At the beginning of this chapter, it was considered that the nature of architectural typologies are evolving definitions that require continual adaption to contemporary circumstance. Therefore, the researcher posits that the contemporary hospice is at another critical point of change.

Since the development of St. Christopher's, in 1967 it is arguable that there has not been any radical re-shaping or innovative re-interpretation of what the hospice building aspires to be despite the changing nature and context of the provision and delivery of hospice care. It is even possible to argue that the over-medicalisation of death and dying has forced the architecture of hospices to move away from the phenomenological aspirations of Saunders vision for St. Christopher's. Despite many hospices announcing the concept of homeliness as drivers for the architectural brief; physical manifestations of this are at risk of being derived from superficial understandings of its subjective nature. The typology requires challenging to avoid creating an echo chamber or one-size fits all approach of perceived best practice that is developed in isolation away from the experience of buildings by patients, staff, and visitors. This parallels the conclusions of Bellamy and others who have called for:

collaboration and opportunities for coproduction to facilitate and promote this;  
for action from a multidisciplinary care team that recognises the strengths of  
each profession in support of the progress of positive experiences for the dying  
patient away from home<sup>256</sup>

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<sup>255</sup> Louis H. Sullivan, *The Tall Office Building Artistically Considered* ([Minneapolis], 1922) pg.5

<sup>256</sup> Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969, p.5

The development of the hospice typology would benefit from co-production, from an evolving dialogue between the expertise of architects in the built environment and healthcare professionals in care practices. Much like the relationship between Cicely Saunders and the project architect of St. Christopher's, Peter Smith highlighted earlier in the chapter, where the client and architect relationship benefit from the mutual recognition of expertise. As this chapter concludes the first part of the thesis, this provides a contextual background to the hospice as a building type as we move to the second part presenting the hospice explored as an organisation through primary fieldwork.

# Practice Note 2

## Models as tools

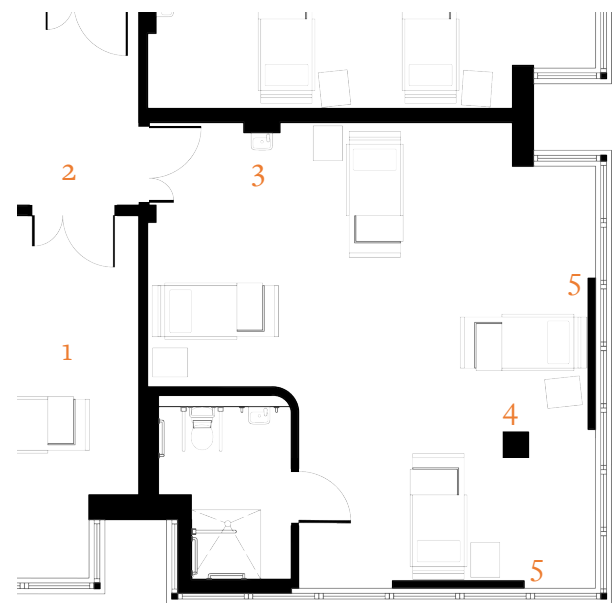
The second practice note documents the ways in which the researcher implemented the common architectural object - the model - as a research tool when interviewing those outside the architectural profession. Discovering the differing perceptions of modelled space between healthcare and architectural professionals, models can go some way to bridging the two to initiate conversations. However, it is critical to ensure that props used in this manner are legible to those without knowledge of architectural symbolism and language.

A vital part of this thesis centres on the investigation of different staff members and their subsequent experiences within the hospice that provide a platform to gather not only institutional but individual observations. The fieldwork was a two stage process, that began by undertaking a number of in-depth interviews from a variety of staff groups. The resulting common themes arising from the interviews would then go onto inform situated building observation. It was critical that the in-depth interviews were able to facilitate meaningful discussion between the participants and myself - yet the meeting of our two professions, care and architecture posed a very real obstacle to the success and development of these conversations.

In considering the design of the interviews, I was acutely aware of a common weakness of architects and designers, who can quite easily forget that those 'outside' the profession do not immediately know how to read a plan drawing or conjure up the same mental images when looking at typical architectural drawings and presentations. The terminology we use to describe architectural conventions could be prohibitive to the natural flow of the conversation. David Wang and Linda Groat have written of the 'critical differences between expert and lay experiences in a variety of settings and contexts'[1] that may lead to the language of architectural research appearing almost indecipherable to the lay research participants. To those outside the profession, the world of architecture is well-known for its somewhat pretentious mode of communication. Rob Fiehn in the *Architectural Review* commented that architects 'have developed their own language, a convoluted construction of strange verbs and outlandish nouns designed to sidestep reality'[2]. And so the question remained, how to best utilise the few hours of interview time to guide the conversation so that the participants could meaningfully engage with their experience from an entirely new perspective and discipline that avoided as far as possible the 'language' of architecture?

I had prepared plan drawings of each floor of the hospice in order to help participants locate specific areas in the building that were being discussed but to also act as a form of record, a space for the participants to make annotations, draw or label in their own time throughout the discussion without being directed by myself. Yet I felt the two dimensional representation may still be too abstract. Therefore I decided to use a series of models that I had made previously to aid my own spatial understanding of the hospice as tools for the interviews. Visual communication, especially through model making is arguably one of the most important skill-sets developed by designers during their education and practice and I had made the models as a means to 'enter' spaces previously inaccessible (patient rooms) to me.





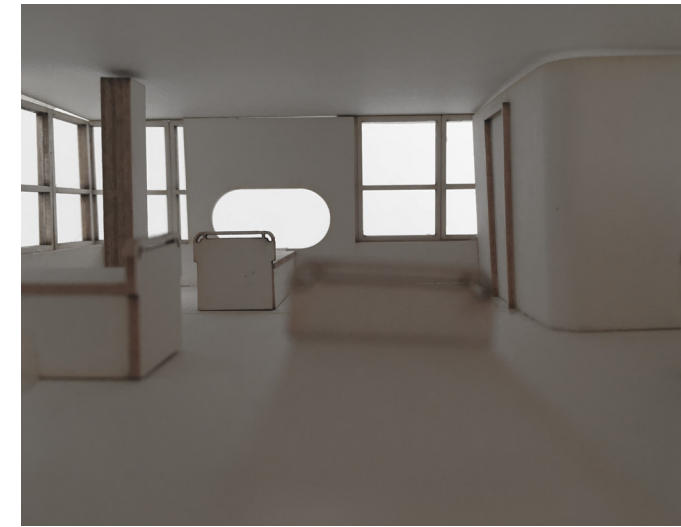
- KEY
- 1 adjacent bedroom
  - 2 main ward corridor
  - 3 column
  - 4 handwash sink
  - 5 infill stud wall

The example model shown opposites depicts a four bed bay in the case study setting that was inaccessible to me due to being occupied by patients and visitors. One of a series of models of patient bedrooms, I was interested in exploring two main aspects that would be visible from the patients perspective in occupying a hospital bed - light/shadow and the views. I modelled this at 1:50, a scale large enough to model an appropriate level of detail, window and doors with indications of frames so as to mimic the effect of natural light passing through. These were made in a neutral white card to avoid any indication of realistic materiality in order to provide a 'blank canvas' that highlights the paths and value of light but also the range of the patients view.

The bed to the right of the entrance door is dominated by views onto the other beds - with a direct sightline to the bed immediately opposite. Where this has the potential to be a long distance view to the sea beyond this is broken by the infill stud wall that has been constructed to provide a solid backing to the bed opposite.



FOLD HERE



Much like the bed adjacent to the entrance door, this bed has views dominated by the others, and is similarly denied a long distance view by the second infill wall panel. The column to the left and the ensuite to the right disturb a clear view out.



The bed that sits onto the infill panel on the east elevation is completely denied a view of the sea beyond. The view here is similar to that of any clinical ward, with no connection to the view beyond.



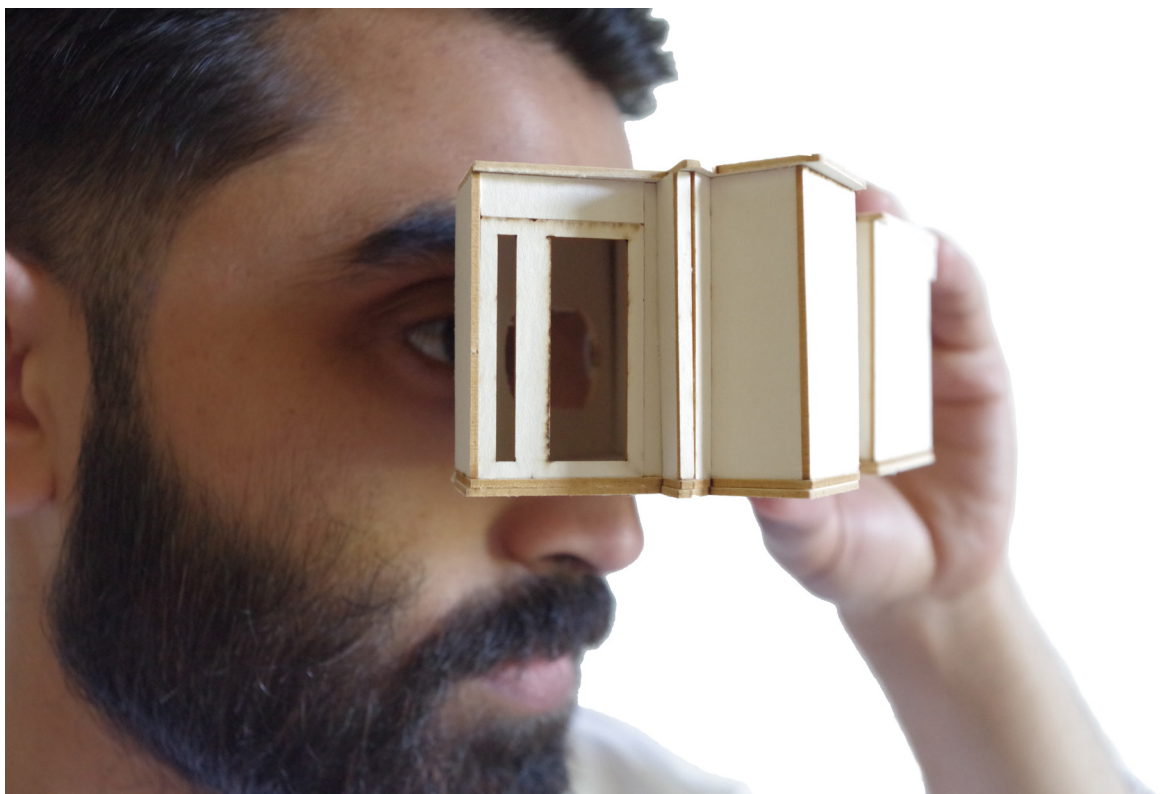
The bed that sits on the second infill panel, feels the most compromised of the four owing to its proximity to the column, a leftover mark of the previous structural envelope of the balconies that were infilled to extend the room to accommodate four beds.

FOLD HERE

*“The model is rather the indication of a principle, of a potential that the building can offer”<sup>3</sup>*



The smaller models of different individual bedrooms of the hospices visited for the scoping tours and the case study were designed - and very much intended - to be interacted with. Taking inspiration from viewfinders and dollhouse's, the act of bringing the model up to the eye, as demonstrated in the images above and below, draw the view immediately into the realm of the internal volume of the bedroom.

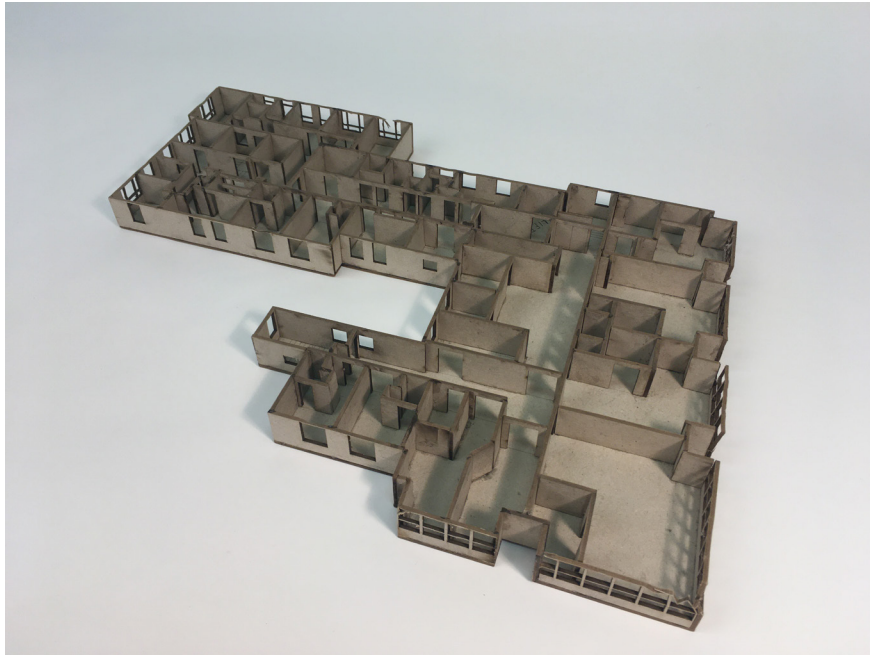




*“one thing is I should say I find looking at maps and plans really challenging”<sup>4</sup>*

The quote above, from the fieldwork was taken as the interview was being set-up, one of the interviewee's upon noticing the drawings on the table immediately declared themselves to be in an 'outsider' position and subconsciously undermined their legitimacy in the interview. As acknowledged previously, an obstacle to overcome within the in-depth interviews was how to facilitate the communication between myself, a trained architectural designer, and the research participants who are not and therefore may struggle with the language and expression of concepts with regards to architecture and design.

Alongside the printed white card models, I decided that it would be particularly useful to construct another model, shown to the right, that depicted the entire floor plan of the first floor of the case study hospice to guide those not familiar with reading a plan drawing of a building. The quality of the grey card, in contrast to the white card models, creates the feeling of a 'background' and supportive tool that is there to assist rather than be a focal point or driver for the conversation. The simple representation of the spaces, that in spite of not being particularly detailed but showing openings for the door and window was enough to prompt interviewee's to connect their experiences within the bigger picture of the hospice building as a whole, rather than a collection of individual spaces. Even the interviewee who had previously stated that they found drawings and maps difficult was able to comfortably navigate the drawings with the assistance of the model to point at. By using the natural tools of architectural practice and design in a research setting they have helped inform and engage the participants with a unfamiliar topic.



The grey card model constructed of the first floor plate of the case study setting, giving the research participants an overview of their workplace.

The image below shows the setup of the meeting room in the case study setting where the first focus group/interview took place. Note the models with an invitation to be picked up and handled.



*“...is that what it really looks like from the bed?!...”<sup>5</sup>*

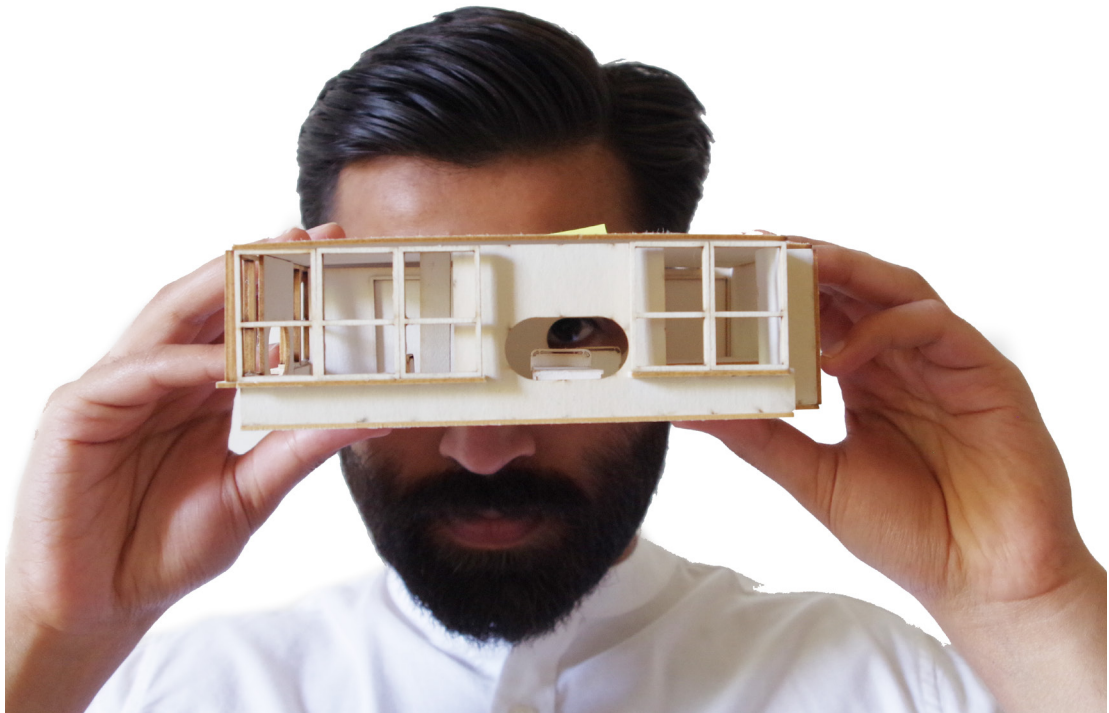
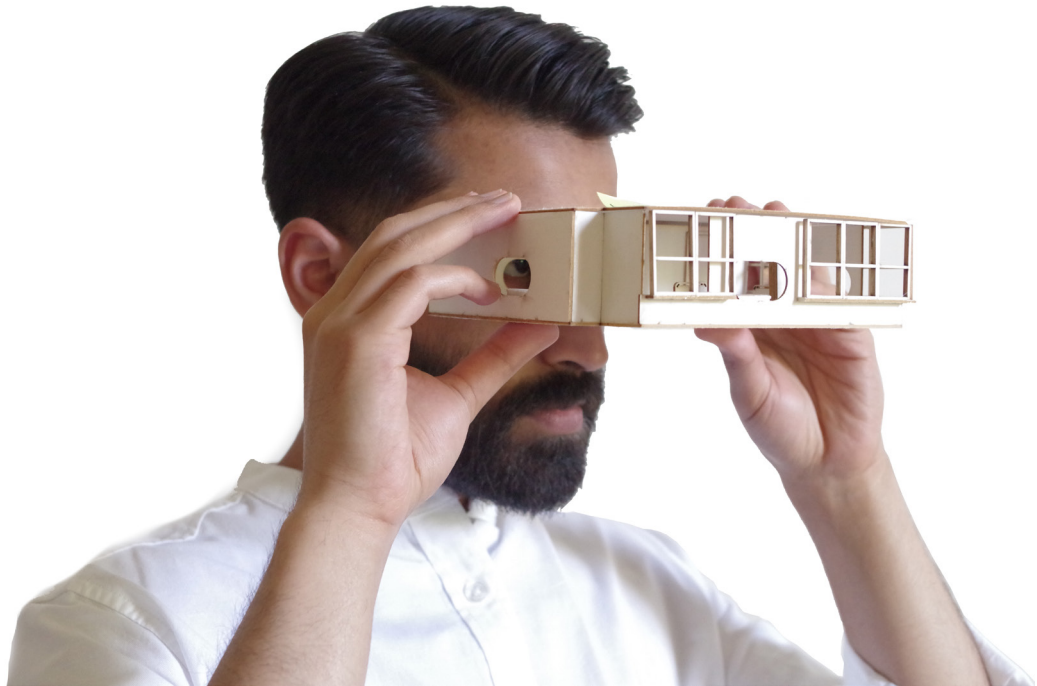
VS

*“...is the wall that wonky in real life?...”<sup>6</sup>*

The quotes above demonstrate two instinctive yet contrasting perspectives on architectural models as artefacts. Forcing a shift in perception of the room’s environment from their position as a care-giver, physically handling the model allowed the participants to ‘enter’ a new viewpoint of a normalised environment and see the space in a new way. This first quote summarises a member of staff’s reaction to picking up the model of a patient bedroom; but only after I had explicitly encouraged them to handle the models, with the participants seeking my permission to touch the obviously precious or delicate objects in front of them - despite my efforts to make them seem distinctly non-precious. Perhaps my efforts did not extend far enough, what I may consider non-precious is from my perspective as an architectural designer not a layperson.

In comparison, the quote below is taken from a discussion had with my partner, an architectural designer currently in practice - who instinctively reached for the model to bring up to his eye-line to inspect and explore the inner spaces. Throughout architectural education and practice, models are commonplace objects, not seen as precious (unless perhaps they are specifically designated as a presentation model, produced once a project is finalised) that you explore at eye-level to assess and understand qualities of space. Where the shift in perspective was startling to the member of staff - the space was quickly read by my partner, hence the criticism instead of the model as a physical object, rather than the space itself.

Models can be an incredibly valuable tool in architectural research, helping those who are not trained to consider three-dimensional space to both see and enter a new mode of thinking. Yet the experience here with the members of staff, hesitant and conscious of even merely touching the models, highlights the need to truly accommodate others, whether research participants or clients, to ensure that collaborative design or research processes are inclusive of those outside the architectural profession and to capture their outside knowledge and expertise.



## Endnotes

1 Linda Groat & David Wang (2002). *Architectural research methods*. New York, J. Wiley. pg.229

2 Rob Fiehn, 'Outrage: Architectural Spin', *The Architectural Review* (2020), <<https://www.architectural-review.com/essays/outrage/outrage-architectural-spin>> [accessed 16th October]

3 Alben Yaneva, *Made by the Office for Metropolitan Architecture: An Ethnography of Design*, (2009) pg.56 (Cardiff, 13th February 2021)

4 Anonymous interviewee, Interview with Annie Bellamy (Cardiff, 26 September 2019)

5 Anonymous interviewee, Interview with Annie Bellamy (Cardiff, 26 September 2019)

6 Anonymous interviewee, Interview with Annie Bellamy,

# 4

## Hospice as an organisation

The previous two chapters formed Part One of this thesis, providing an in-depth investigation into the contexts of care for death and dying that considered both the contemporary nature of hospice care and the development of the hospice as a unique building type. This chapter signals a move into Part Two of the thesis, the case study. Here, this chapter will introduce the initial scoping visits of hospice providers in Wales that were undertaken to orientate and contextualise the primary fieldwork to be discussed in Chapter 5.



## In-patient hospices in Wales

In discussion surrounding the context of care provision available in Wales, HospiceUK's *Future Vision Cymru* report states that:

Pre-pandemic, an estimated one in four people were missing out on the right palliative care, which is equivalent to around 6,600 people in Wales each year. Our geography, with swathes of rurality and a varied distribution of palliative care facilities, and our relative deprivation intersect with demographic characteristics and illness profiles with the effect that not all people have the same access to palliative care in their local communities.<sup>257</sup>

Loss of industry has contributed to the degradation of nuclear families that has in turn led to an observed reliance on organisational care for EoLC in Wales with an inequitable spread of access, as evidenced by the quote above. At the time of writing, there was a range of hospice care providers that made up the landscape of EoLC care available to the Welsh population. Fig.4-1 & 2 locate these services across Wales in relation to the local health boards and the principal areas they serve. Of these twenty, two are specialist hospices for children under the age of eighteen, and four are specialist palliative wards for in-patient care located within the grounds or buildings of district general hospitals.

The remaining fifteen services consists of eight organisations that run a mixture of hospice-at-home services and day-hospice sites; the last six hospice organisations provide specifically in-patient care, the focus of this thesis. Combined, these in-patient hospices offer ninety-seven beds, meaning that for the Welsh population - estimated to be 3.19 million in 2022 - there is one bed for approximately every 32,886 people. The average number of beds in each hospice is fifteen, however this includes a spread of six beds in the smallest to thirty in the largest. As shown in Fig.4-2, the six hospices primarily focused on providing in-patient care are clustered to the northern and southern regions of Wales. There is a noticeable lack of in-patient services located within the large central principal area of Powys. The clustering of hospices in the north and south suggests centres that serve more densely populated areas around a town/city that hosts their services. Many areas in the Powys region due to the lack of nearby hospices are included within the catchment area for hospices across the border, such as the Severn Hospice in Shrewsbury, England.

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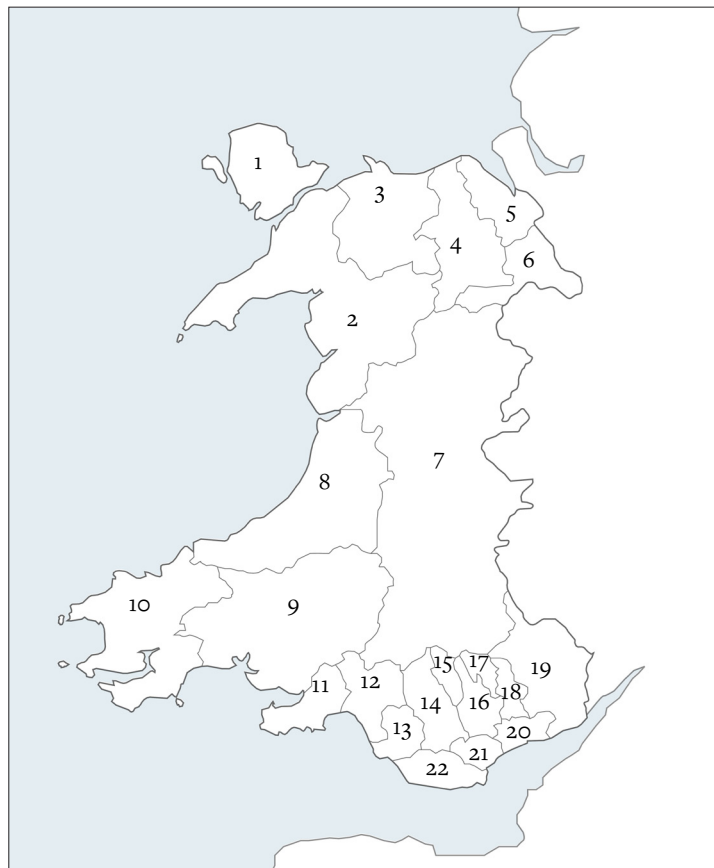
<sup>257</sup> HospiceUK, 'Future Vision Cymru: Seamless and Sustainable: Report on Engagement Discussions and Ways Forward', (London: HospiceUK, 2021) p.6



Health boards in Wales

- 1 Betsi Cadwaladr
- 2 Powys Teaching
- 3 Hywel Dda
- 4 Swansea Bay
- 5 Cwm Taf Morgannwg
- 6 Cardiff & Vale
- 7 Aneurin Bevan
- 8 Velindre University NHS Trust

Fig. 4-1 Health boards and principal areas in Wales



Principal areas in Wales

- 1 Isle of Anglesey
- 2 Gwynedd
- 3 Conwy
- 4 Denbighshire
- 5 Flintshire
- 6 Wrexham
- 7 Powys
- 8 Ceredigion
- 9 Carmarthenshire
- 10 Pembrokeshire
- 11 Swansea
- 12 Neath Port Talbot
- 13 Bridgend
- 14 Rhondda Cynon Taf
- 15 Merthyr Tydfil
- 16 Caerphilly
- 17 Blaenau Gwent
- 18 Torfaen
- 19 Monmouthshire
- 20 Newport
- 21 Cardiff
- 22 Vale of Glamorgan



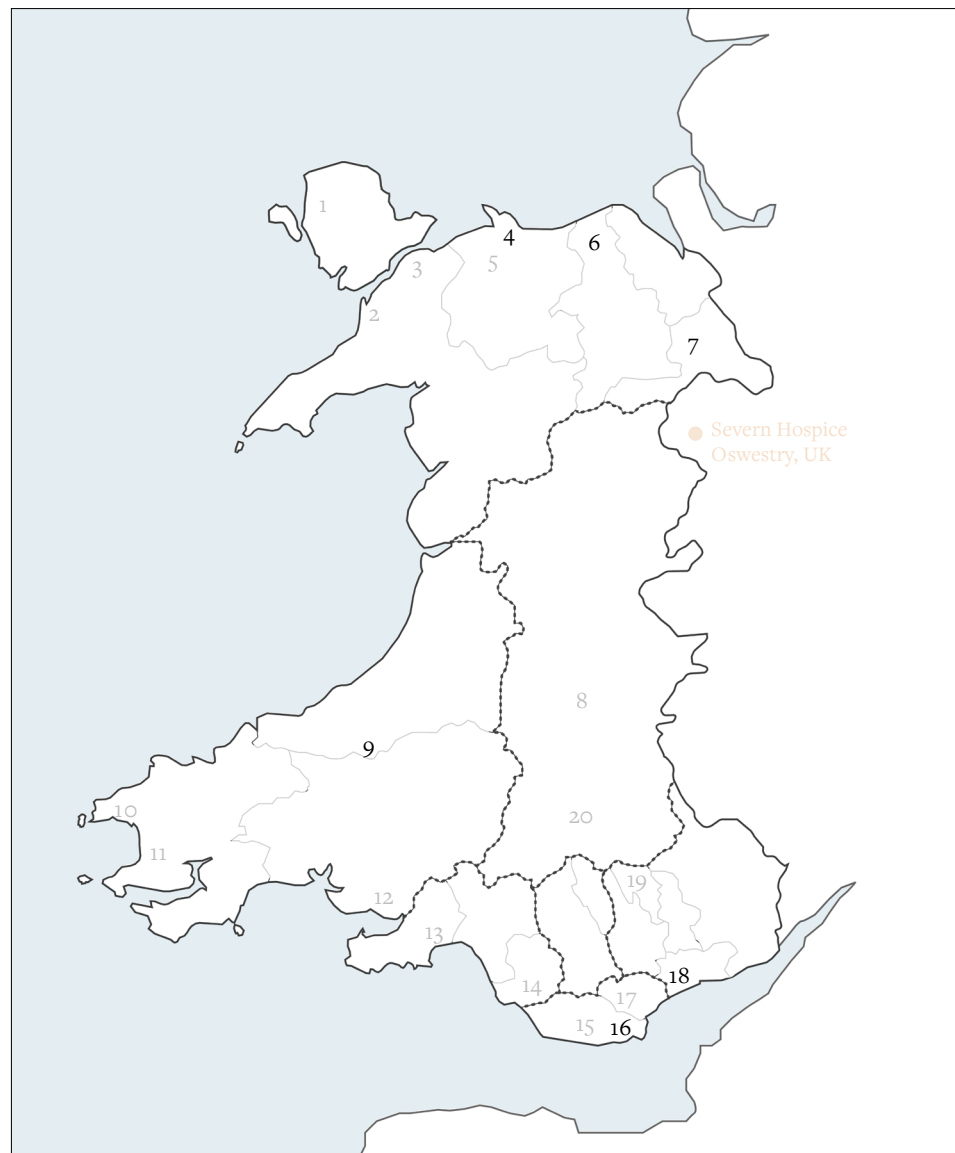


Fig. 4-2 Hospices in Wales

[day hospice, hospice at home,  
in-patient hospices]

- 1 Anglesey Hospice, ward within Ysbyty Penrhos Stanley Hospital, Holyhead
- 2 Hospice at Home Gwynedd and Anglesey, Caernarfon, Gwynedd
- 3 Hafan Menai Day Hospice, Caernarfon, Gwynedd
- 4 St Davids Hospice, Llandudno, Conwy
- 5 Ty Gobaith, Conwy, Gwynedd, children and young people
- 6 St Kentigerns, St. Asaph, Denbighshire
- 7 Nightingale House, Wrexham,
- 8 Bracken Trust, Llandrindrod Wells, Powys
- 9 Skanda Vale, Llandysul, Ceredigion
- 10 Shalom House, St Davids, Pembrokeshire

- 11 Paul Sartori Foundation, Haverfordwest, Pembrokeshire
- 12 Ty Bryngwyn, Llanelli, unit within Princess of Wales Hospital
- 13 Ty Olwen Palliative Care Services, unit within Morriston Hospital, Swansea
- 14 Y Bwythn, Bridgend, ward within Prince Philip Hospital
- 15 Ty Hafan, Sully, Cardiff - children
- 16 Marie Curie Holme Tower, Penarth
- 17 City Hospice, Whitchurch, Cardiff
- 18 St Davids Hospice Care, Newport
- 19 Hospice of the Valleys, Ebbw Vale, Blaenau Gwent
- 20 St Davids Hospice Care – Usk Day House, Brecon, Powys

The convenience sampling of Welsh in-patient hospices allowed the scoping studies to capture a geographical spread of locations - from urban, suburban to rural that are representative of a cross-section of Welsh society. Furthermore, these locations provided a range of hospice providers that utilised a mixture of different funding streams, from the Welsh government, UHB's and charitable donations. These hospices, though united by their commitment to in-patient hospice care operate within varying backgrounds and contexts. Fig.4-3 introduces core information on the in-patient hospices identified for the scoping and primary case studies. This table, amongst other information, highlights a key implication for this study, their age. Two of the identified hospices are now over twenty years old and have undergone numerous significant refurbishment and alteration projects to bring their environments up to date to support contemporary practices of care. This has also included work to improve compliance with new standards and expectations around access and dignity, as outlined for example by the Disability Discrimination Act 2005, the subsequent Equality Act of 2010 and UK Building Regulations Part M. This additionally includes the subsequent upgrade of the physical built fabric such as improved door and window systems to provide better thermal performance. The further two hospices represent contrasting environments, one a recently completed new-build project and the other a previously residential building that had been converted to be fit for purpose. To frame the primary fieldwork, a scoping study to be discussed in the next chapter was undertaken to garner further understanding with regards to the context and situation of commissioning and delivery of architectural work in palliative care settings.

## Scoping visits

The scoping visits were used to more broadly understand the significance and/or role of architectural design in palliative care environments that subsequently inform the research design of the main study. As this thesis draws on ethnography to interrogate the lived experience of architectural environments, these scoping visits took the form of 'micro-ethnographic' studies. Fusch, Fusch and Ness describe these micro studies, or 'focused ethnographies' as particularly valuable when the 'investigation focuses on a specific or a narrow area of inquiry, particularly when time or monetary constraints are evident'.<sup>258</sup> This method was felt appropriate in relation to the time constraints of the research process and the availability of hospice providers to participate in these early studies owing to construction work being undertaken at a number of the six hospices. The methodology

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<sup>258</sup> Patricia I. Fusch and others, 'How to Conduct a Mini-Ethnographic Case Study: A Guide for Novice Researchers', *The Qualitative Report*, 22 (2017), 923-41, pg.925

SCOPING VISIT LOCATIONS







Name	Nightingale House	Skanda Vale Hospice	St David's Foundation Hospice Care
Location	Wrexham	Saron, Ceredigion	Newport
Founded	1986	1993	1979
IPU Opened	1995	2016	2017
Beds	16	6 (respite only)	15
Bed type	12 en-suite single, one 4-bed single sex bay	en-suite singles	en-suite singles
Day Unit	Yes	Yes	No
HIW Registration Status	Hospital, Private/Independent, (specialist in-patient palliative care services)	Hospital, Private/Independant	Hospice, Private/Independent, (specialist in-patient palliative care services)
Funding	22% Welsh Assembly Government + LHB, 78% Community fundraising incl. wills + gifts	100% community based, additonal Lottery Funding	Information not provided
	 	 	 

Fig. 4-3 Scoping visit locations



offered a space to collect data governed by draft research questions that effectively rehearsed methods ahead of the primary fieldwork, such as how the design of the built environment has supported or hindered everyday care practices in the hospice. These then additionally brought to the surface key themes and areas of interest for the future fieldwork.

### Walking tours

In keeping with the proposed ethnographic approach, the scoping studies utilised walking interviews with key members of staff as research participants. A key aim of the scoping studies was to investigate the broader context of architecture and design in the management, commissioning, and delivery of in-patient palliative care environments. Walking interviews, or more commonly referred to as 'go-along interviews', were chosen as an appropriate method as the study outcome relies on understanding the environments from the participants own perceptions.<sup>259</sup> Walking or go-along interviews take the form of loose or semi-structured interviews that explore and move within contexts with the research participants. In this manner the traditional interviewer/interviewee roles are reversed with the participant describing the meaning of the environment in question.<sup>260</sup> Walking interviews offer a mode of research enquiry that illuminates the relationship between people and the 'places they inhabit, much of which lies in substrates of people's inner lives and hence is often inaccessible by quantitative<sup>261</sup> research methods. Moving in and around the hospice environment whilst holding a simultaneous conversation – walking and talking – in contrast to the potential constraints of traditional sit-down interviews conducted in a single space allows the research participants to respond dynamically to their environment and offer a deeper understanding of the environment and its context.

This method helps create a way in which to understand the 'rich and varied perspectives of environment'<sup>262</sup> as experienced by the participant, without requiring a highly structured and formal approach of questioning that may unconsciously make myself, the researcher appear like

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259 Carolyn M. Garcia and others, 'Conducting Go-Along Interviews to Understand Context and Promote Health', *Qualitative Health Research*, 22.10 (2012), 1395-403, pg.1

260 Ibid.

261 Alexandra C. King and Jessica Woodroffe, 'Walking Interviews', in *Handbook of Research Methods in Health Social Sciences*, ed. by Pranee Liamputtong (Singapore: Springer Singapore, 2017), pp. 1-22

262 Garcia and others, 'Conducting Go-Along Interviews to Understand Context and Promote Health', *Qualitative Health Research*, 22.10 (2012), 1395-403, pg.1

an 'interrogator or indifferent observer'.<sup>263</sup> The act of walking and sharing a situated environment creates an atmosphere in which information discussed and shared is prompted by physical and spatial stimuli. This was a critical factor for the scoping studies, as the outcome was to understand the way in which architecture and design was important to the hospice provider's experience of commissioning and delivering palliative care without - the researcher and a visitor with an architectural background - sub-consciously manipulating the interviews. The act of being guided by the research participant also highlights what Margarethe Kusenbach describes as 'street phenomenology'<sup>264</sup> whereby walking interviews can provide greater phenomenological sensibilities to traditional ethnographic methods in the shared in situ experience of a place. This is particularly pertinent to the architectural agenda of this thesis, which by engaging with key stakeholders of hospice organisations seeks to understand how they have worked with architectural professionals to commission, design or re-configure and deliver hospice environments.

### Settings and voices

The three hospice settings identified for the scoping studies offered a chance to explore the research agenda within three distinctive contexts; one hospice located in a rural setting, housed in a refurbished residential environment, one in an urban centre undergoing an extensive renovation process and one an architecturally award-winning new build located in the metropolitan area of the nearby city. The scoping studies took place over the course of a single day at each location and involved being taken on a guided tour led by the research participant, in each case, senior members of staff, (two of the three whom have clinical backgrounds) around their respective hospice. The routes taken are marked by orange markers on the plans provided, highlighting areas that were of particular interest. During this, the research participants were asked to describe and explain the environment as they navigated the hospice environment for between two to three hours before concluding with a sit-down discussion. The walking interviews were audio-recorded for later transcription, but this posed a limitation in the loss of non-verbal information, such as hand gestures or movements pertaining to elements of the built environment.<sup>265</sup> Though this method poses a potential loss of intangible research data, the scoping studies aim to broadly contextualise

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263 King and Woodroffe, 'Walking Interviews', in *Handbook of Research Methods in Health Social Sciences*. ed. by Liamputtong (Singapore: Springer Singapore, 2017), pp. 1-22

264 Margarethe Kusenbach, 'Street Phenomenology: The Go-Along as Ethnographic Research Tool', *Ethnography*, 4.3 (2003), 455-85

265 This could be perhaps movements, such as pointing at a particular window or the experience of a shadow or opening and closing a door to demonstrate spatial relationships.

the issues and experiences of hospice providers working alongside architectural processes rather than focusing on finer detail aesthetic or individual architectural strategies. Furthermore, this offered the researcher a form of rehearsal of research methods to be used in the primary fieldwork that looks to document the experiences of key members of staff in the case study setting.

The scoping visits move the setting of the thesis from a mode of desktop research into the field of study and marks a noticeable shift in tone. The thesis thus far has focused on a broader landscape of contextual studies written in traditional academic prose. The subsequent section signals a change of location and tone into the field of study using first-person narration and the present tense. The use of a first-person account draws on qualities of 'storying' or storytelling, which within architectural research as Frascari describes is 'for making sense of both individual experience of architecture and social interactions that take place in it'.<sup>266</sup> This method of recounting rich descriptions of inhabitation could be argued to contribute to understanding the implications of architectural design in the manner of a 'post-occupancy evaluation'<sup>267</sup>, providing feedback to architects and designers that have the potential to inform future making and designing of buildings. The first-person account places, myself, the researcher, directly into the field engaging and reflecting on the experiences of the stakeholders.

### Skanda Vale (West Wales Hospice)

Located in a rural village in the principal area of Ceredigion, this hospice stands out amongst the other Welsh hospices owing to its unique founding and context of care provision. Skanda Vale was established not by local healthcare professionals or community members but rather by members of a multi-faith monastic community, the grounds on which the hospice is located. The monastery itself was originally established in 1973<sup>268</sup> with non-clinical home-care services being offered since 1993 in response to the lack of services available at that time to the South-West Wales region. Most distinctively, Skanda Vale uses a predominantly volunteer based workforce and relies fully on charitable donations to fund their services. In 2016, the monastic community opened the six

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266 Mario Frascari, 'An Architectural Good-Life Can Be Built, Explained and Taught Only through Storytelling', in *Reading Architecture and Culture: Researching Buildings, Spaces, and Documents*. ed. by Adam Sharr (Abingdon, Oxon [England]: Routledge, 2012) pg.288

267 POE is a commonly used term in the architectural profession for the process of collecting feedback regarding the measured success and/or performance (traditionally environmental) of a recently completed project.

268 Skanda Vale, *The History of Skanda Vale* (n.d) <<https://www.skandavale.org/history/#>> [accessed 20th November]



bedded in-patient unit, though this has so far only been registered to provide part time respite care. It was a long drive to the hospice, as towns turned to villages that turned to swathes of countryside. I was reminded of the critical rurality of many communities in Wales' and the potential difficulties in accessing appropriate and necessary EoLC and palliative care services. I arranged the visit with a member of the hospice's management board, also a senior member of the monastic community, who met me at the reception of the hospice. He guided me to a small office room within the reception area to place my coat and bag and to introduce himself. As we began talking, cheers broke out, and happy birthday began to be convivially sung. It was explained with a broad smile, that there were currently celebrations being held for a day hospice patient in the adjacent lounge and sunroom. These spaces are the main communal spaces of the hospice and occupies most of the ground floor, opposite the office space we were currently in, and is accessed from the main entrance hallway - meaning the cheerful chattering of the party reverberated around the ground floor. Whilst the celebrations continued, the walking and talking tour remained static and largely took place in the office until it was felt appropriate to continue outside.

Developed as an independent project of the monastic community, Brother Thomas explained that their experience of opening the hospice had been a protracted process. The original aspirations were for a 'large twenty-bed hospice...but you know you can't just go and build a hospice somewhere'.<sup>269</sup> The hospice's current site opened in 2016 and was the culmination of previous architectural projects undertaken by the monastery. Brother Thomas explained that they had previously commissioned a local firm of architects to apply for planning permission for the renovation of disused farm buildings on donated land into a small in-patient facility. A stone farmhouse was to be converted to a day centre connected by a new link to a single-story barn building that would house five bedrooms with additional converted outbuildings providing clinical and administrative space. However, this scheme was refused planning consent as it did not comply with a policy in the *Carmarthen Local District Plan*.<sup>270</sup> Despite the scheme's refusal, Brother Thomas spoke positively about the involvement of the architects in the delivery of the scheme but stated that 'we did a lot of the design ourselves, a lot of the work ourselves'.<sup>271</sup> This included survey drawings,

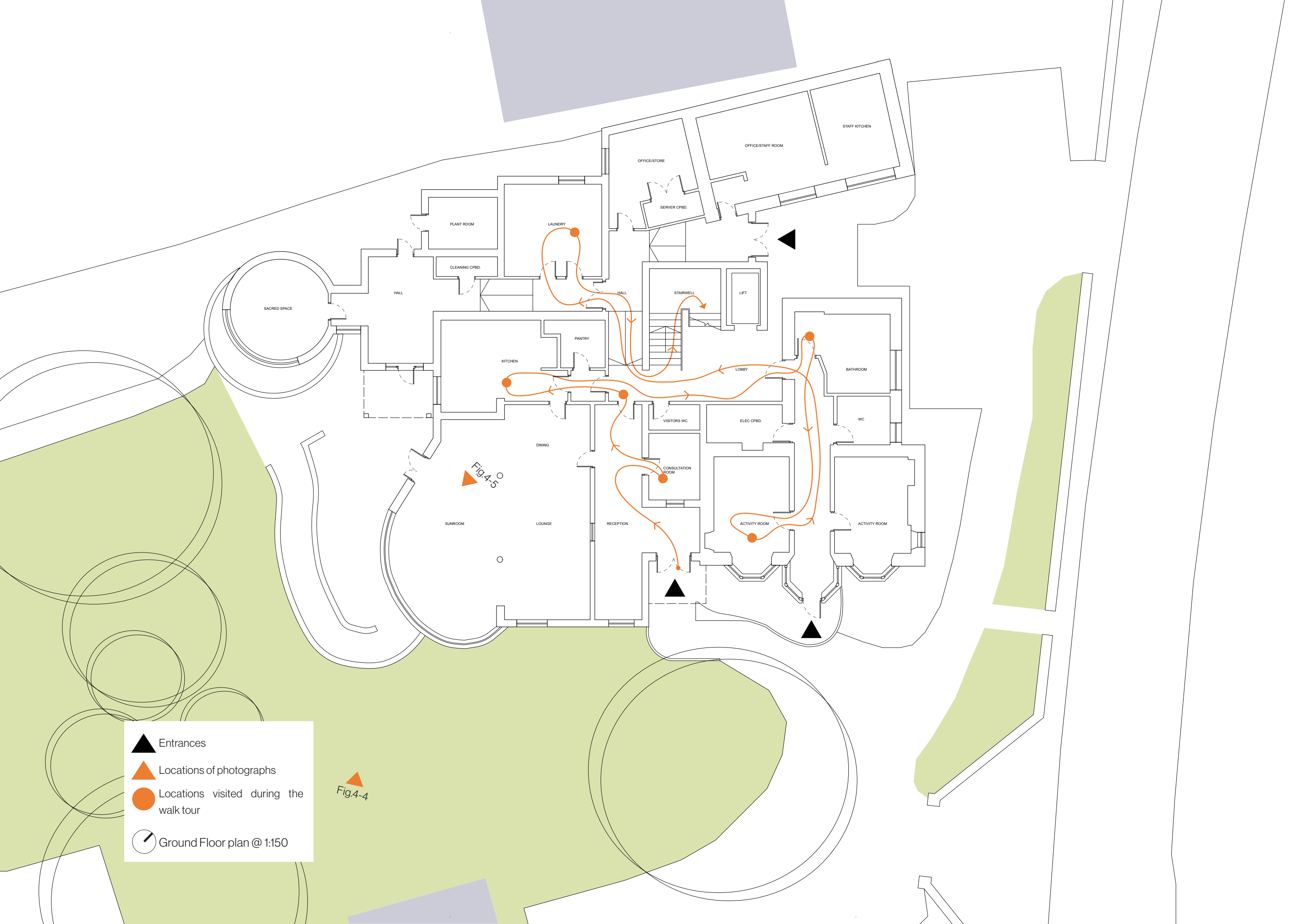
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<sup>269</sup> Ibid.

<sup>270</sup> The planning application refusal letter from the local County Council stated that the scheme was 'contrary to Policy CE15 of the District Local Plan: Conversion or Re-Use of Rural Buildings – outlining that 'concerns regarding the structural integrity of the existing buildings are such that it is considered they will not be able to be converted for the use proposed without the need for substantial re-building and without significant new build extensions'. The hospice was of the view that re-use of the buildings was a sustainable contribution to the local surroundings and that the buildings were not as ruined as the Council viewed them to be.

<sup>271</sup> A, 'St David's Hospice Interview', ed. by Bellamy, 2020)





- Entrances
- Locations of photographs
- Locations visited during the walk tour
- Ground Floor plan @ 1:150

Fig.4-4

Fig.4-5



▲ Entrances

▲ Locations of photographs

● Locations visited during the walk tour

○ Ground Floor plan @ 1:150

Fig. 4-4 Exterior view,  
West Wales hospice  
Note the curved glass  
facade to the new  
extension to what was the  
original residential building



Fig. 4-5 The sunroom,  
West Wales hospice  
Interior view of the curved  
facade shown above, this  
room was occupied with  
a birthday party during my  
visit



development of the design including setting and calculation of room dimensions and adjacencies. Liaison with the local planning authority was undertaken by the architects, as was the preparation of formal architectural drawings for the planning application. We might observe that this approach by the hospice formalised the role of the architects to the delivery of key packages of information with little engagement in-between supporting the development of the brief and the design.

Shortly after the refusal, the hospice purchased its current site, a former residential building that had been converted into a care home. Though the aspiration was for an in-patient unit, the monastery decided that initially the building would be refurbished to facilitate day hospice services on the ground floor. Brother Thomas explained that for this project, unlike the previous, the monastery did not commission an architect, instead that:

we did all the design ourselves, we employed a local builder, we supervised the building works, ordered the materials, we were very hands-on, we supervised the building works and it was done on a pretty low budget and it took about six months planning, I did all the drawing myself on a piece of paper, no AutoCAD, nothing like that, all line drawings, all dimensioned with a tape measure, it was all done by hand and we had full input. Then we also specified the doors, we did all the research in terms of fire, alarm system and what was required for a day hospice, at the time, day care services, if you weren't providing clinical services didn't require registration.<sup>272</sup>

This quote highlights what might be described as the hospice 'cherry-picking' architectural services, effectively qualifying themselves as equally able to deliver the same outcomes as architects. The act of 'absenting' the architect in both the design and construction process, is emphasised by the organisation's prior preference to develop and maintain their own land, that aligns with observations that as do-it-yourself (DIY) and self-build approaches have become more popular, the role of the architect is seen as unnecessary.<sup>273</sup> Brother Thomas went on to further explain that the next phase undertaken by the monastery to renovate the existing building to incorporate in-patient facilities was a critical juncture in the hospice's involvement of architects in the design and delivery of their environment 'just because of the complexity of it, a massive sea-change from what we were doing originally...we're talking about major building works'.<sup>274</sup> This process happened slowly, Brother

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<sup>272</sup> Ibid.

<sup>273</sup> Flora Samuel, 'Why Architects Matter : Evidencing and Communicating the Value of Architects', (2018) p.16

<sup>274</sup> A, 'St David's Hospice Interview', ed. by Bellamy, (2020)

Thomas stated that the monastery spent between 2008-2012 researching and networking with other hospice providers in Wales to allow them to fully understand the parameters of in-patient care and to define what was needed in terms of a care environment. As the birthday party celebrations carried on around us, Brother Thomas explained that despite the decision to engage architects they were keen to remain as involved as they could be as clients:

so what we did, we set a brief, by that stage we understood we wanted five or six beds, day-care facilities and various things to be in the building and various external this and that – so we had a quite a clear idea of what we wanted and what we needed because we'd done a lot of work on it<sup>275</sup>

Building on accumulated knowledge of hospice care from initial planning of the infrastructure – Brother Thomas explained that the monastery 'felt it was vital we could actually work with, there had to be a relationship and...what we didn't want was some airy-fairy architectural company'.<sup>276</sup> It was evident during the conversation that Brother Thomas and the rest of the Skanda Vale's board, perhaps heightened by their status as a pre-existing monastic community with certain ambitions, saw the process of design as a collaborative exercise in which they played a primary, rather than secondary role. At this point, Brother Thomas realised that the birthday celebrations had quietened down enough for us to venture out into the hospice without causing a distraction. We walked into the main communal space opposite, the 'sun-room' that sits at the heart of the hospice building. I was expecting a traditional rectangular volume given the previous residential use of the house but was instead greeted by a large array of faceted glass panels, see Fig.4-4 & 5. The room is the focal feature of hospices atmosphere, to which Brother Thomas explained the story of its inclusion:

we had a feeling quite late in the day that we wanted to change a significant part of the design in terms of the whole visual from the garden, to soften, and create character and this became a drama in the architect's mind. You see the architect was pre-occupied with trying to get it through planning, but we weren't prepared to compromise<sup>277</sup>

As we spoke about the back and forth and the dynamic of the 'client' and 'architect', Brother Thomas reiterated that 'we're very hands on, we were going to be very involved in the process'.<sup>278</sup>

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275 Participant A, 'Skanda Vale Hospice Interview', ed. by Annie Bellamy, 2019)

276 A, 'St David's Hospice Interview', ed. by Bellamy, 2020)

277 A, 'Skanda Vale Hospice Interview', ed. by Bellamy, 2019)

278 Ibid.



## Nightingale House (North Wales Hospice)

Nightingale House is in the centre of a major town, providing in- and out-patient care to the region of North Wales. The hospice first opened as a ward within the nearby hospital in 1986, following the campaign of a local consultant interested in pain control and management.<sup>279</sup> In subsequent years, a charitable foundation was started and fundraised the necessary funds to commission and build a purpose designed in-patient facility that opened to the community in 1996 with sixteen bedrooms. As outlined in Chapter 2, many hospices are seeing major changes to the needs of their service users, and as such the hospice undertook in 2019 a major refurbishment project to accommodate this. This was spread across three phases to facilitate the hospice's aspiration to offer further one-to-one rehabilitative and therapy led care alongside their in-patient services.

My visit to Nightingale House was facilitated by the hospice manager 'Rebecca', who met me as I arrived at the hospice drenched from a heavy rainstorm. To dry off, the hospice manager led me to 'Caffi Cwtch'. It is worth noting that the Welsh word 'cwtch' has no literal English language translation but can be roughly translated as meaning both a cuddle or hug and a small cubby-hole or cupboard with its sentiment described as an 'emotionally significant embrace'.<sup>280</sup> The word has seen an increase in use in new contexts such as care, for example the Maggie's Centre in Cardiff, Wales that opened in 2019 featured a small contemplation space named the 'cwtch'. Cafés have become common features of many hospices, offering an alternative atmosphere to canteens or serveries reminiscent of institutional buildings like schools or hospitals. As I dried off and warmed up with a coffee, the café was full of life. Rebecca explained to me that the café was a vital part of the hospice atmosphere offering both in- and out-patients and their visitors a safe space to socialise, with the comfort that care was nearby if needed. But she also described how the café had become a valuable place for the local community, for those looking for a freshly cooked meal or coffee and cake with friends. Like the dual function of the café, the commercial kitchen serving the café also prepares the catering for the hospice. The café is a large open-plan space of approximately 90 square metres with a sweeping curved glass wall that connects the building to the public streetscape beyond, being a visible focal point from the main entrance. It is a focal point as you walk past the hospice's entrance on the street - so much so that you might be forgiven for not knowing

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279 Nightingale House Hospice, *The Nightingale House 20th Anniversary* (2016) <<https://www.nightingalehouse.co.uk/the-nightingale-house-20th-anniversary/>> [accessed 10th November]

280 Kate Leaver, 'Cwtch: The Hug Invented by the Welsh', (2018), <<https://www.bbc.com/travel/article/20180624-cwtch-the-hug-invented-by-the-welsh>> [accessed 10th August 2021]





that the hospice was the main purpose of the building if not for the signpost of the hospice, see Fig.4-6. The café was decorated neutrally, in pastel greens and fashionable grey<sup>281</sup> timber veneer flooring. As this is space for both patients and the public, it has a dual responsibility in creating an atmosphere that is both comfortable and secure for patients, but not so institutional that members of the public are dissuaded from visiting by appearing too clinical.

We set off from the café at one end of the building to see more of the hospice whereby Rebecca told me about how the café was the first of many changes the building has seen, being an extension to the original footprint designed by the locally based architects who were the original designers of the hospice. As we discussed its history and how it came to be built, Rebecca explained the long-standing and on-going relationship the hospice has formed with the architects and how they have returned to them for all the refurbishments and design changes they have needed. As we moved around, and as Rebecca pointed out previous uses of space, walls knocked down and rooms extended, the relationship formed between the hospice management team and the architects had created a reciprocal and mutual approach to designing appropriate spaces for their shifting needs, with both architectural and clinical parties summarising their expert contributions to bring together through the design process.

As we walked around the ground floor, we approached one of the areas currently being stripped, ahead of renovation works that will see it turn into primary spaces for the day hospice. Our conversation turned to the future vision of the hospice, and the three phases of planned works to help it meet its aspirations. Rebecca explained that whilst the hospice does not currently have a vision for its building, it does have a broader trajectory for its care services. She commented how looking ahead to the changing shape of how palliative care might be delivered was under continual review by not only themselves as an individual organisation, but at a national level. The tension between national policy and the hospices' independent ability to plan, places constraints on proactively planning for their future aspirations of the built environment. This conflict is further highlighted by a subsequent discussion of regulatory guidance, as Rebecca described to me the standards to which they have been upheld. Hospices, as she explained, seemingly exist within a grey area, not classed as an independent building type with specific needs and requirements but have different identities depending on local authority.

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281 The colour grey has seen a rise in popularity in interior design, particularly residential, perhaps owing to its neutral colour.

Fig. 4-6 The approach, North Wales hospice

Next to signage for the hospice, there is a small sign advertising Rodda's Cream Teas - a hallmark of afternoon tea.



Fig. 4-7 Exterior view, North Wales hospice

The entrance to the hospice, Caffi Cwtch, the cafe open to the public is visible to the right as the curved glass element

Historically, hospices had been categorised as 'nursing/care homes', but under HIW rules, hospices are currently registered as 'Independent hospitals (other)' meaning they are assessed against regulations that also cover private hospitals and clinics that offer aesthetic procedures. Whilst these share clinical characteristics, these standards do not capture the unique form of care that in-patient environments offer. Furthermore, in-patient hospices do not offer, nor, have the capacity to provide medical interventions or procedures as independent hospitals would, signalling a clear differentiation of the necessary standards and requirements of acute clinical environments. The lack of definition, as Rebecca described, creates an open playing field, that the design and direction of the hospice environment is left open to the perceptions and opinions of those that are in charge, and or is guided by those with prior experience. These guidelines in her opinions are perpetually out of date with regards to the clinical standards and do not provide measures by which to aspire to or provide the basis for innovative design thinking.

Sitting back down in her office, Rebecca began to speak more freely about their experience with refurbishment and renovation works. Referencing her own point about a lack of standards, Rebecca described how unlike hospitals that have centralised resources to draw upon, hospice providers have established their own sharing culture, with many hospice teams visiting other hospices when in need of inspiration or advice when embarking on building projects. This network of support affords hospice providers opportunities to learn not only different approaches, but a chance to reflect on the success of innovations or changes to traditional models of care environments. Drawing on close expertise was not limited to other hospice providers, but also their own staff. Reflecting on the experience of other hospices, Rebecca was adamant that the input of members of staff is fundamental to any renovation work, not as a token gesture during early feasibility stages but across all stages of work, including construction. I wondered if this open communication and collaboration affords a sense of ownership and contribution that works against typical clinical authority figures, such as infection control.

Telling stories of alterations 'gone wrong' in other hospices, Rebecca emphasised a simple yet powerful point. As healthcare professionals, they are experts in their field and whilst they can identify their requirements to deliver high quality care; they are not design professionals with the required skillset to translate this information into efficient and exemplary spaces that support all the nuances of in-patient care. Furthermore, crucially Rebecca highlights the need to be an intelligent client and the difficulty of knowing if they are asking the right questions to ensure they get the

Fig. 4-8 Main corridor, North Wales hospice, Just visible to the right is a double height space that draws light into the ward otherwise lit by electrical lighting.



Fig. 4-9 Typical patient bedroom, North Wales hospice

The bedroom has views out into the courtyard garden, there is a tension here between the clinical, e.g the hoist versus the domestic nature of the floral patterned curtains.



building and space to which they aspire to. Rebecca described that for the current refurbishment project they employed two distinct project managers – one, who undertakes the responsibilities typical of a project manager that works within the hospice management to support the delivery of the project and another who acts as the hospice's quality assurance. This role, as Rebecca explains further, was undertaken by a previous board member whose professional background is within the architecture and construction industry, whom the hospice relied upon to be a mediator between the architect and themselves. A role akin to a design advocate, who can be a neutral voice within the process to champion the needs of the client during the construction process to ensure that the original vision and aspiration is not diluted.

### St David's (East Wales Hospice)


Based in the suburbs of a city in Wales, located on a site that faces the open countryside, St. David's sits alongside a separate day hospice building completed in 2012 by KKE Architects, who were re-hired to design a new in-patient unit that was completed in 2017. Both the day hospice and in-patient unit have won numerous architectural accolades, with the in-patient building winning the Eisteddfod Gold Medal for Architecture in 2018 bringing the hospice as specific building type to broader architectural audiences and marking itself as an exemplary contemporary precedent.<sup>282</sup> In addition to the partnership with its local health board, St. David's is unique in its collaboration with the local city council. Owing to this the hospice received a significant portion of the build costs as statutory funding. The in-patient unit offers fifteen single bedrooms, all provided with hotel inspired wet rooms<sup>283</sup>, with five of the rooms large enough to provide overnight stays for relatives and friends. The building itself is L-shaped, with supportive functions located on the external perimeter, with a central corridor that protects the patient bedrooms on the inner perimeter with views out over the garden.


As I waited for Anna, the hospice's CEO, I enjoyed a coffee in the hospice café, sitting overlooking the landscaped garden and the day hospice in the background. This was not the same as my time in 'Caffi Cwtch' at Nightingale House however that was situated on a main road pulling in the local community. Here, the café was a communal area for patients and visitors, more like a living room


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282 Eisteddfod Wales, Gold Medal for Architecture Winners (n.d) <<https://eisteddfod.wales/archive/eisteddfod-winners/gold-medal-architecture-winners>> [accessed 5th January]

283 A wet room being a bathroom in which the shower is open and/or set to a single wall with the floor finish flush with the rest of the room to allow for drainage without the need for a level change via a traditional shower tray.

 Entrances

 Locations of photographs

 Locations visited during the walk tour


 Ground Floor plan @ 1:250



Fig. 4-10 Tactile materials,  
East Wales hospice

The distinctive non standard materials visible in a patient bedroom, notice the use of curtains in place of typically used blinds which are considered more cleanly.



Fig. 4-11 The quiet room,  
East Wales hospice

At the end of the corridor, this again demonstrates the use of non-standard materials, such as stucco plaster and slate flagstone tiles.





– as very few members of the public would be attracted to come here specifically. As a recently completed new build hospice, the environment was distinct in its atmosphere in comparison to my previous two visits to the Skanda Vale and Nightingale House. There was a tangible freshness to the finishes and the furniture, and recognisable natural materials, such as cedar, local stones and flagstone flooring. Anna arrived, and before we set off to explore the building, she briefly explained the background to the project. Having taken over the in-patient services of St. Anne's Hospice, previously located on the grounds of St. Joseph's private hospital nearby,<sup>284</sup> it was decided that the existing facilities were not fit for purpose and a new building was required. Anna here emphasised the uniqueness and advantage of St. David's in being funded by multiple organisations, namely the local health board, who provided 60% of the £5 million build cost. In contrast to the previous two scoping visits, which relied upon public funding – this highlights the different context under which the hospice building was conceived and the authoritative voices during the process.

It is made clear by Anna at the beginning of our conversation that the hospice building was a direct result of her clear vision about the way in which hospice care should be delivered, reflecting her experience of working in the profession. The vision had clear objectives to provide an environment that specifically was not anything else clinical and should reject what she described as the typical healthcare architecture aesthetic. To do this Anna stated this necessitated taking risks and pushing back against clinicians to do things against common practice. Moreover, she explained how this also meant not building by committee but by having a tight team - herself, the architect and input from the contractor - with no project manager. This was described as having multiple benefits; in managing the development of the brief but also the finances of the project. We can observe that such firm control on the process by Anna helped deliver on her aspirations for the building; however conversely this may create narrow parameters defined by a single vision of 'best practice'.

We left the café and began the tour of the building, passing first the open seating area opposite the entrance and reception area and with a large set of bi-fold doors that connect the space to the 'back' of the building, the landscaped garden, that was a key feature of the design. Moving from this area along the linear corridor, Anna pointed out various other features, such as stone work-surfaces and the lack of internal windows to the clinical meeting areas and staff breakout area to deter disruption from patients or families. As I walked the corridor, I noticed the lack thereof of the

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284 South Wales Argus, St Anne's Hospice to Be Taken over by St David's Hospice Care (2013) <<https://www.southwalesargus.co.uk/news/10272967.st-annes-hospice-to-be-taken-over-by-st-davids-hospice-care/>> [accessed 1st July]

expected noise of feet and trolleys underfoot, looking down to see carpet that was muffling our movements, see Fig.4-12. Anna noticed my surprise and used this to stress the risks taken by this project – the introduction of carpets was highly criticised, by infection control and some members of staff. On one hand this offered an auditory peace not afforded by busy hospital environments – but on the other it was oddly still, and I found myself a little unsettled. Unexpectedly the medical store was a feature of the tour, owing to the highly technological system that the hospice had introduced that directly fed back to the pharmacy at the local acute hospital to ensure the stock of medicines was monitored and supplied automatically. This was perhaps a hallmark of the way in which the hospice was commissioned and developed; driven by healthcare professionals pushing against the norm.

We stopped along the corridor for Anna to show me one of the patient bedrooms. Each bedroom has its own linen store and small station for members of staff to stop at. It was revealed that the individual linen store was borne of a desire to remove linen trolleys from the ward environment and to accommodate personalisation for each patient and their visitors, see Fig.4-13. Small details such as these were clearly the result of Anna's overarching vision for the atmosphere of the space to be as non-clinical as possible; though I wondered to what extent these features were in response to the needs of the staff as well. The conversation in the bedroom turns to a discussion of infection control and materiality, and once again, Anna refers to the risks and boundaries that were pushed. She explained that the approach of the design was to provide a new perspective on the expectations and reality of hospice services. For example, by balancing the understanding that bedrooms do not host complex clinical procedures at high risk of infection and if a situation were to arise that a serious infection was present the room could be independently quarantined, and all materials subsequently replaced. This approach I wondered could only be possible through determination, to push back against common practice. Would this have been successful if it was only the architect or design professional that had suggested this, or was the success of these due to the joint effort of both Anna and the architects?

As we made our way to the opposite end of the corridor (and the building) we found ourselves seated in the quiet room further discussing these risks and the different scales at which these occurred. A fundamental aspect of the hospice building is its geographic location. There is a tentative shift toward new build hospices being built on the grounds of existing acute hospital sites to benefit from shared infrastructure, which St. David's does not do. Zooming down to a finer level of

Fig. 4-12 Material palette, East Wales hospice

A seating area within the main corridor, the carpeted floor is visible, alongside the natural timber used for the bench.



Fig. 4-13 Functional joinery, East Wales hospice

The boundary between each pair of rooms acts as a 'stop-off' point, where staff or visitors can wash their hands, and linen and other necessary items can be stored close to the patient bedroom.



detail, Anna summarised that the architects brought value to the projects acknowledging that she and fellow members of staff are not experts in design and space, despite there being aspects of the brief that she was certain about prior. Questioning the involvement of individual staff, as Nightingale House had mentioned, Anna was resolute that the approach taken was not design by committee. She described her opinion that as healthcare professionals, staff are overly practical regarding the potential for their work environment and so remain pragmatic in their suggestions and cannot contribute new, innovative or aspirational ideas towards their place of work.

## Chapter reflections

Considering the landscape of palliative care within Wales, in-patient facilities make up only a small proportion of the way in which hospice care is delivered, despite it being demonstrated that there is sufficient need for more beds. The scoping studies discussed in this chapter present the experiences of three in-patient hospices in Wales, revealing the ways in which each hospice provider has approached construction projects of varying scales. Each scoping study provided different perspectives on specific issues they encountered in building specialist care environments and illuminated strategies that they have used to navigate the process. Skanda Vale is a relatively young and unique hospice provider in Wales; its origins rooted in the religious movement of its founders who recognised a gap in local palliative care services. With this background Skanda Vale sits on the outskirts of traditional clinical influences – reflecting the self-sufficient approach of the religious commune that runs it. In conversation with Brother Thomas, it was evident that self-sufficiency was an approach carried through the organisation's relationship with design and its subsequent architect regarding the conversion project undertaken to provide the in-patient environment. From his account of project managing, it was stressed that most of the early design work was in fact carried out by themselves, including architectural drafting and underlying development of the design brief. However, we must note that the voice of the architects in question were not heard and therefore, the statements of Brother Thomas must be considered cautiously.

The Skanda Vale team invested time in research regarding the clinical and spatial requirements necessary and worked to create a network of support by visiting and communicating with other more established hospice providers to share their experiences. However, it is key to note that experience referred to here may not necessarily translate to design expertise. Knowledge transfer in this manner would aspire to ensure that known mistakes are not repeated, which may

be true of aspects relating to care practices. However, we may argue that issues or deficiencies regarding architectural elements are subject to the possibility of being perpetuated, as hospice providers may not have the training or awareness to notice and highlight issues or deficiencies in design layouts or details thus further emphasising the potential missed opportunity to engage in meaningful co-production in benefit of the hospice environment. Solely undertaking the bulk of this early-stage work prior to engaging with architects for the formal planning application meant that Skanda Vale were clients with a certain level of understanding of a hospice building with a clear vision. However, within this context it appears that the relationship between the client and architect was perceived by the Skanda Vale team to be less co-productive but more transactional as they had previous experience of working with their own self-build projects. Furthermore, the discussion of management and the unpredictable nature of construction - especially when dealing with an existing structure - served to highlight the criticality of financial pressures on hospices.

Nightingale House presents the most similar background to that of the primary case study setting of this thesis – it being a similar age building that has been subject to many ad-hoc alterations and extensions. Unlike Skanda Vale discussed previously, Nightingale House is an established provider and moved into purpose-built accommodation following time as a ward at the local acute hospital. Despite the hospice having experienced numerous building projects over the years to keep up to date, Nightingale House, uniquely, has managed a level of coherency via a long-standing relationship with the local architects who were responsible for the original design. We might observe that this type of relationship affords a greater degree of institutional knowledge; of not only the things that have taken place over time with regards to the fabric of the building but also potentially key members of staff and stakeholders. The architect in this case, was at the time of writing, involved in an ongoing refurbishment project, and whilst not employed to create a plan of how the hospice could grow - as Rebecca acknowledged this was a moving target with regards to patient needs – might be better placed to understand the client needs. Unlike Skanda Vale, the relationship between architect and client of this scoping visit appeared to be based on not only mutual understanding of the different expertise that both healthcare and architecture professionals can contribute to the built environment, but a clear acknowledgement of this.

To navigate the process of design and construction, Nightingale House's utilisation of a design advocate offered a strategy by which it could be resilient in its decision-making. The design advocate, in the context of Nightingale House acted as a neutral mediator between the architects

and hospice management ensuring that quality and needs were recognised by both parties. The advocate in this role could be seen as quality assurance for the process of co-production, ensuring that one side did not dominate the other. In addition to this method of co-production, Nightingale House was staunch in its approach to the role of staff in the process of any building work that should take place. The team emphasised that they felt staff members should be meaningfully consulted throughout the whole process and not solely during early 'fact-finding' stages. Though a different context, this presents a similar point that architects, and therefore projects benefit from early and sustained involvement.

The scoping visit to St. David's, offered a unique perspective on the role of architecture in hospice care owing to its status as the most recent new-build hospice in Wales. Able to begin from a clean slate, without the constraints of existing buildings as the two previous scoping studies, the conversation regarding the approach toward architectural design highlighted an intense ambition from the Chief Executive, Anna, to be innovative and develop an exemplary building for in-patient palliative care. This was a singular vision that was supported by the expertise of the architects and the chosen contractor. It was described that having no project manager was a conscious decision by Anna to facilitate her control of the project, with regards to both design and finances. This is a clear contrast to the previous studies and is furthermore reflected by the absence of staff involvement throughout the project. The lack of engagement was a conscious decision taken as a strategy to manage the innovative aspirations of the project. In comparison to the previous two studies, St. David's had the closest relationship that resembled co-production with the design team, with Anna stating that this allowed the brief to be kept to very tightly with little outside input that may add constraints or lessen the vision. This relationship in addition presents similarities to that of Dame Cicely Saunders and Peter Smith of St. Christopher's Hospice, in which co-production was a driving force to the outcome, but co-production that was limited to select pre-chosen voices. This somewhat mirrors the approach of Skanda Vale – but St. David's demonstrates that where architects may have made suggestions, authoritative managerial input added weight to challenging discussions for example, regarding infection control. This demonstrates that the approach of co-production can be beneficial in challenging perceived standard or best practice that may be problematic for architects or healthcare professionals to overcome alone.

We can observe that all three of the hospices placed value on detailed and clear brief development, though utilised different strategies by which to achieve this. Skanda Vale and Nightingale House's



championed informal networks of support to facilitate the sharing of information regarding best practice as a method to perhaps fill the void of practical guidance and to familiarise themselves to – perceived – successes and failures of other hospice providers. It was also clear that an ability to invest time into early stages or research and vision-planning to facilitate more collaborative practice with the architects enabled greater opportunities. The exploration of the brief and client's needs, though covered by Stage 0 'Strategic Definition' of RIBA's Plan of Work<sup>285</sup> is not often able to be met due to demands of time and finances. What has been highlighted by these scoping studies is that the approach with regards to communication between hospice management, members of staff and the design team, and the relative agency of members of staff in co-producing their environments is critical to understanding the role of architectural design.

Additionally, the scoping visits served to highlight the sensitive nature of the research location, the hospice. The walking tour led by a member of staff was able to judge the appropriate spaces on the day that could be explored. In all three studies the walking tours were limited to areas which were unoccupied by members of the public, barring communal spaces such as cafes and reception areas. Despite this, the visit to Skanda Vale coincided with a celebration event being held for a day hospice user and as such it was not appropriate to walk and talk meaning that most of our discussion was held in an office to not disturb the event. Though this change to a method of a more traditional face to face interview resulted in a less self-directed conversation, it is not felt that this had an adverse impact on the overall value of the experience for the purposes of the scoping visits. What this did highlight, however was the unpredictable nature of undertaking ethnographic research in environments of care, and that their erratic nature requires resilience and adaptability on behalf of the researcher.<sup>286</sup> This is foremost an ethical consideration to protect both potential participants and the researcher themselves from distress of unexpected situations, such as the decline of a patient's health during the visit. Whilst this unpredictable nature may place additional barriers to research taking place in care environments, in some regards walking tours can be a positive mitigation strategy for this as the member of staff can act as a 'live' gatekeeper checking the status of the environment as we move around.

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285 RIBA, Royal Institute of British Architects, Plan of Work is a framework by which the process of design, construction and operation of buildings in the UK are organised. The latest publication from 2020, splits this into 8 distinct categories and describes key expectations and outcomes.

286 In this case, the overall mood of the architectural environment shifted due to a social event being held, but in a critical clinical environment this could also be the result of medical emergencies.



# 5

## Hospice as a lived experience

This chapter introduces the contextual setting of the thesis' case study, the Cardiff and Vale Hospice, exploring its history, location, and the evolution of its built environment over time. The chapter will then present and disseminate the primary fieldwork that is divided into two distinct yet connected phases, comprising (i) focus groups/in-depth interviews with staff members of the hospice that were followed by (ii) non-participant observation of the hospice building in use. The data collected from the workstreams will share initial observations of the hospice by the researcher, followed by five accounts of lived experience as told by staff each with different roles within the hospice, before concluding with an evaluative account of the observation of the building. By incorporating the hospice building itself as an actor within the fieldwork, the research promotes architectural understanding of the connection between experience and workplace, identifying if, and where there are opportunities for co-production and 'effective information exchange and shared decision making that respond[s] to complex and unique users' needs'<sup>287</sup> to take place.

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<sup>287</sup> Realpe and Wallace, 'What Is Co-Production?', (London: The Health Foundation, 2010) p.8

## The hospice by the sea

### Selection

As discussed in Chapter 4, there are currently six in-patient hospice providers within Wales. However, due to the scope of this research it was decided that these would be narrowed down to a single hospice site as the primary case study where ethnographic research could be undertaken. Owing to several factors, predominantly geographic and an existing relationship via a key gatekeeper, a hospice run by a wider national end of life care charity was chosen. Situated in a seaside town the hospice is a short distance away from the Welsh capital and offers its services to those living in the wider area of Cardiff and the neighbouring Vale of Glamorgan. The Cardiff and Vale Hospice (C&V) has existed within the community since the early 1950's and remains an active and well-supported service in the town. The range of services occupies what was purpose-built accommodation<sup>288</sup> that is spread over five storeys and offers twenty-eight bed spaces across two floors for clinical care. These beds are provided in a mix of single and multi-occupancy patient bedrooms (of three and four beds) that are split by sex. The case study setting provides not only an in-patient unit for end-of-life care (EoLC) and respite care typically for up to two weeks<sup>289</sup>, but an associated Day Therapy Unit that offers a 'therapeutic environment'<sup>290</sup> for the ongoing management and care for those who are aged 18 and over and living with terminal illness. It is a twenty-four hour facility with services delivered by nurses and healthcare assistants specifically trained in palliative care of which there are approximately fifty registered nurses and healthcare assistants, and volunteers who support a variety of roles such as receptionist and supporting the café.<sup>291</sup> In addition to the nursing team there is a clinical team, a full consultant and junior doctor, and a variety of other supportive healthcare professions such as physiotherapists, occupational therapists, social workers, bereavement support workers and a spiritual co-ordinator. Furthermore, the hospice is supported by a variety of other paid roles, such as housekeepers, a maintenance team, chefs, and cooks.

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288 The hospice building was originally designed for the purposes of hospice care, albeit in 1985. However, the label of 'purpose-built' could be considered now a misnomer as the building, as will be evidenced in Chapter 6, is no longer aligned with the requirements of contemporary hospice care.

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291 Ibid. p.1

## Case study context

The town in which the case study setting is located consists of Victorian and Edwardian architecture with much of the town within a conservation area. The hospice is located parallel to the seafront promenade below, typified by large detached and semi-detached villas. The adjacent streets are characterised 'by its close relationship with the coastline and includes the seafront and notable parks and gardens associated with the development of the town at the end of the 19th century as a residential suburb and resort'.<sup>292</sup> The elevated position of the road affords the buildings with long-distance views out over the sea and beyond. The case study setting has had a long-standing history within the community and has been located at two neighbouring locations since it was first opened. The original accommodation of the hospice was within a Victorian detached villa named Pierview and was built during at an unknown date during the 1890's, designed by Welsh architect Edwin. J Jones, see Fig.5-1. The villa is characteristic of the Tudor Revival style that was popular during the latter half of the nineteenth century, complete with the typical 'front facing gable or multiple gables and half-timbered wall surfaces'.<sup>293</sup> The villa was used as a private residence up until 1948 when the villa was purchased by a local charity to be used as a care home for Jewish pensioners.<sup>294</sup> The national cancer charity that runs C&V hospice acquired Pierview in 1959, as one of their first residential homes for cancer care.<sup>295</sup>

There is little surviving information regarding the original interior of Pierview and its use as a hospice, though we can observe from a historic drawing, shown in Fig.5-1, in the top right-hand corner a small version of the ground floor plan. This floor plan would have shown the villa during its residential use, and it is likely the rooms were adapted or sub-divided to accommodate the needs of the hospice. Pierview was in many ways reminiscent of the proto-hospices of London from the turn of the century - as discussed in Chapter 3 - in occupying a previously residential environment with potentially little modification for the purposes of hospice care. The implications of this type of adaption could have meant isolation of patients, with little opportunity for connection with staff and visitors, lack of efficiency for staff moving around the building, and spaces that were not adequately spatially planned for the needs of care.

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293 Pennsylvania Historical and Museum Commission, Tudor Revival Style (n.d) <[https://www.designingbuildings.co.uk/wiki/Tudor\\_revival\\_style](https://www.designingbuildings.co.uk/wiki/Tudor_revival_style)> [accessed 7th October]

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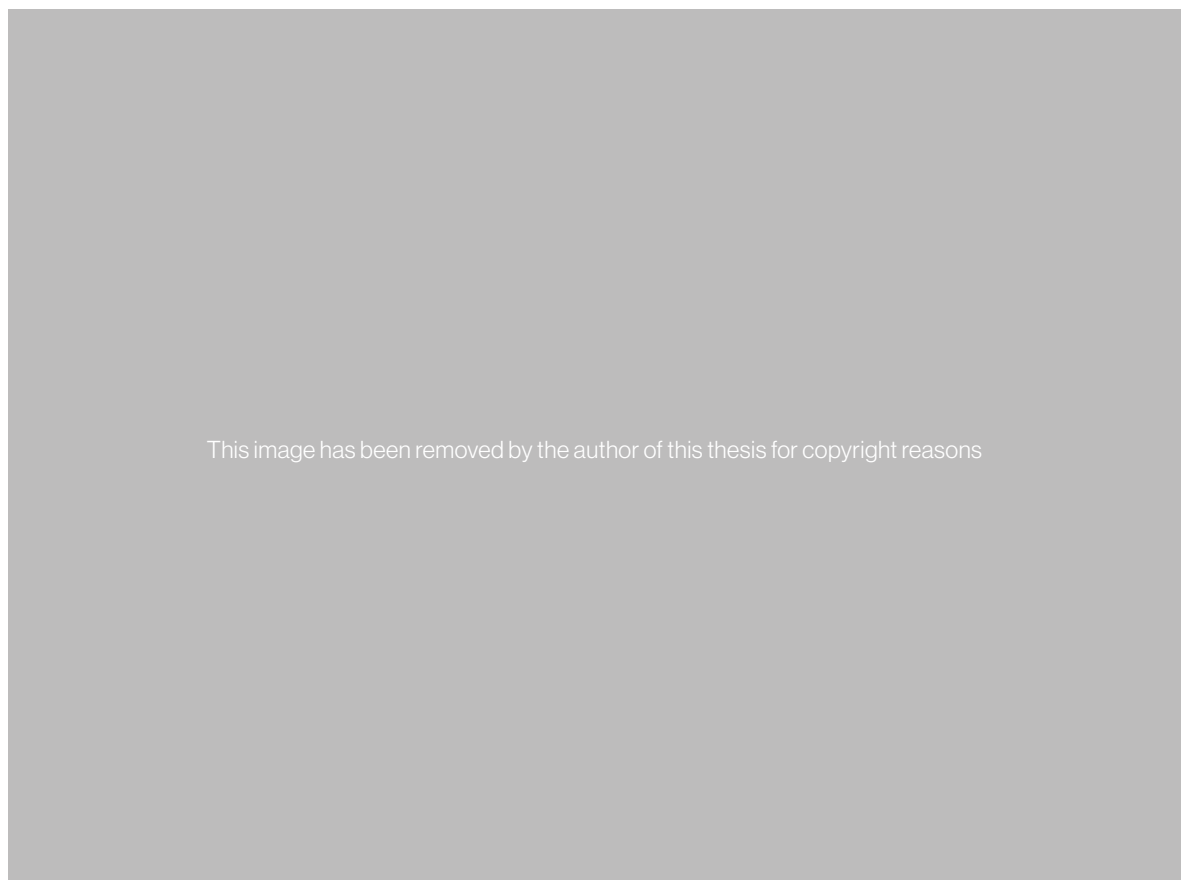


Fig. 5-1. Drawing of the original building

Dating from 1901, this drawing depicts the front facade of the original building on the site. Note in the top left there is a small plan of the ground floor, showing the residential focused spatial layout.

The C&V hospice remained in the original Pierview until the early 1980's, at which point they were gifted the villa and plot of land immediately next door. The land was donated with the sole condition that the plot be used to erect a 'purpose-built hospice' that would replace the then unfit for purpose accommodation at Pierview. The plot of land next door was originally part of a much larger estate that spanned along the sea-facing edge<sup>296</sup> as a private allotment and later housed a villa named Courtlands. This followed the charity's decision in the 1960's that all homes 'would be purpose designed and built'<sup>297</sup> and that their existing homes would be replaced – the donation of Courtlands enabled the hospice to fulfil this, and work began on the design and fundraising of the new building, see Fig.5-2.

The use of the terms 'purpose-built' and 'purpose-designed' is not explicitly defined in any depth – perhaps underlining a historical misunderstanding or confusion regarding the scope of the hospice building as a unique typology. In 1982, the charity was granted Listed Building Consent to demolish the existing Courtlands villa<sup>298</sup> and simultaneously granted full planning permission for the construction of a '38 bed hospice and day centre with ancillary accommodation'<sup>299</sup> that was completed and opened in 1985. There are no surviving records of the hospice as built, though elements of the original layout and functions remain to be seen. We do know however that the new build hospice was designed by Stanley Peach and Partners, a now defunct architectural practice in London. Despite not being able to consider the original designs for the hospice and the background expertise of the architects Stanley Peach and Partners is not known, the directive of the national cancer charity sought to proactively respond to the needs of palliative care at the time reflecting key aspects of the built environment exemplified by St. Christopher's.

A key example of this is the inclusion of balconies as accessible external spaces. The hospice utilised its unique seafront vantage by placing patient bedrooms on the eastern elevation affording patients and visitors direct morning sunlight with projecting bays that offered long distance sea views and additional space for visitors or sitting, not dissimilar to the 'internal balconies' of St. Christopher's, discussed in Chapter 3. The communal lounges, offering a shared informal space

<sup>296</sup> [REDACTED]

<sup>297</sup> [REDACTED]

<sup>298</sup> [REDACTED]

<sup>299</sup> [REDACTED]



This image has been removed by the author of this thesis for copyright reasons

Fig. 5-2. Local support from the community

A float from a local parade in early 1980's showcasing the call for donations to help the new building be finished. The building in progress theme is evident.

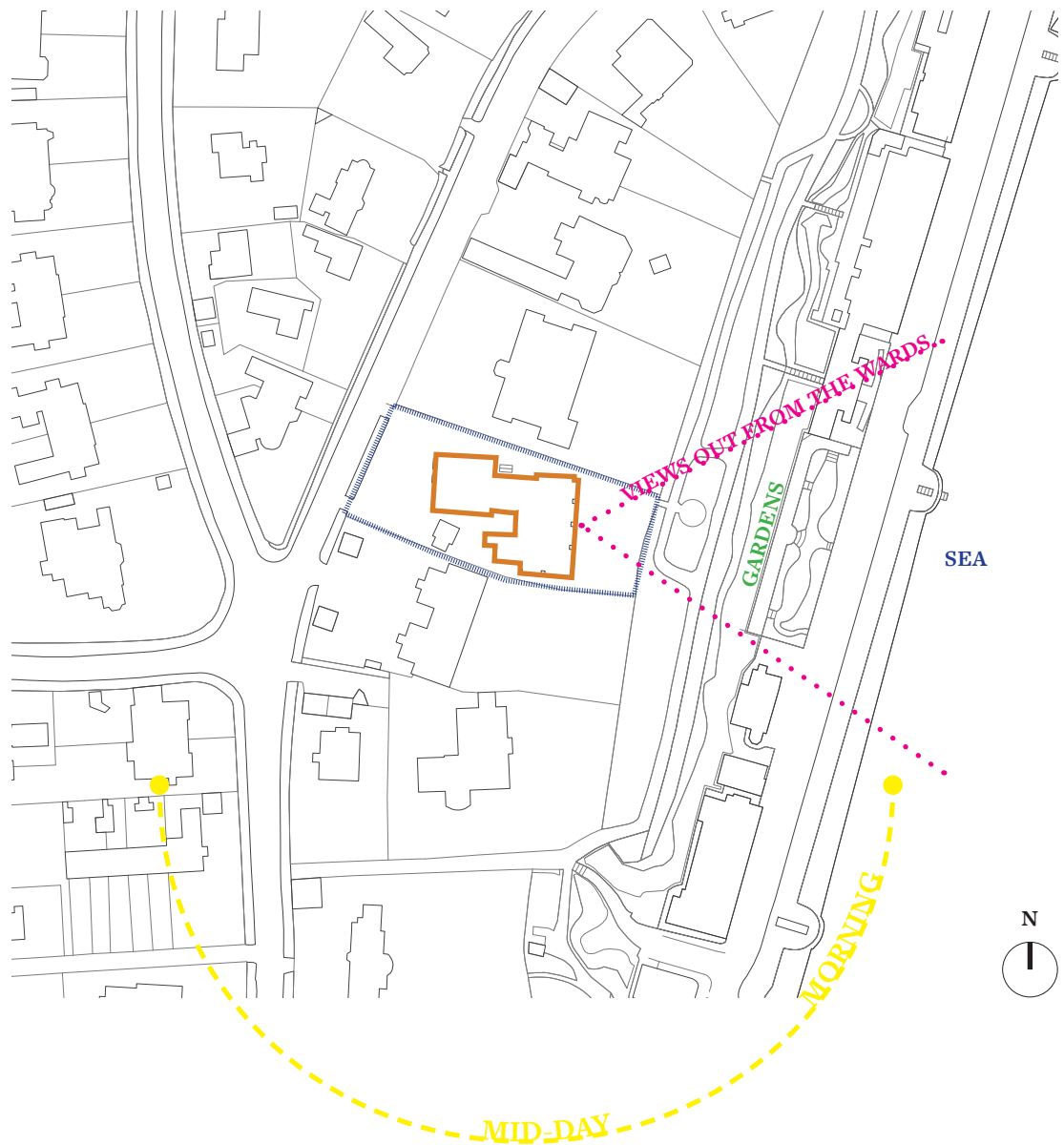


Fig. 5-3. Site analysis

Key environmental factors of the site, highlighting views out over the Bristol Channel



for staff, patients and visitors alike were located on the south-east corner of the identical ground and first floor wards with external balconies that wrapped around the corner. The location of the hospice is unique, one of very few hospices that have direct views of water, and though perhaps it may seem obvious to connect patients to the external scenery, the relationship between patient and the external world was an important principle of the growing hospice movement and would have necessitated the involvement of an architect or designer to plan in conjunction with the necessary spatial adjacencies for clinical care.

The hospice sits in the middle of the plot and is more or less aligned with the cardinal axes<sup>300</sup>, with public access from the adjacent main road that leads into a moderately sized forecourt to provide a small number of car parking spaces for visitors and a porte cochère<sup>301</sup> large enough for ambulances. The porte cochère is an architectural feature that, whilst functional, both materially and formally has connotations with institutional settings such as hospital and grand hotel entrances. There is a maintenance lane that runs along the northern boundary which allows access for deliveries, the storage and collection of clinical and non-clinical waste and access to the mortuary. The new building would have been constrained by several planning concerns at the time, notably responding to the sensitivities of building in a relatively new conservation area and fitting the required floor area for the function of a hospice without 'over-development'; that is to say, respecting and/or reflecting the two-storey residences nearby.

The site however has a steep topography, with a 5.5 metre change in level, that allowed the hospice to be built into the land, appearing as a conservative two storey building from the public highway in keeping with neighbouring dwellings but opening at the rear to reveal five storeys on the east elevation facing the public garden and sea beyond. The hospice's overall plan organisation, see Fig.5-4, was governed by a public to private hierarchy, the ground floor has a reception and entrance to the west, staff rooms and administrative spaces in the middle, followed by the ward spaces that sit along the eastern edge of the hospice facing the sea - the first floor is identical with additional administrative space. The second floor originally accommodated the plant/service room and an

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300 That is, each of the four elevations of the building face due north, east, south and west.

301 This is the name given to a porch or covered entrance that allows vehicles to pass under in order to drop off passengers under cover.

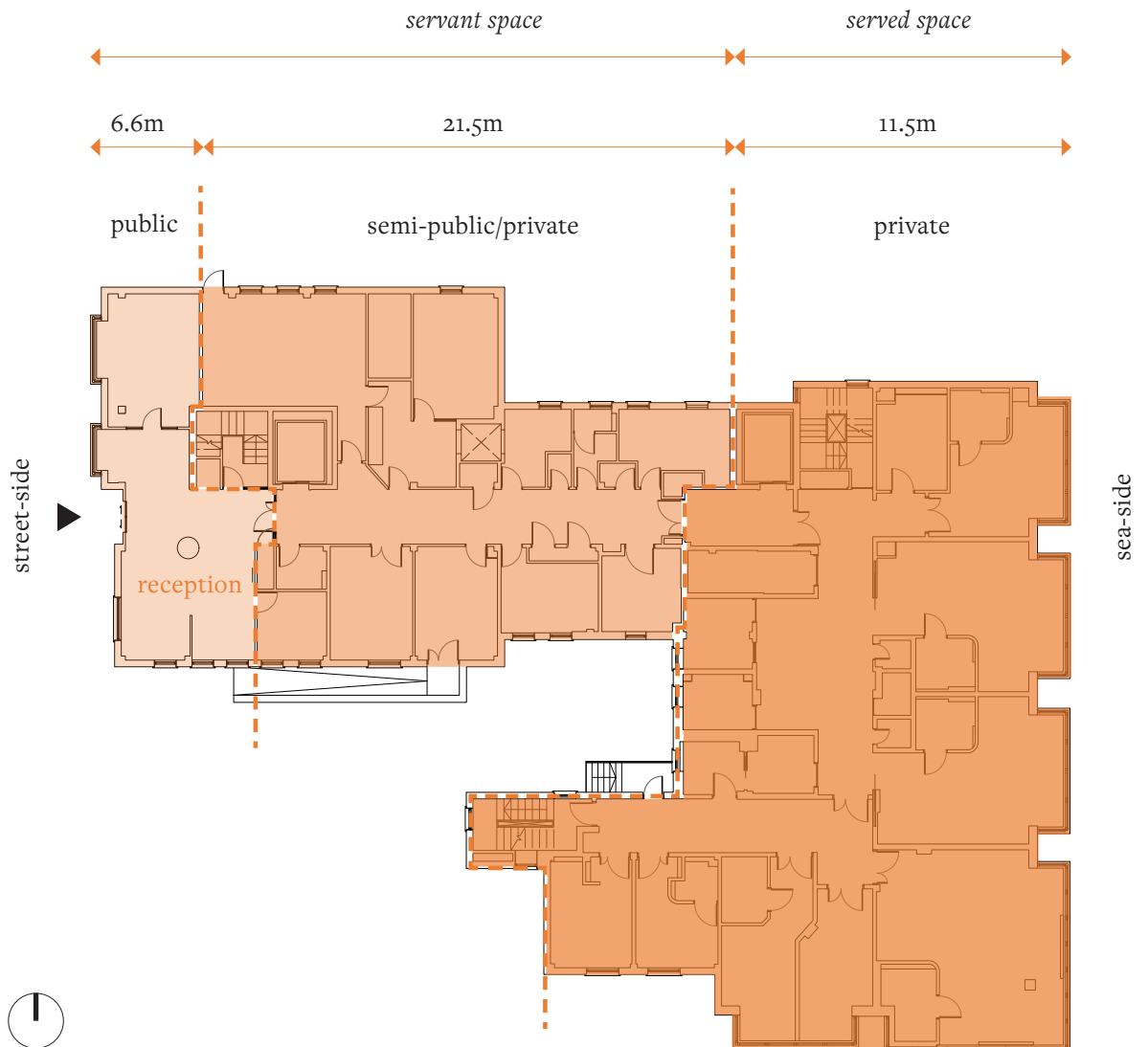


Fig. 5-4. Spatial hierarchy of the case study setting

As the building depth increases, so does the relative private hierarchy of space. The main entrance, to the far left, is controlled by the reception, with the main clinical area again divided by another set of doors announcing the final change. These areas are thus protected by layers of control, both electronic and human. The dotted lines of the diagram represent access controlled doors to each further layer of space.

apartment for the live-in Matron<sup>302</sup> with a small kitchen, bathroom and living and bedroom that is now a series of sub-divided offices. The lower ground floor was used to accommodate the kitchen and associated rooms, the mortuary, additional offices, and the day hospice unit. The basement, with access to the private garden housed additional office space, a library, and a 'garden' conference room, of which the latter two no longer exist. This mirrors St Christopher's hospice with its clinical/educational focus in disseminating more widely the philosophy and practice of EoLC.

## Fieldwork methods

### Stakeholder engagement

The previous section introduced the background of the case study setting, exploring the historical and planning context of the current architecture and design of the hospice ahead of the discussion of the primary fieldwork of the study. The following part of this chapter takes the form of a collection of research encounters that capture the research practice undertaken to examine the everyday narratives and lived experiences of varying members of staff and the building itself at the case study. Much like the scoping visits detailed previously in Chapter 4; the research encounters of the case study encompass a shift in narrative moving from third to first-person narrative. Furthermore, they reflect their chronology, documenting the way the activities evolved as the research process adapted to recruitment, organisation, and contextual obstacles. The section begins with an account detailing the experience of the researcher's first formal visit to the hospice building, before moving into five accounts of staff members working in different capacities within the hospice: Colleen, from facilities management, Louise and Kelly, from hospice management and housekeeping, Rob and Mike, from the maintenance team, Rachel and Steph, from nursing and lastly Fergus, a clinical consultant. The chapter closes with an account that revisits the case study setting through the lens of the formal Building Observation undertaken during the fieldwork.

The fieldwork can be classified as an ethnographic study that engages with both the environment and stakeholders during a defined period because of access and the sensitivity of EoLC.<sup>303</sup> As

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302 A Matron was a historical role within hospitals in the UK before being abolished for an updated hierarchy; this role was often the most senior nurse position in a hospital, overseeing patient care and the running of the building. Typically, a female held position, this was seen as a lifelong calling that negated any personal life as they were expected to live on-site.

303 Fusch and others, 'How to Conduct a Mini-Ethnographic Case Study: A Guide for Novice Researchers', *The Qualitative Report*, 22 (2017), 923-41, pg.925

Bloomer and Moore consider, buildings are 'a sympathetic extension of our sense of ourselves'<sup>304</sup> whereby the phenomenology of lived experience and our immediate environments are mutually intertwined. The hospice environment and the experiences of those who work there exist within a highly complex context of care and practice that when being explored from an architectural perspective cannot be sufficiently unpacked via a single mode of inquiry. Moreover, though the researcher has personal experience of hospice that offers a certain subjective 'closeness' to the subject and field, undertaking only interviews or only observation would constrain the research space needed to rigorously understand the relationships of building and inhabitants.

It was intended that the focus groups/in-depth interviews with members of staff was to be the first phase of the fieldwork. This would ascertain the basis for the observation of the building, by highlighting areas of the environment identified from insights and themes from the respondents. Focus groups are commonly used to gather qualitative feedback from building inhabitants within Post-Occupancy Evaluations (POE) within the construction industry<sup>305</sup>; thus, were proposed at the hospice. Focus groups offer a 'relaxed, interactive platform for individuals to share their unique perspectives and goals'<sup>306</sup> in response to structured activities and questions that pertain to the aims and objectives of the research. It was furthermore hoped that they would provide an opportunity for staff members with varying roles to engage in peer-led discussion. The resulting data and organisational insight were to then be analysed to shortlist concepts and locations within the hospice that would be the focus of the second phase of primary research, observation of the hospice building in use. This opening stage of the fieldwork was to uncover, in the context of the hospice environment, what Rolf von Eckartsberg describes as the 'specific experiences of specific individuals and groups involved in actual situations and places'.<sup>307</sup> As the hospice is a little researched architectural environment, it was hoped this manner of inquiry would unveil rich understandings of those directly involved in the everyday activities within the hospice building, see Fig.5-5.

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304 Kent C Bloomer and Charles Willard Moore, *Body, Memory, And Architecture*, (New Haven: Yale University Press, 1977) p.78

305 Rowena Hay and others, 'Post-Occupancy Evaluation in Architecture: Experiences and Perspectives from Uk Practice', *Building Research & Information*, 46.6 (2018), 698-710, p.701

306 J. Barnes and R. Born, *Perkins+Will 1315 Peachtree Street Pre/Post Occupancy* (Atlanta, Perkins+Will, 2012) p.157

307 Rolf von Eckartsberg, 'Introducing Existential-Phenomenological Psychology', in *Phenomenological Inquiry in Psychology : Existential and Transpersonal Dimensions*. ed. by Ronald S. Valle (Boston: Springer, 1998), pp. 3-20, p.4

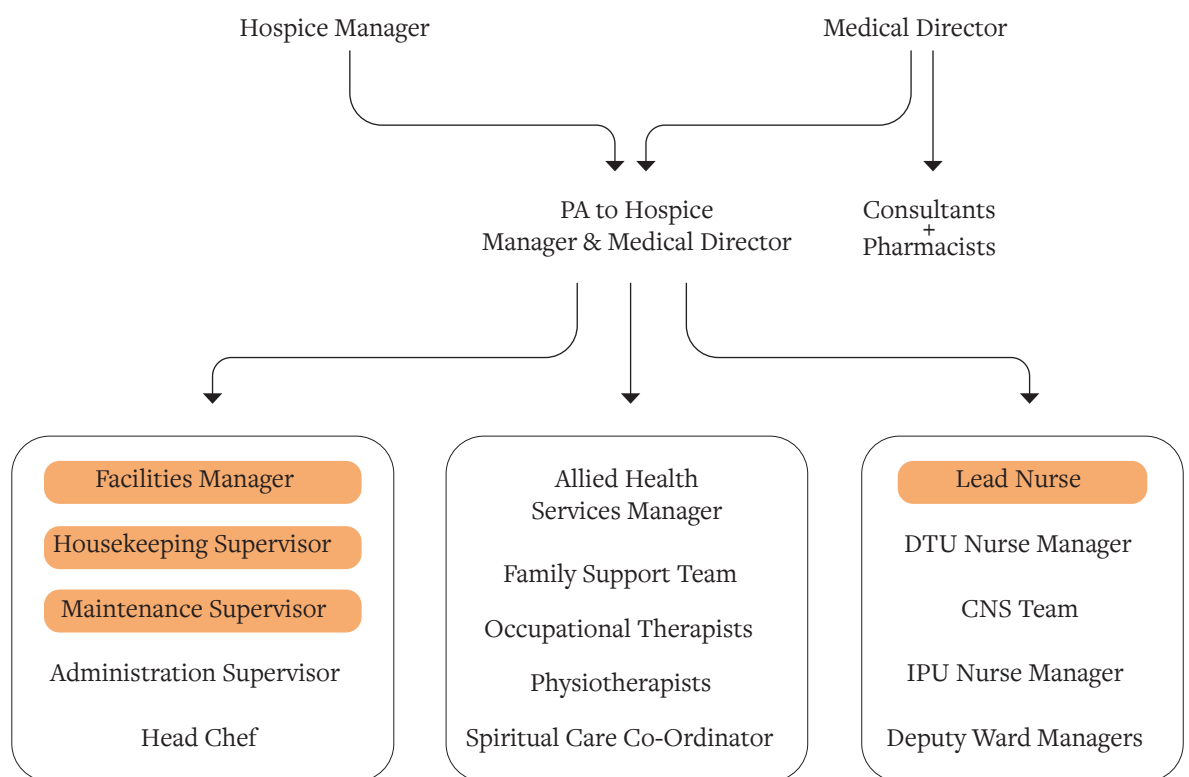


Fig. 5-5. Organisational roles within the case study setting

The hierarchy within the case study hospice; those highlighted in orange are those that were recruited as research participants. This structure is adapted from one provided by the case study hospice, and as such we can see there are roles that are not included, such as volunteers.

The focus groups were a critical part of the fieldwork, not only were they the first formal research activity to be held at the hospice, but the subsequent phase was also dependant on their success. After gaining the necessary ethical approvals and logistics were organised, the focus groups were poised to go ahead - yet they failed - or at least failed to operate as intended. Prior to the focus groups, the researcher attended a staff development day to introduce themselves and their personal connection to the hospice environment and the architectural nature of the research. A sign-up sheet was made available during the session to record if any staff members expressed an interest in taking part in the research; by the end of the session this was full and had been continued overleaf on the page. There was clearly an interest in the research, perhaps due in part to the researcher's personal connection to the research, and/or the novelty of non-clinical research taking place from outside the healthcare profession. Despite being widely advertised by hospice management and the expressions of interest from staff, it was evident that the activity had fallen victim to the realities of the hospice being an intense clinical environment. The proposed focus groups necessitated periods of absence of clinical and non-clinical staff shifts that would have had to be covered by others to avoid negatively impacting on the care of patients and the running of the hospice and additionally may not have co-ordinated with lunch breaks/rest periods. The failure of the focus groups in conjunction with the barriers faced by gaining the necessary ethical approvals (further discussed in Chapter 7) demonstrate the significant obstacles to conducting academic research in healthcare locations, particularly by researchers 'outside' healthcare.

## Research dyads

Whilst the recruitment and turnout for the first focus group session was initially discouraging, the immediate events after marked a contrastingly important juncture for the approach to the fieldwork. Returning to the first focus group session, after a period of waiting, another member of the hospice management team, Louise arrived. With Kelly and Louise at the table (prepared for a group of five or more) our ensuing conversation, partly guided by the questions I had prepared for the focus groups and partly by the conversation itself evolved into an exhaustive in-depth interview revealing significant findings. Having time dedicated to hearing the narratives of their respective roles, housekeeping, and management, provided specific insights into the minutiae of lived experience for Kelly and Louise that would have been wholly unfeasible to capture under the conditions of a focus group. The resulting semi-structured interview overcame multiple potential concerns of focus groups; of time constraints, ensuring that the discussions held were thorough, and offered a

democratic platform for both participants to speak without fear of a single voice dominating group dynamics that interrupts natural discussions.<sup>308</sup>

Following the success of what the researcher termed the 'accidental interview' it was decided that moving forward focus groups would be instead replaced by a series of in-depth semi structured interviews with pairs of staff members organised by their respective roles in the hospice. Though in-depth interviews are typically conducted with individual participants, an unexpected benefit of the 'accidental interview' was the rich peer-led dialogue between the participants themselves, commenting and developing upon the context and shared lived experience of the hospice building with regards to their specific roles. Where focus groups could offer a higher quantity of participants, interviews offer a mode in which to document lived experience in a manner more profound than merely a spatial relationship to a geographic location. One that is closer to Heidegger's concept of 'being-in-the-world'<sup>309</sup> to comprehend the hospice building as an environment that facilitates a workplace and the role it plays in their personal delivery of care. The switch to interviews provides a basis for the analysis and interpretation of the variety of lifeworld's that exist in the hospice. Wang and Groat state that 'when individual descriptive accounts are thoughtfully analyzed and considered collectively, meaningful themes will be revealed'.<sup>310</sup> Analysis of the interviews as considered as above provide robust foundations for the focus of the subsequent phase of fieldwork, observation of the hospice building.

### The building as an actor

Following the research encounters of the individuals working within the case study setting, the second phase of fieldwork focuses on the hospice building and its supportive role in the care team. As any building, though static, is not an inert background but it 'provide[s] the conditions of possibility for these stories [that is to say...] buildings make stories possible'.<sup>311</sup> The hospice building enables and works with members of staff to enable processes of care. Understanding the role of architectural design in the delivery of care therefore cannot exclude interactions with the hospice

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308 Ivana Acocella, 'The Focus Groups in Social Research: Advantages and Disadvantages', *Quality & Quantity*, 46.4 (2012), 1125-36, p.1132

309 Wheeler, Michael, "Martin Heidegger", *The Stanford Encyclopedia of Philosophy* (Fall 2020 Edition), Edward N. Zalta (ed.), URL = <<https://plato.stanford.edu/archives/fall2020/entries/heidegger/>>.

310 Wang and Groat, *Architectural Research Methods*, Second edn (New Jersey: Wiley & Sons, 2013) p.232

311 Paul Emmons and Luc Phinney, 'Introduction: Homo Fabula', in *Confabulations : Storytelling in Architecture*. ed. by Paul Emmons and others (London; New York: Routledge, 2017) p.4



building itself which were collected via fieldnotes and sketches. Drawing on the data collected from the previous interviews with participants from varying roles within the hospice building, themes such as sensory atmosphere, thresholds, and furniture, and key locations, wards, the main corridor, and the reception were identified. Observation of these elements first-hand in their original setting offers richer understanding of these insights with regards to their potential contribution to the design process. The Building Observation was conducted as environmental observation, inasmuch that solely the building and its tangible and intangible qualities were the focus. Non-participant observation of this kind was proposed 'so as not to interfere with the ongoing actions and behaviour of the people being studied'.<sup>312</sup> This was vital from an ethical perspective; the point of interest was the building itself and the way it is used and not those inhabiting the building, whether staff, patient, or visitor. The hospice staff and management, already wary of allowing non healthcare related research to take place on site meant that overt observation in this manner ensured that my presence was as close to invisible as possible. In being 'silent', a compromise was made that only manual fieldnotes would be used, recording observations and phenomena with pen and paper, sketching, writing, and reflecting. Therefore, the fieldnotes record elements of the lifeworld of the building such as its 'self, sociality, embodiment, temporality (with its events), spatiality (with its objects), project, discourse, and moodedness'.<sup>313</sup> This prohibited digital methods, such as photography or audio recording to capture raw data from the hospice, such as the materiality of the floors or walls, the changing quality of light between day and night or the fluctuations in the sounds of the building between busy and calm. The above furthermore highlights the medical influence on the research design that placed limitations on architectural ways of observing familiar to the researcher.

### Phenomenological space

To ground the encounters at the case study setting this section will open and close with accounts from the researcher themselves, documenting both first impressions and formal building observations of its environment. The first encounter, drawn from fieldnotes written after the researcher's first visit to the hospice, details their early reflections and perhaps naïve observations of the environment. Much of these accounts draw on the phenomenology of the researcher's own position of experiencing the hospice building as a visitor or 'actor', in the manner which Seamon describes

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<sup>312</sup> Wang and Groat, *Architectural Research Methods*, Second edn (New Jersey: Wiley & Sons, 2013) p.225

<sup>313</sup> Peter D. Ashworth, 'The Lifeworld – Enriching Qualitative Evidence', *Qualitative Research in Psychology*, 13.1 (2016), 20-32, p.23

as using their 'own first-hand experience of the phenomenon as a basis for examining its specific characteristics and qualities'.<sup>314</sup> Portraying the hospice building through the research encounters enables both an 'insider' and 'outsider' perspective to be drawn upon to build a collaborative narrative of the building.<sup>315</sup> As the 'outsider' the researcher brings an academic perspective and certain rigour of investigation to the participant interviews, yet as an 'insider' explores the first-hand experience of the building as a visitor and someone who has previously experienced hospice as a relative. Combining these perspectives offers 'a method in which to critically synthesise spatial practice with social authenticity and human emotion in a way that is inaccessible to typical desktop research methods'<sup>316</sup>. The two accounts that bookend the chapter offers a contrasting understanding of the hospice building as an 'actor' in the day-to-day life of its inhabitants and concludes with reflections on the hospice building in support of care, and to what extent the first impressions were accurate.

## Research encounters

The section below, though outlining the researcher's first visit to case study setting is not their first involvement with a hospice environment owing to their personal history. This prior experience imbued a tentative nature with regards to tacit knowledge and bias toward how a hospice environment may feel.

### The first visit

I approached along the tree lined streets lined with grandiose Georgian and Edwardian villas. It was quiet and peaceful. The only person I saw was the postman, and a few families returning from school. I was not close to it by any means, but I could smell the salty sea air, feel the slight humidity and sea breeze ruffling my coat. The sea appeared and disappeared in glimpses, peeking out from in between the gables and rooftops. I turned the last corner and the case study setting emerged into view, a dark seventies brick 'behemoth'. It is a stark contrast to the beige sandstone of the period

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314 David Seamon, 'A Way of Seeing People and Place: Phenomenology in Environment-Behavior Research', in *Theoretical Perspectives in Environment-Behavior Research: Underlying Assumptions, Research Problems, and Methodologies*. (Dordrecht, Netherlands: Kluwer Academic Publishers, 2000), pp. 157-78, p.165

315 'Nonparticipant Observation', in *Encyclopedia of Case Study Research*. ed. by Albert J. Mills and others (Thousand Oaks, California: SAGE Publications, 2010)

316 Bellamy, 'The Insider Vs the Outsider: Architectural Investigations of Palliative Care Environments as Both Researcher and Daughter', in *AHRA Young Researchers Symposium* (Newcastle University 2020)

villas. Their soft colour feels warm and calm on the eyes, like a soft blanket to the touch. The brown brickwork on the other hand feels harsher, blunt. Like its neighbours, it perches on the top of a cliff that leads down towards the sea, with a steep driveway that leads to the entrance. I tentatively walk down, in an awkward jog / fall toward the entrance and its canopy, which feels steep even for me, able-bodied. Standing under the canopy/porte cochere, I can smell a faint scent of burnt plastic, the type that superheats the stale air underneath when warmed by the slightest touch of the sun. I had journeyed to the hospice by foot, but the approach was clearly designed with a vehicle in mind, car, or ambulance, as there were plenty of road markings indicating where I should go if I were a car.

As the automatic doors slid open it hit me. I immediately register a mix of smells...chlorine or bleach of community swimming pools and hospitals corridors...the plastic preserve of linoleum like materials...and the scent of school dinners lingering in the air from days ago. Buildings collect and are smells<sup>317</sup>, they are unavoidable and mark the human life occurring within, but what happens when they are not so pleasant? Can others smell this smell, or is this a symptom of my unfamiliarity with the environment? I am reminded of my previous personal experience, where Jen's illness meant that the chemical fragrances of cleaning products led to migraine-like headaches, and the close encounters of the hospice's shared family kitchen with the merged aroma of different meals and food being cooked. The smell as I entered felt like a wave rushing over me, as if when the doors opened it was the building 'breathing' out. Releasing the old air and sucking what fresh air it could back in. I took a seat on a vinyl covered sofa in the reception area that was almost completely solid and shallow that meant I kept a very upright posture as I waited for my guide. The material was odd, like it was once a natural material that had been 'preserved' in plastic, kept alive and clean. As I looked around, I thought of Juhani Pallasmaa's description of a door handle as the handshake of a building<sup>318</sup> - was the reception area then the welcoming outstretched arms? But here the welcoming arms draw you in but abruptly keep you at length, the rest of the building hidden. Directly opposite the entrance doors are secure double doors with fob access that leads onto the ground floor ward. A very necessary security measure especially as the hospice is technically open twenty fours a day. I wondered how this worked in times of urgency if emotions run high, or how it feels for staff to enter directly with no transition space. My experience of a hospice reception was also of a communal lounge space –this was very much a secure area, an airlock. Opposite me was the

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317 Off-gassing or out-gassing is the process by which materials release chemical particles into the air, certain materials, such as man-made materials or those with high VOC content (Volatile Organic Compounds). This process usually happens when a material is new, but this can continue to happen during the lifespan of a material.

318 Juhani Pallasmaa, *The Eyes of the Skin : Architecture and the Senses* (Chichester; Hoboken, NJ: Wiley-Academy ; John Wiley & Sons, 2005) p.65

quiet room, a space where distressed relatives or those not wanting to enter the hospice further could come to collect belongings or death certificates. I could see it had lots of places to sit and I wondered if this meant it was for multiple families. At least there was a space aside for them as a protective layer after their time there. Once I had become accustomed to the smell and I sat quietly, I noticed the feeling of sunlight and its warmth, and noted the feeling of a connection to the place and town beyond, the intermittent chirping of birds and the hum of cars passing by. My host, a key member of staff arrived, and we ventured down further into the hospice starting at the basement garden level. On the way I spotted a breakout space in one of the corridors. This was a wider point of the corridor where two high backed wipe clean chairs had been placed with a small side table. It was an odd space, with doors either side and no natural lighting, I couldn't imagine sitting there as a space to retreat to, though perhaps it provides a good place to stop if you cannot easily make long journeys. My host showed me the location of where they were planning to create a new café / garden space for the hospice, and we discussed the constraints of renovation projects in existing buildings and the compromises this causes. I asked if they had used an architect or designer to help them plan and manage the project, my host stated she didn't think this was the kind of thing an architect would do.

We headed up to the ward level and entered the metaphorical and physical heart of the building. It was alive, with a plethora of noises, where I could hear the tell-tale beeps of clinical equipment and a background bustling of people's voices. The main space of the ward is focused on the nurse's station, a long reception desk which is surrounded by the patient bedrooms and bays<sup>319</sup>, and houses everything necessary to day-to-day life on the ward, from care of people to care of the building. Deep in the plan, with no natural lighting or sense of connection to the world outside I felt as if the building was weighing down upon me. Luckily, one of the four-bedroom bays was empty, and we were able to go inside. It felt surprisingly spacious, light, and bright with east-facing windows. The four beds were arranged on each side of the square room. One bed faced out to the views of the sea beyond, two had side/oblique views of the sea and one was facing back at the other beds with no view, directly facing another bed and the door.

Here in the room my host described several changes that had been made following charitable donations, their intentions to fix problems highlighted by the patients and their visitors, but quick fixes seemed to have resulted in further issues. The changes seemed well-intentioned but rushed

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<sup>319</sup> Patient bedrooms are single occupancy, the bays are multi-occupancy. On the wards there are a mix of bays that have three or four beds.

and I wondered if there was a pressure to spend donations quickly to show they have been utilised and made a 'difference' to the patient experience.

Next on my tour was the fifth floor – the attic – of the hospice that housed staff rooms and various office spaces. There were small kitchen spaces on each ward that were available to the staff to use during their shifts, but their main facilities were up here in the eaves and the basement. The locker and hygiene facilities felt tired and old, the hospice recognised this and were about to embark on their renovation. It was such a compromised space owing to the large areas of reduced head height and sub-divided plan, and my first thoughts were that the staff had been allocated the left-over space. My time spent in a hospice years ago with Jen means I have the utmost respect for those who work in the field of EoLC and can imagine that burnout and emotional pressure from the environment must be a palpable concern. Up in the attic, though peaceful and quiet, I felt confined, and it struck me just how hard this building must work to truly care for everyone who uses it, not just the patients and visitors, but every member of staff too, from housekeeping to the cooks to the nurses. As we meandered our way back down the floors of the hospice, my host described how managing the hospice can sometimes feel like air-traffic control, with the building accommodating many different functions, day hospice, respite care and those at the very end of life, different groups of people, staff, patients, friends, and families of current patients and those recently deceased. Seeing the building first-hand I could understand that the case study setting, and all other hospices are tightly caught up in a balancing act, providing on one hand a secure and comfortable environment for those at the end of life but also the supportive infrastructure that enables this. The atmosphere of the spaces however felt caught in the middle of this. The case study setting, like other hospices, isn't a hospital, yet this first visit exposed both tangible and intangible characteristics of that sense of place.

## Colleen

The second research encounter, and first report of the participants exploring life at the case study setting, is that of Colleen, the Facilities Manager. Colleen was one of the very first members of staff I met from the hospice. At the beginning of the research, she generously offered her time to give me tours of the hospice building and provided resources helpful to the study. A softly spoken yet discerning presence, it was clear to me from our previous encounters that she not only had a vast wealth of knowledge regarding the physical building but the day-to-day running and influence on the planning and evolution of the building. Colleen does not have clinical duties as Facilities

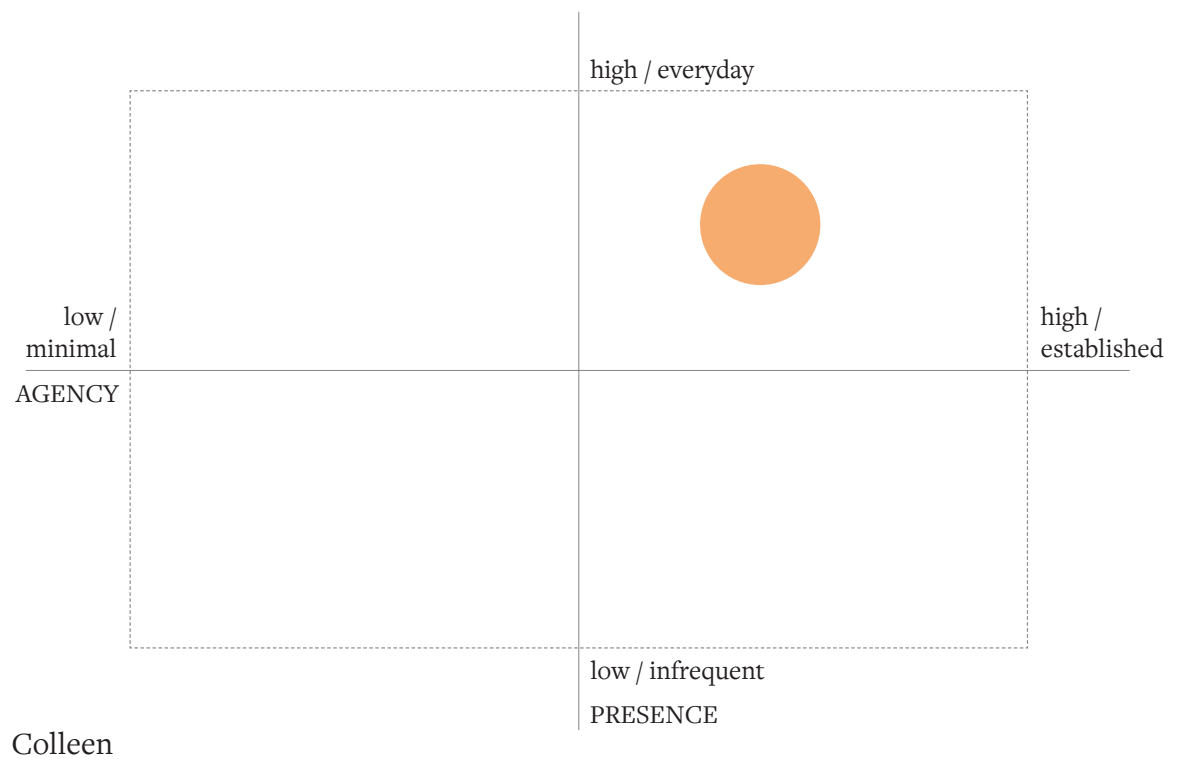


Fig. 5–6. Colleen's engagement with the hospice building

Manager, but her role requires an awareness of the breadth of activities and their specific needs. Her responsibilities extend beyond merely the use, running and maintenance of the physical spaces, but additionally juggling their financial implications with the available budget of the hospice, see Fig.5-6.

I had arrived at the hospice at midday on the day the first focus groups were due to take place. Nervous about hosting my first focus groups I eagerly set up the room in a neutral way to lessen the distance between myself as researcher and the participants as researched. I came armed with bags of paraphernalia more typically found in architecture studios to help me bring the session to life. Plan drawings on A1 paper, physical models of the floor plan in case the drawings weren't easy for the staff to understand, two models of patient rooms to highlight the view of the patient from their perspective, a plethora of coloured pens and post-it notes carefully placed in the hope the attendees would feel comfortable to pick them up and start drawing. My nervous energy filled the room, excited to finally be in the field after a long and arduous process of ethical approval. After a period of waiting in which it was clear the focus groups would not be running as intended – Colleen's familiar face popped round the door asking if I was still running the session. She had seen the advertisement for my session and purposely kept the afternoon free. The discussion with Colleen differed slightly to the subsequent interviews, in that she had purposively set aside a whole afternoon for the activity and owing to our previous meetings we had a familiar rapport, able to jump into a discussion with a level of familiarity.

Sitting down at the table, Colleen immediately set about marking up the plans in front of her to point to the different layout changes and interventions the hospice had been through over the years. Colleen pointed out that the hospice must cater to a lot of people, but patients are always the priority. Many of the recent works to the hospice funded by legacy donations specify that there should be a visible improvement to patient facilities for example the recent renovation of a new spa bathroom. Whilst Colleen appeared proud of the difference this was to make to the patient experience; this was mixed with pragmatism about the realities of day-to-day life in the case study setting:

...we've got an old building that's falling apart, and I think what people don't see  
– is the amount for upkeep and things...when I first came here you were lucky if  
you could run a tap upstairs to get hot water...<sup>320</sup>

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320 B & C Participant A, 'C&V Hospice Interview 2', ed. by Annie Bellamy, 2019), p.18



Colleen recognised that the building itself needs to be comfortable and pleasant for everyone, describing how small changes they have made such as colourful chairs can make a difference 'just to soften it, to make it a bit homely'<sup>321</sup> but that these changes are insignificant if 'you know nothing behind the scenes works'.<sup>322</sup> In discussing the environmental comfort, Colleen describes a current conundrum that the hospice is facing, in which the old inefficient radiator heating system in some of the rooms is logistically too difficult and expensive to replace, so they are looking to instead install air conditioners which in turn requires additional electrical services to be installed. There is little Colleen can do, constrained by both the existing building services and financial limitations. Action must be taken to ensure the building is comfortable to occupy in all seasons for staff and patients alike, this example highlights an approach of reactivity and mitigation in contrast to one of futureproofing and control. Yet the management of aesthetics and technical performance are not the only aspects that Colleen described juggling in the management of the hospice building – it's 'the practicalities and the money isn't it'.<sup>323</sup> The different interventions the hospice has borne over the years highlights the painstaking balance and shrewdness needed to balance the hospice as workplace, a place of care and perhaps most importantly, as a business.

Colleen's role is a practical one - managing the key services and processes that support the hospice's function. There is an obvious tension when Colleen describes the decision making in considering the holistic needs of the building. In describing the purchase of chairs for the patient bedrooms 'it might not be your super comfy things but actually it's doing what it needs to do... we've got the best for what we can and something that is replaceable as well'.<sup>324</sup> This reconciliation between comfort and or design and cost is seemingly a barometer for many, if not all decisions, as Colleen states 'we've still got to account for the pennies'<sup>325</sup> and to ensure that everything is done within the bottom line of being sensible for the ongoing upkeep. Colleen laughing, uses the example of wallpaper to explain her point and her disbelief at some of the past decisions. On a micro scale past work to the interior of the hospice included the addition of expensive wallpaper to patient bedrooms. The money for not only buying the wallpaper and its hanging could have been used to purchase equipment or new furniture, or the wall could have been painted so that it would be easier to clean than the textured finish of the wallpaper chosen. I could understand that this now

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321 Ibid. p.17

322 Ibid. p.19

323 Ibid. p.16

324 Ibid. p.23

325 Ibid. p.18

dated wallpaper, was a means to achieving a softer feel to the clinical spaces but was a decision too far. On a macro scale, however Colleen knows there are parts of the hospice that are lacking 'if we had a day room on each floor, you know, a room you can escape your bedroom would be ideal, converting, bay 4 on each floor, is a lovely sized room'.<sup>326</sup> But the balancing act of finances versus vision involves the making of hard decisions. Bay 4, the four-bed ward on each floor with panoramic views of the sea beyond was previously a common room for the wards, yet bed space was needed. More pertinently the number of beds is correlated to the amount of funding the UHB provides. Converting it back to a common room now would mean a relatively large loss of income that the hospice would not be able to accommodate.

During our conversation it strikes me that despite a lack of a broader organisational vision for the hospice, Colleen in many ways also acts as a design or project manager; organising not only the physical work to be done, but gaining an understanding of the brief and trying to get the input of others on any projects 'everything we did, all the pieces of work that was done it wasn't just facilities and the hospice manager making the decision, there were groups'.<sup>327</sup> Though it seems that getting the input of others is not a formal requirement in any way, Colleen speaks about this approach as part of the responsibility to ensure that the changes that are made will be long-lasting. The inclusion of other groups of staff, those who particularly use a space in the decision-making process is also a way to ensure that changes are fit for purpose, 'that's what we are trying to do, as a multi-team decision now, is to sort of meet halfway really'.<sup>328</sup> Yet thinking back to some of my first visits to the hospice I remember Colleen describing changes made where communication may have not been so clear:

...they're fine the cupboards they're durable but they're not ergonomic for the nurses, and there's lot of cupboard space but not pull-out drawers so it's not, where they were put in quite a few years ago, the right people weren't spoken to for the use, so now we're looking to change those, rip them out and putting them new back in...<sup>329</sup>

I wonder about the practicalities of approaching staff to be involved in any renovation projects, and if there is time for them to be meaningfully involved in the feasibility or design phase as typical

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<sup>326</sup> Ibid. p.15

<sup>327</sup> Ibid. p.11

<sup>328</sup> Ibid. p.18

<sup>329</sup> Ibid. p.13

activities of Stage One: Preparation and Briefing of RIBA's Plan of Work<sup>330</sup> and if there was any mechanism to allow this to happen and at what point in the process it happens. Colleen tells me that when they were working on the layout of the new sluice, they physically fit as many people as they could into the room during the decision-making process - 'so there was a lot of discussion, actually yeah that's too big a sink or that's too small, uhm, it needs to go over there, there was a lot of tweaking'.<sup>331</sup>

This 'tweaking' seemed to have happened when construction was underway, perhaps limiting the extent the design could be amended following new input. Despite Colleen endeavouring to get input from others, it appears plans for this approach are often contradicted by the unpredictable nature of renovation and construction works without a lead designer/architect or clear project plan. With contractors on site in the past, Colleen co-ordinating has meant that she is sought for on-the-spot decisions posed by the contractors with little or no time to involve others; though it must be noted that the engagement of an architect does not necessarily prevent this happening. When undertaking work on the staff toilets, she described a situation where:

...it was a spur of the moment and it was only when they came to me to ask about the staff toilets, what colour do you want in here, well we'll have blue because it's blue in the corridors and what colour do you want in the other one. I was like well, I could have had two but at the time I was told I could only have one colour...<sup>332</sup>

Spontaneously approached, and with confusion on what was allowed, Colleen clearly speaks about having a vision for the hospice and its environment but is managing the projects in addition to her other responsibilities and duties.

As Facilities Manager there is a practical element to her role managing the logistics of all the necessary office spaces due the growing number of ancillary services who are based in the hospice. It is not only space required but the necessary relationships between the different teams, and their proximity to each other so they can be efficient in their respective job roles. As the hospice becomes more of an integrated community hub for other associated services, Colleen is astutely aware that even since she has been here the types of patients and their needs are changing:

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330 RIBA, 'Riba Plan of Work 2020', (London, Royal Institute of British Architects, 2020)

331 Participant A, 'C&V Hospice Interview 2', ed. by Bellamy, 2019) p.11

332 Ibid.

...we're trying to meet a cross-section of needs aren't we and we have to become much more specialist...we've done a lot to meet current needs and what we're thinking for the next maybe two years or so, but once the decision comes then we need to start planning sooner then, because it won't come cheap...<sup>333</sup>

The changing needs of patients inevitably require modifications to be made to the fabric of the building too and that brings about further complications for Colleen and the hospice:

...how do we need to change...and until that sort of decision is made as to where we, what are we gonna do with our ward space, what type of patient are we gonna need then there will be another change of the building then you know...<sup>334</sup>

There is a palpable desire from Colleen to future-proof the building and to make sure that the environment continues to provide the best care it can, that moves away from a short-term reactive nature to a forward-thinking proactive approach. Day to day it feels as though her role in managing the building is caught between the expectations of staff and their needs for the building as a workplace and the practicalities of the hospice as a business. She is very much 'of' the day to day within the hospice and the responsibility that weighs on her that 'you might see something that someone has missed, you know 20 pairs of eyes all see something different.'<sup>335</sup> Yet from conversation it is evident that Colleen is also fielding broader expectations, from the hospice as an organisation needing to meet requirements set by external bodies, such as infection control audits by Health Inspectorate Wales (HIW), the Care Inspectorate and the UHB to the unknown direction of national policy changes to palliative and end of life care.

### Kelly & Louise

The third encounter of life at the hospice introduces Kelly and Louise, two other members of staff intrinsically embedded within the hospice's everyday life. I met both shortly after finishing with Colleen in the late afternoon of the intended focus groups. Louise, who works with my contact helping to facilitate my research at the hospice had been checking in sporadically to make sure we had everything we needed, and she had promised to return to take part once a conference call was over. As she was settling into the room, she began familiarising herself with the mass of

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<sup>333</sup> Ibid. p.21

<sup>334</sup> Ibid.

<sup>335</sup> Ibid. p.12

paper, drawings, and models in front of her. Colleen had left but swiftly returned with Kelly, a young member of the housekeeping team whom she had bumped into in the corridor outside who was more than happy to come and join the next conversation.

Louise is a confident middle-aged woman who had previously worked as a palliative care nurse at another hospice, before volunteering at the case study setting and now transitioning into a permanent member of staff working in practice development. As an ex-nurse, Louise was seemingly confident in discussing both clinical and non-clinical matters, perhaps because of her experience of the contrasting perspectives of wards (though of a different hospice building) versus office spaces at the case study setting. Louise spoke with ease about the way she had observed the building and its atmosphere affecting both staff and patients/visitors; undoubtedly having gained different familiarities with the hospice building from her time as both a volunteer and a member of staff.

Similarly, Kelly, having worked at the hospice for a long time as part of the housekeeping team is intimately familiar with the hospice building, as a custodian and 'carer' of the building itself, see Fig.5-7. She was a bubbly and positive presence, who was more than happy to join the conversation. However, as I was introducing the research, she began to falter, stating 'because I'm a cleaner see, it's different like, because what I would think is important'.<sup>336</sup> It was clear that she was somewhat apprehensive or self-conscious about the validity of sharing her own experiences and the importance of her voice within the broader narrative of the hospice organisation. I reassured her that her voice was equally valid as any other, and that I was especially interested to hear the voices of those perhaps previously overlooked when considering the hospice and its functions. With her confidence restored, Kelly became an almost unstoppable invaluable voice, drawing upon first-hand experience of not only herself, but the working knowledge of the opinions and thoughts of others having witnessed the ongoing tinkering and changes to the hospice building over the years. The plan drawings taken along were originally intended to be part of a group exercise in the focus groups but with Kelly and Louise, they took on a new purpose. The large-scale drawings served as a tool to help them map out areas key to their experience of the hospice building becoming a natural catalyst for discussion. In doing this Louise and Kelly's combined lived experience cultivated an almost archaeological atmosphere recording smaller areas of the hospice building that had been changed but not formally recorded by bigger planning applications.

Becoming acquainted with the hospice building but in 'birds eye view', Kelly was quick to comment

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336 Participant B & C, 'C&V Hospice Interview 3', ed. by Annie Bellamy, 2019) p.2

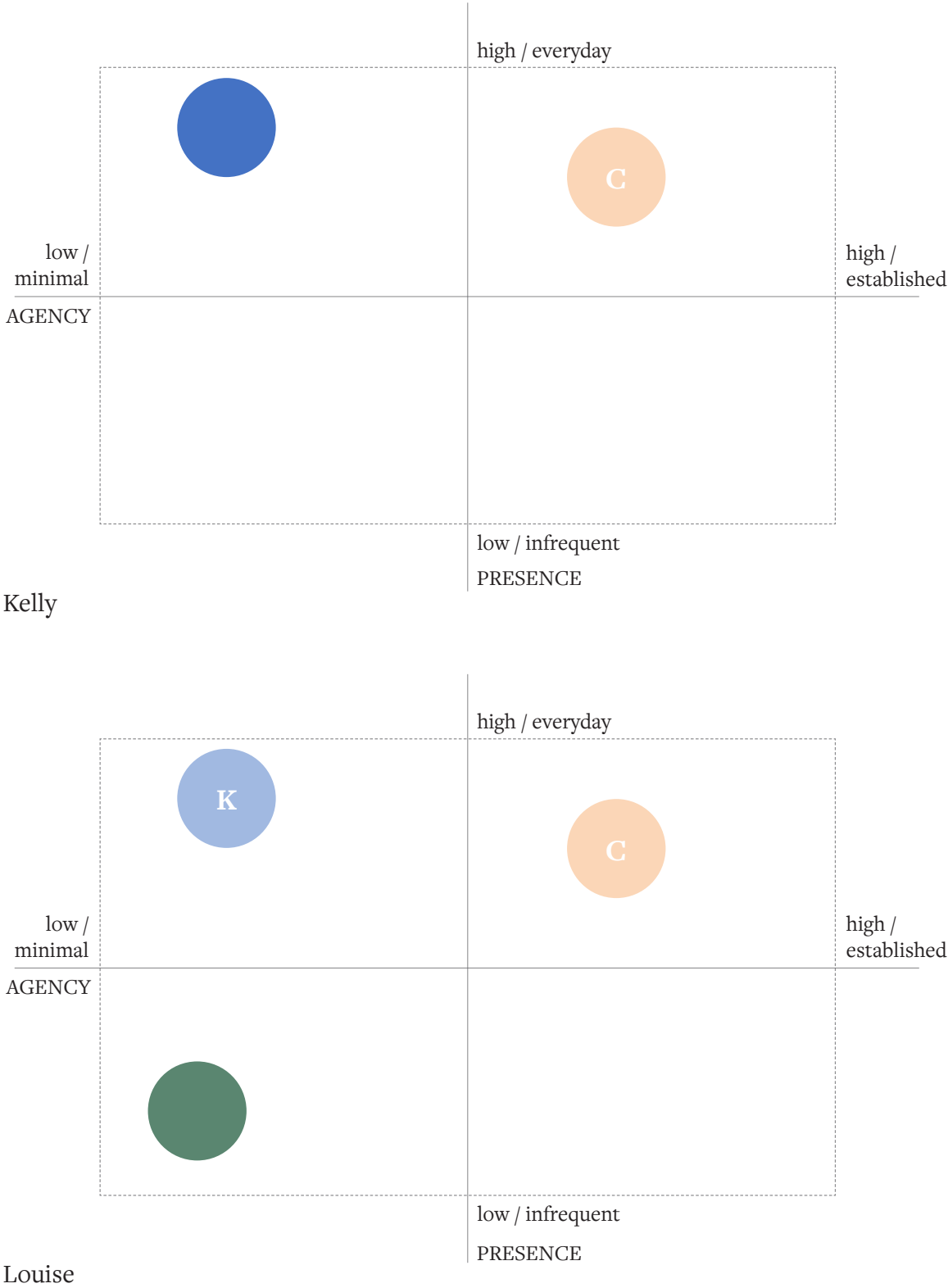


Fig. 5–7. Kelly and Louise' engagement with the hospice building

on the patient bedrooms, one of the bedrooms at the end of the ward's main corridor and far away from the nurse's station. The bedroom in question is one of the four single bedrooms in the hospice, offering a more private intimate space – however Kelly quickly remarked 'its claustrophobic I find, if you've got like a big family as well, that room's not ideal, it's nice if you want peace and quiet, because you're out the way'.<sup>337</sup> Kelly might not be a patient herself or a member of a patients family, but her personal knowledge of feeling the generosity or constraints of a space in her own role offers a new perspective on the building. As a member of the housekeeping team responsible for the daily upkeep of the hospice environment Kelly is not confined to areas of the hospice building but rather finds herself experiencing all spaces, often with a large cleaning trolley in tow. Manoeuvring her body to perform manual work in the spaces of the hospice building highlights the very human scale experience of 'being' in the all the spaces. Hovering over the sluice on the plan with her pen, Kelly explains her experience:

...you've got the sink haven't you by there - and you open the door and bang into, and I'm heavy handed! So I go right into the door and right into the sliver of the sink and then you've got like the linen bags say on top of the sink in the aisle part, and then you've got the sluice type thing... its if you're in there like, say you got a cleaner, with us, you gotta clean there, you literally, it's all on top, that's what I find... we got to drag it all out and put it all back it, it's just, it is a nightmare...<sup>338</sup>

Kelly's cramped recollection of the sluice in practice highlights the proximity in which the respective teams within the hospice must co-exist. The spatial layout and design of these shared spaces are therefore required to be not only functional but generous to be as efficient and comfortable as possible for those working in and amongst each other. Kelly's telling of her experience of the new sluice differed to the account of its design as previously told by Colleen – who used the space as an example of multi-team decision making in the hospice. Gathering the input of those using the space is a useful design exercise but can only be successful when all potential users contribute to the discussion to ensure equity and a valid reflection of the space in use. I wondered if the housekeeping team may be assumed or dismissed as 'of the background' or having little connection to the clinical aspects of the function of the hospice. Yet, the housekeeping team are very much part of the environment, embedded and present in day-to-day rituals. They serve a vital role as custodians of the hospice environment - due to the primary concerns of cleanliness and infection control - that means they witness and feel the impact of the changes to the hospice environment.

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<sup>337</sup> Ibid. p.4

<sup>338</sup> Ibid.



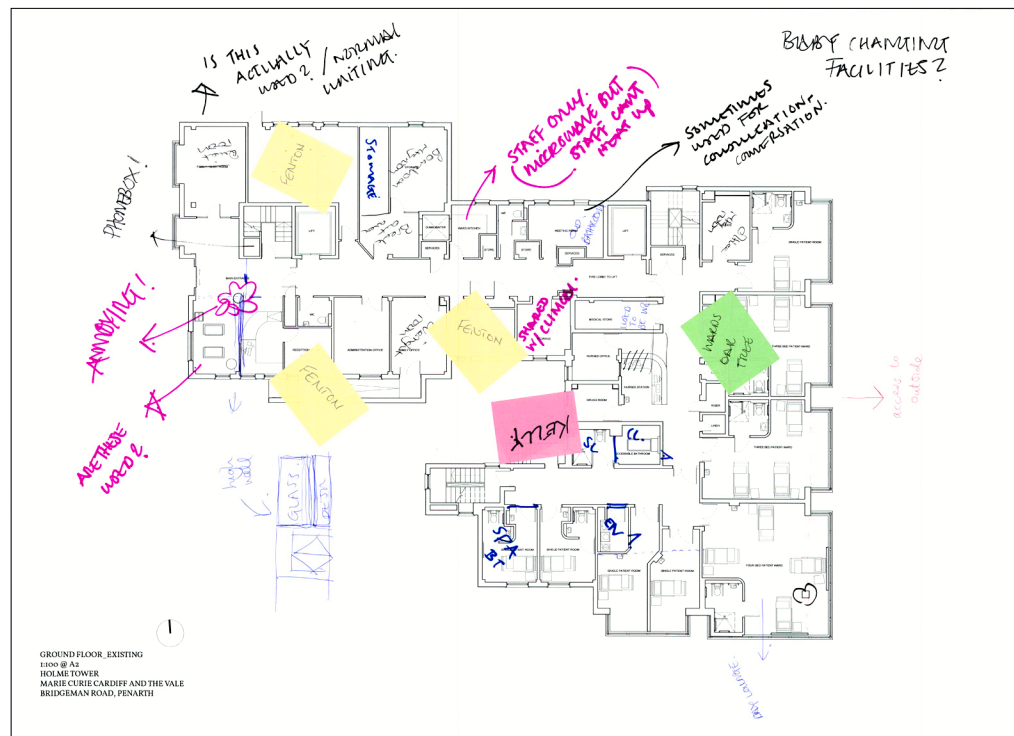


Fig. 5–8. Examples of annotated drawings from interviews

The above drawings are the result of the conversation with Kelly and Louise, though both unfamiliar with architectural plan drawings, once orientated were able to spot things that were either not a reflection of the building, or historic changes, drawing on their familiarity with the building.

Discussing the overlap in spaces between the teams and Kelly's first-hand experience turns the conversation to the very nature of the hospice building itself. Both Kelly and Louise agreed that they have felt the hospice become more and more clinical feeling. Kelly describing the hospice now, she describes how:

...it's got too much like the hospital hasn't it, over the years I find, compared to when...it's getting, it's not, on a hospital level as such, but I think it is getting more and more clinical, more and more, hospital based...<sup>339</sup>

Louise strongly agreed with this sentiment, offering her thoughts on how even the décor has begun, whether intentionally or not, to reflect that of the stereotypical image of a hospital - 'they're all quite...cold colours'.<sup>340</sup> Whilst both Kelly and Louise identified visible and tangible aspects of the hospice as having grown more hospital-like – the conversation moved to commentary on the way in which the spaces within the hospice building itself were being used and the impact of this. The hospice in one of its larger scale refurbishment projects had seen shared communal spaces on the south-east corners of the ground and first floor transformed into four-bed rooms to boost patient accommodation; the loss of which Kelly lamented:

...they used to have a day room, like where room 4 is, that used to be the day room, that's where like, especially at Christmas time like, people used to have their meals in there with their family if they could, Salvation Army used to come in, they used to take people in and uhm they could go in and just listen in the day room - but now they're stuck on a corridor blocking the way...<sup>341</sup>

The day room, occupying a proportionally large area within the wards with large walls of glazing overlooking the Bristol Channel, appeared to be a diverse space as described by Kelly and Louise. The day room offered a flexible space to accommodate the different activities and groups of people, for staff, families, and patients, with Louise adding 'at least if it was on the ward, if you're bed-bound or not feeling great at least they can walk...wheel all the beds'<sup>342</sup> making the room a safe space for patients with close contact to the ward if support was necessary. Louise in agreement with Kelly, commented that the loss of this multi-purpose space has meant that life in the hospice 'can't be as

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<sup>339</sup> Ibid. p.7

<sup>340</sup> Ibid. p.8

<sup>341</sup> Ibid. p.8

<sup>342</sup> Ibid.

spontaneous...you know it could be somebody's birthday... or you get a family get-together'.<sup>343</sup> Both Louise and Kelly talk fondly of the benefits of the day room, with it offering a space that counteracts institutional feelings of being in a care environment. Though the hospice now has a public café on the lower ground floor, having knowledge of the previous day room, Kelly and Louise appear wary about how far the café can replace the day room, querying how accessible the café is for patients who are not mobile and to what extent it can accommodate different groups. On the wards there are separate, smaller relative rooms that are often used as flexible spaces for other purposes, such as difficult conversations between relatives and the care teams, 'what you'll find as well is that even though this is a family lounge by here, they have quite a lot of meetings in there as well don't they, so like a lot of relatives can't go in there'.<sup>344</sup> These rooms are located off the main ward corridor and are a bit softer as Louise describes, perhaps due to their separation from the public areas. Whilst a private space like this is much needed with no alternative spaces close this can prove difficult for other visitors. The day room was very much a space to retreat to, for not only patients but staff as well; yet the café occupies a more public location and is open to those outside the hospice.

Discussing the realities of her role day-to-day, Kelly, highlighted a well-known and much maligned issue – storage. It is a recognised problem that the hospice building has insufficient storage space and is limited to the constraints of the existing building structure, resulting in small spaces dispersed across the floors of the building or some areas with no storage at all. Referring to the fifth attic floor, with no lift access, Kelly tells me that the housekeeping team 'haven't got a storage cupboard up there, so we got to carry everything up, we do leave the Hoover up there, we leave it on the corridor'.<sup>345</sup> Though the fifth floor is known to be a compromised space with low eaves and skelings, this highlights the impact of the lack of storage on the corridors of the hospice building, key routes that need to be kept clear for not only accessibility but are potential hazards for fire safety and egress. Despite this Kelly pointed out a room on the plans in front of us describing how 'that one that works, that's where our washing machine...tumble dryer that's where everything is'<sup>346</sup> – the room though still small, was able to consolidate into one area key pieces of equipment that was needed for the role, minimising time spent moving between different rooms in the building. Time spent walking reduces efficiency and increases potential time pressures on members of staff, for example, the staff changing rooms are located on the very top floor of the hospice in the attic,

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<sup>343</sup> Ibid. p.9

<sup>344</sup> Ibid. p.16

<sup>345</sup> Ibid. p.22

<sup>346</sup> Ibid. p.10

accessible only by stair. Talking about circulation in the hospice, Kelly described how:

...we wear these [points to uniform] we got to change every shift, so say you're in the kitchen on this floor...for us, like nurses, housekeeping are on these two floors, we got to go all the way up here to get changed [points to changing room on second floor]...<sup>347</sup>

The staff changing area is just that, a changing area, and does not have sufficient space for members of staff to sit or rest without the need to change or move to another area on lower floors. Moving up and down floors via staircases, I wondered how much additional time this consumes for those needing or requiring a break during their shifts, especially for those with limited accessibility. Much like the issue of storage, Kelly and Louise's experience appears to highlight the building in use as having a divide between the clinical spaces of the wards with other functions dispersed around the perimeter of these.

As our discussion turned to the entrance area of the hospice building, Kelly made what at first seemed like a curious point, in describing the changes that had been made to the reception, she dwelled on the vulnerabilities of members of staff and the volunteers who manage the entrance:

...I find, if you work in reception, I think you're more vulnerable...because these doors lock [pointing to double doors leading to ground floor ward] so unless she opens them say the receptionist they don't open, so if someone comes in being aggressive, and we have had in the past like angry relatives, and angry... they are basically on their own aren't they. But on our old reception used to be like locked off, from like, it was protected in such a way like...<sup>348</sup>

Safety, is of course an important issue, especially given the 24/7 nature of hospice care– but until Kelly highlighted this, it had not struck me. The wards, at the back of the hospice building are protected by the entrance open to the public and a series of corridors. As the notion of hospice becomes more visible in the community, public-facing areas of hospices are becoming much more open to lessen connotations of institutional facilities. Yet, as Kelly has noticed, this must be balanced with the practical needs of those for whom the hospice is a place of work.

From our conversations, Kelly and Louise have intimate knowledge of the workings of the hospice in day-to-day life, with their experience as non-clinical members of staff offering a distinctive

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<sup>347</sup> Ibid. p.20

<sup>348</sup> Ibid. p.11

perspective of the hospice building, perhaps even being able to see the impact on visitors and patients with less clinical bias. Yet having seen the changes that have happened over the years, and knowing the realities of the building, both Kelly and Louise expressed a feeling that decisions appear to be made with little communication:

...that's why I think they should start talking to their staff more as well, about what they think would work better, if they don't approve of it they don't approve of it but at least, they're the ones actually working on the wards and the offices and everything else...<sup>349</sup>

As discussed earlier, with regards to the experience of the new sluice area, this contrasts with Colleen's efforts to instigate multi-team decision making. Kelly and Louise's experience's highlight a hurdle within the practice of co-production – that is how to manage appropriate engagement with members of staff. Gaining feedback from every individual member of staff could potentially amount to a large task that would inevitably lead to multiple opinions and could potentially create a barrier to effective decision making. This interview obviously is only the record of two individual voices, but it is clear from this conversation that Kelly and Louise, as part of their respective teams, feel disconnected from the design and consultation processes and that vital narratives of teams are not being considered as equal.

### Mike and Rob

Shortly after my first interview sessions, Colleen and the member of staff acting as gatekeeper organised for me to sit down with the two members of the maintenance team at the hospice, Mike and Rob. Set up in a similar manner to the first sessions, with a fresh set of plan drawings ready to be drawn over, and models to help visualise the rooms; Mike arrived in the room first, but shortly after introducing himself, his walkie-talkie buzzed to life. Mike quickly left the room to investigate what was needed of him, and soon after I was joined by his team partner, Rob. Only having been working at the hospice for a year or so, Rob is young and friendly, with an outgoing and cheerful disposition, and as we were waiting for Mike to arrive, he was full of questions eager to understand what my research was about. Much like others working in the hospice that I had engaged with in my research, there was an expression of support for my research into the building itself, with Rob

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<sup>349</sup> Ibid. p.29

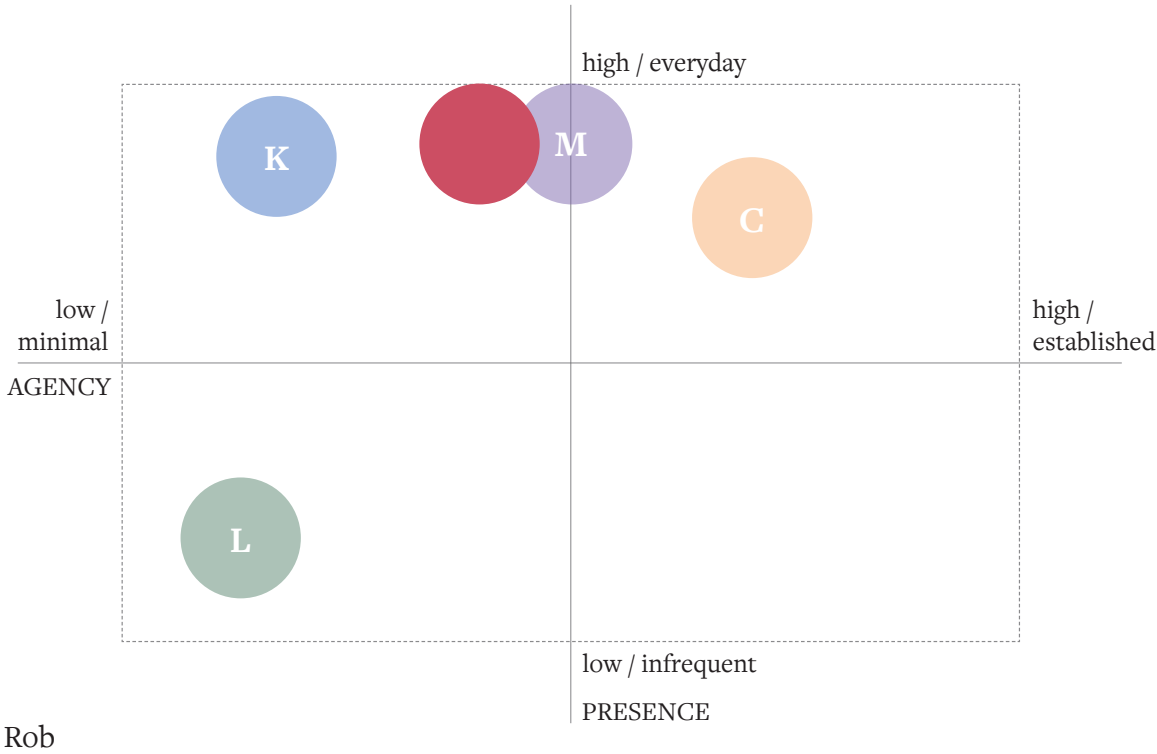
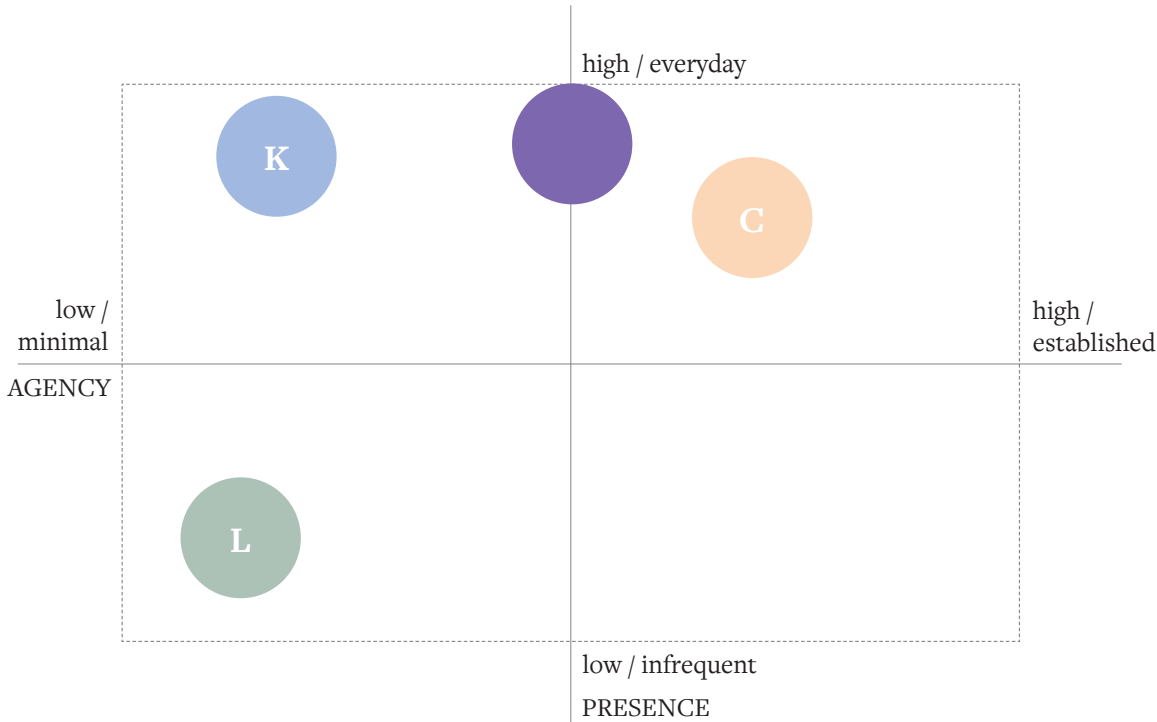


Fig. 5–9. Mike and Rob's engagement with the hospice building

stating that they are happy to assist. Mike soon arrived back to the room and settled himself down in front of the drawings and models. Older than Rob, Mike had a practical and stoic manner, with a personality that conveyed a sense of reliability, with what appeared to be an almost surgical knowledge of the building, see Fig.5-9. As we began our discussions, it was initially Rob who took the reins of the conversation, with Mike quieter and only interjecting short statements here and there. A stalwart of the hospice, Mike gradually opened up as our conversations deepened.

Just before Mike had arrived back in the room, a piercing alarm had sounded through the air, with Rob being quick to point out it wasn't the hospices - noting 'if it was our fire alarm, you'd hear it in here'.<sup>350</sup> Part of the responsibilities of the maintenance team are for Mike and Rob to test and ensure that hospice at its basic functional level is running safely for those inside:

...I think the Nurses hate it, because it just makes them jump every time, even though it's the same time every week...we time it, we wait for, there's a door by the panel, which we set it off on, a fire door and when the fire door closes, that silences it straight away, so we just wait until that door closes and then we know once that's closed all of em' have closed in the hospice...<sup>351</sup>

Both Rob and Mike are acutely aware of the hospice environment and the sensitivities of those within, on the one hand the patients who may not be well and the staff who are hard-working and perhaps tired from long shifts. Many of the necessary checks have been fine-tuned by Mike and Rob to be well-oiled processes that minimise as far as possible the disruption to the patients and staff, whether that is planned maintenance such as the noise from the weekly fire alarms to the management of one-off reactive work that might create construction dust and mess. Describing their day-to-day experience in the hospice, both were quick to respond that they are on the wards most days. They find themselves as roaming agents, on-call, ready to be able to quickly respond to things that go wrong and caring for the upkeep of the hospice environment, for example, Rob noting that the 'water temperatures have to be checked regularly'<sup>352</sup> for hygiene purposes. Perhaps more so than anyone else I have spoken with, Mike and Rob undoubtedly have intricate knowledge of the hospice building, not only its physical fabric but its operation.

As we look over the plan drawings in front of us, Mike and Rob point out elements that are out of

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350 Participant D & E, 'C&V Hospice Interview 4', ed. by Annie Bellamy, 2019) p.4

351 Ibid. p.4

352 Ibid. p.7



date or new additions to the plumbing. In pointing out a new sink, Mike commented on how the ever-changing nature of the hospice and its services had a decided impact on their roles:

...sometimes people are a bit naive they think that they can just change the use of a room you know, just tell you today, and tomorrow they expect it to be done... but it doesn't work like that does it you know. You've got to organise things; you've got to get materials...<sup>353</sup>

It is not only the everyday life of the hospice that Mike and Rob must manage in undertaking their work but the very fabric of the building. Mike and Rob acknowledge that despite years of maintenance, there remain some areas that have not yet been tinkered with, and with minimal formal records available there can be technical difficulties in delivering the changes asked of them. Mike summarises that sometimes it is not as easy as just installing a new sink, 'we're always getting problems with water, water's a massive one'<sup>354</sup> and that they are at the mercy of what services can be made available in new locations from the existing plumbing and electrical systems.

As noted from previous conversations with Colleen, Kelly and Louise, as more and more services are moved into the hospice, pressures on space have resulted in frequent changes to room functions. Mike and Rob dealing first-hand with the implications of these requests do their best to meet the requirements of the hospice, but noted that there can be hurdles to meeting expectations when balancing the working life of the hospice, 'at the end of the day, the rooms are used every day, so sometimes the only way you can do it is at the weekend, when you can move, sometimes they don't see that side of things'.<sup>355</sup> As Mike additionally points getting the physical work completed also means 'lots of contractors you know to do this work, so, it's not at the drop of a hat, you know it's got to be planned'.<sup>356</sup> As Rob had alluded to with the fire alarms, Mike explained in more depth, choosing the recent replacement of the patient bedroom windows as an example, Mike recounted the process of undertaking the works:

...starting on room 1, that room will be closed for a week from Monday to Sunday night, we've already spoken they reckon it will take them three days to get the window, so whilst that room is empty, myself and Rob will be there painting, they move out on the Thursday then the housekeepers go in, deep clean, it

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<sup>353</sup> Ibid.

<sup>354</sup> Ibid. p.15

<sup>355</sup> Ibid. p.7

<sup>356</sup> Ibid. p.8

over the weekend we then move the patients from room 2 into room 1 Monday morning...<sup>357</sup>

For what might be considered a relatively simple intervention, replacing the windows in the context of the hospice represents a task requiring the co-operation of multiple teams. Maintenance works that are not able to be fixed there and then with the resources available on-site to Mike and Rob evidently require meticulous planning, for not only people's time but to safeguard financial resources. As Mike stated, 'even though we are a charity, but we also got to accept we are also a business'.<sup>358</sup>

The pair acknowledged that there is often a time pressure to the work they are asked to do, and like the narrative of Kelly and Louise feel that there are often missing channels of communication - 'they don't invite anybody from maintenance department to be in on the meeting'.<sup>359</sup> Discussing in more detail Mike describes how he and Rob might be asked to adapt a room:

...they come out and say right we want now to um, turn this room [points to the rooms we're in] into three people can work in here, ok. Can it be done by Friday? Probably not because...ordering furniture, so they, they quite like that you know, so if one of us been in the meeting we could say yeah right, let's be practical about it...well do we need more lighting in here? Do we need more power in here? Do we need more data points in here? Do you know what I mean? It's, you think, cos it's our role we're thinking outside the box from what they're thinking of...<sup>360</sup>

Here, Mike echoes an observation also made by Kelly from the housekeeping team - that there are key insights from non-clinical voices that could be drawn upon when considering the hospice building. During the recent café renovation, Mike explained that in this instance there was a project manager involved to steer the project from a higher level, 'he's forward-thinking so you know he's looking at that side of it...he's hands on, you know, he knows, he understands the role that we've got as maintenance guys'.<sup>361</sup> It was evident from both Mike and Rob that in this case this had made a positive difference to their role within the project, having opportunities to discuss their involvement.

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<sup>357</sup> Ibid. p.27

<sup>358</sup> Ibid. p.13

<sup>359</sup> Ibid. p.9

<sup>360</sup> Ibid.

<sup>361</sup> Ibid.

From both Mike and Rob's description of the nature of working in such a sensitive environment, it is evident they are acutely aware of how their roles impact on the experience of the hospice for others. Despite the difficulties that they encounter in managing the performance of the building and ensuring the comfort of the patients and staff and the bigger expectations of hospice management in adapting the building to fit current needs – both Mike and Rob express a strong sense of responsibility and care toward their role and place in the eco-system of the hospice. Telling the story of how he came to work at the hospice, Mike explained that his initial contract was for two weeks, and friends and family warned him that the hospice would be a hard place to work emotionally, yet:

...the fortnight became a month; the month became and then you... six and a half years later...still here you know what I mean. But there's something about working here that gets you, inside you, I can't put my finger on it, do you know what I mean? We all take pride in our work, we all do the job the best we possibly can but there's something about giving something, the time...<sup>362</sup>

Rob was quick to agree with Mike, describing how prior to joining his first thoughts of what life would be like working in a hospice was that it would be stereotypically sad and depressing seeing people die. He seemed almost happy to describe how that he has found that:

...it's not always sad here, it's uhm, I think the staff make it uhm, some wicked [great] staff here, but it's not all sad and we do feel a sense of achievement when you've done something and you've gone home at the end of the day, the days we hate is when they've been fiddly days and you've been doing this, that and a training course online, and you don't feel you've done anything...<sup>363</sup>

Demonstrating the unexpected positives of working within the hospice, Mike adds in that there is also a similar feeling felt by the local community saying that 'the [local] people... are proud, there's a lot of local money that's been ploughed in over the years, so a lot, a lot of attachment'.<sup>364</sup> Throughout the interview, Mike maintained a quiet sense of duty, which seemed to have inspired Rob who looked up to Mike in a deeper manner than just learning the practical realities of their roles. Both were taking on responsibilities beyond the maintenance of the building, but facilitating maintenance of the clinical needs, often making trips to the local hospital to collect tests and bloods. Further

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<sup>362</sup> Ibid. p.10

<sup>363</sup> Ibid. p.11

<sup>364</sup> Ibid. p.21

highlighting this attitude, Mike recounted the story of his first experience with the mortuary:

...they [patients] come into reception, they never leave through reception, they always leave through the back door, they have a high standard, everything, the care they get, everything, and yet they leave this building via a back door which is rotting, the vinyl on the floor was in pieces, there was tiles missing off the wall, it was horrible, old yellow fluorescent, I thought, I'm just totally actually shocked... when the body goes from there to there [pointing on the plan drawing to the mortuary door indicating where a hearse would park by the kitchen entrance] I hated the thought they're wet, I know they don't know, but do you know what I mean...<sup>365</sup>

His experience as an outsider, never having been in that environment before, unveiled a new perspective on a normalised experience by those already working in the hospice. Mike's poignant reaction moved him to campaign for the installation of a small glass canopy over the mortuary door to offer protection from rain and wind for people leaving the hospice to the care of the funeral directors, and the timber door itself. This was a design intervention motivated by his concern for dignity and empathy more so than other practical needs.

Reflecting on their roles it seems that Mike and Rob operate at two divergent scales – one that is direct and ultimately hands on with the hospice building itself, and the other end of the spectrum that works to organise and manage the logistics of larger scale projects. In discussing the larger scale, Mike feels the working relationships fostered over the years with local companies and contractors have been beneficial, as having existing knowledge of not only previous decisions, for example, what product was used as a floor material in a specific room, but also the experience of working in a hospice environment. From the conversation it is clear to me that regardless of the scale they are working within, Mike and Rob are driven not by the minimum requirements of keeping the building functional day-to-day but feel a much broader sense of care toward the environment and the people within, seeing their role as creating a comfortable environment for patients and staff and doing their bit for the patients.

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<sup>365</sup> Ibid. p.22

## Rachel and Steph

The previous research encounters documented narratives of those in the hospice building that are potentially less visible to patients and their visitors and perhaps perceived as being behind the scenes assisting in keeping the hospice environment running. The next encounter however marks a shift toward the clinical voices, of which have become more dominant as the experience of dying has become more medicalised. Much like the previous conversations conducted in pairs, for this I met with Rachel, the Clinical Nurse Manager and her colleague Steph, the hospice's Practice Development Manager (who had also previously worked as a clinical nurse at the case study setting). I set up the session in one of the many small meeting rooms; this one was adjacent to a cluster of offices in proximity of the first-floor ward and could sit no more than eight people, perhaps ten in an uncomfortable squeeze around a conference table. It was noticeable from the outset of our meeting that both Rachel and Steph were confident and relaxed in their reception toward me as a researcher perhaps due to having met me a few times prior to the interview. This may be perhaps owing to exposure to clinical research practice, or the more academic nature of clinical training, and due to their close working relationship (much like Mike and Rob previously) were seemingly bounced off each other's commentary. Unlike the others I have spoken with, who are embedded in the hospice environment in custodian roles, Rachel and Steph's participation within the hospice building is more removed, their focus being the care of patients, see Fig.5-10.

Steph who works as a key member of the clinical team, and Rachel who is a critical liaison for the clinical staff members have been and are very much embedded in the clinical day-to-day work/practice. Yet in senior and managerial roles, Rachel, and Steph's involvement with and of the building is not exclusively confined to the clinical areas of the case study setting but has seen them inhabit additional other spaces. It was quickly established that the key spaces of the hospice building for both Rachel and Steph are primarily the two wards on the ground and first floors, with Rachel labelling it her domain. Going into further detail, to the spaces within and around the wards themselves, Rachel pointed out that she spends a lot of time in the reception area 'troubleshooting and liaising with the reception staff [as] I sort out the admissions and things like that'<sup>366</sup> - revealing that despite this area being typically labelled a public-facing space for patients and visitors it is also a critical place of work and where clinical/non-clinical boundaries begin to blur.

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<sup>366</sup> Participant F & G, 'C&V Hospice Interview 5', ed. by Annie Bellamy, 2019) p.4

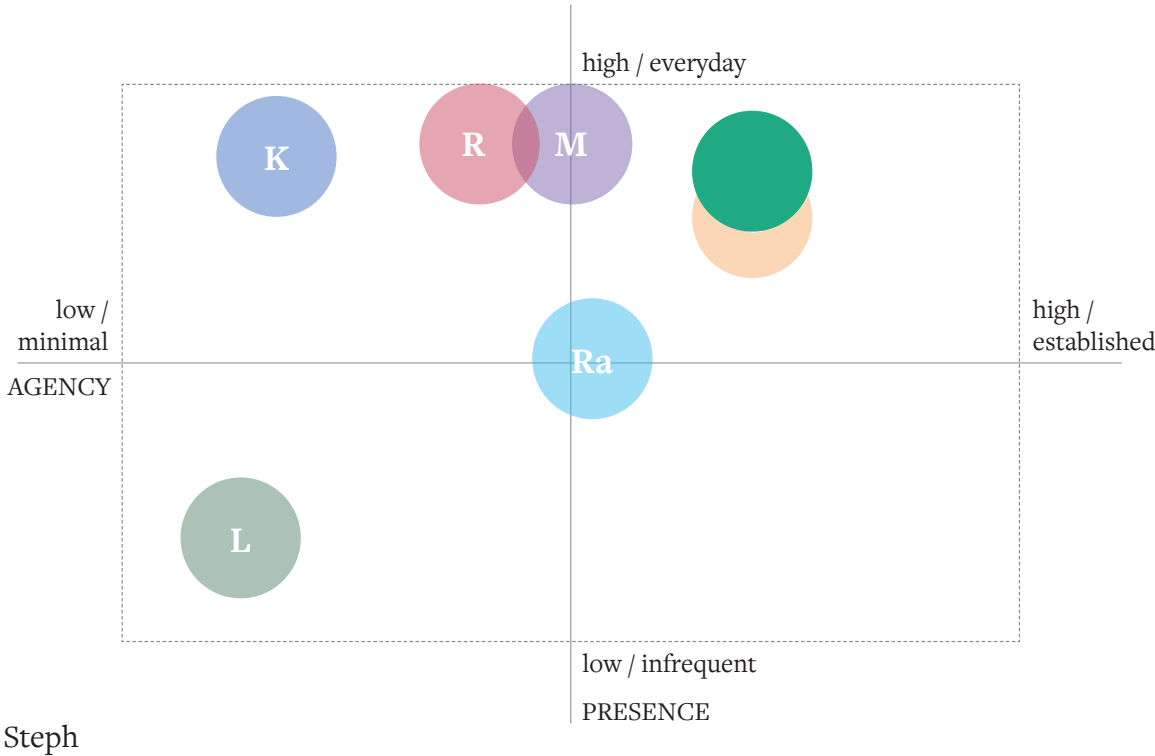
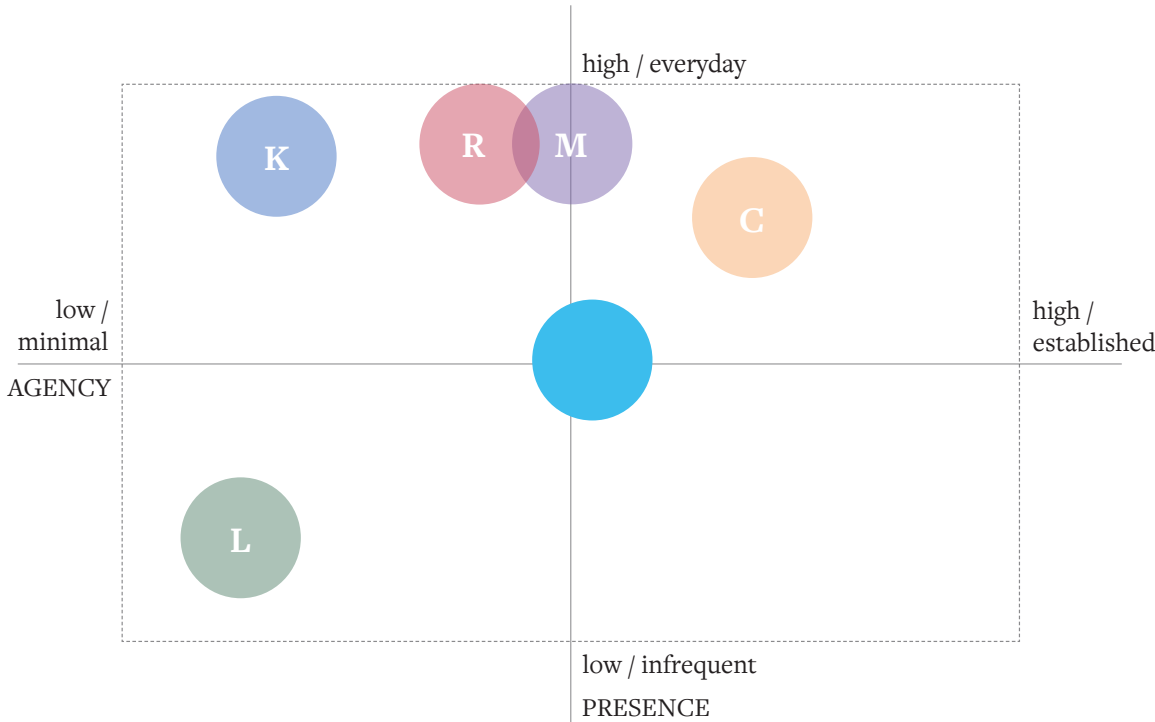


Fig. 5–10. Rachel and Steph's engagement with the hospice building

One of the critical spaces within the ward footprint that Rachel and Steph repeatedly refer to throughout the discussion was the dayroom, a communal room, somewhat like a living room, that has been re-purposed to become the four-bed bay on the south-east corner of both wards to provide more bedspace within the hospice. It has views out across the gardens below and long-distance views out across the sea, see Fig.5-11. Both Rachel and Steph are nostalgic about the dayroom, reporting that, 'it was used by staff and used by patients, and it was used a lot'<sup>367</sup> and explaining that the space was used by patients and their relatives for social activities, for example, 'there was a big round table, so if they did want to, everyone could sit at a table and have their meals'.<sup>368</sup> Whilst fulfilling a vital role for patients and their visitors it had also become a significant space for the staff, with both explaining that the dayroom was previously the setting for 'what was called grand rounds that was what it was called, which is now MDT (Multi-Disciplinary Team Meeting) ...[it] meant that all of the healthcare assistants, and housekeepers, and people involved in the whole, could all attend'.<sup>369</sup> The dayroom, in its generosity of size was the only space that could comfortably accommodate all members of staff on the ward itself, and critically not only clinical staff. Steph reflected on the unconscious importance that this had on staff dynamics,

...you could have a HCA (Healthcare Assistant) and be part of the decision-making process, and just beyond the door if a bell went and somebody needed them they could nip out, whereas here, in this more formal meeting space...it makes it far less accessible for people like HCA's because they feel like they're in a formal meeting...<sup>370</sup>

This is recounted in contrast to the way in which clinical and handover meetings are now held on the wards, typically 'in the office behind the nurse's station'<sup>371</sup> that does not offer enough space for all members of staff to attend. The office referred to here, see Fig.5-12 is a small room located directly behind the nurse's station on both the wards. As seen on the plan drawing, there is only one entrance to this room that requires navigating between the desk space and the entrance to the busy medical store. From my subsequent observation of the hospice, this area is not only the geographical but managerial centre, that hosts a consistent flow of staff members from all teams. The office behind is marked by the desk and implies a sense of clinical hierarchy that, these

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<sup>367</sup> Ibid. p.9

<sup>368</sup> Ibid.

<sup>369</sup> Ibid.

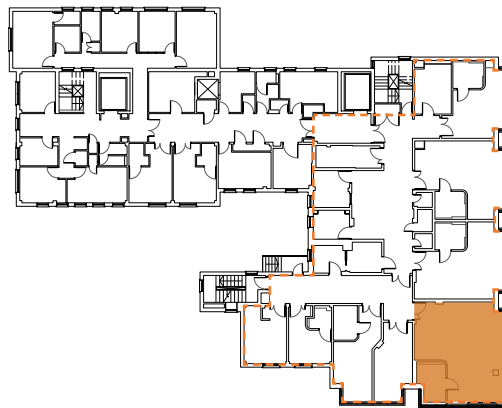
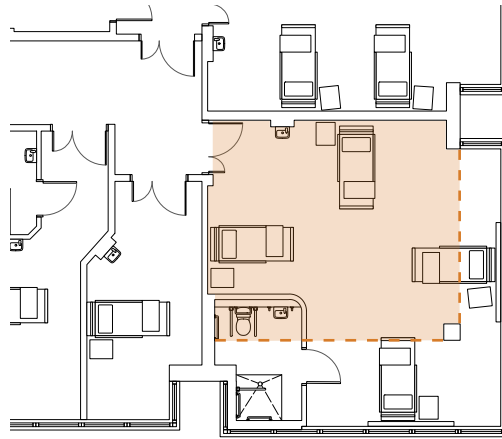
<sup>370</sup> Ibid. p.10

<sup>371</sup> Ibid.



Fig. 5-11. Location of the dayroom,

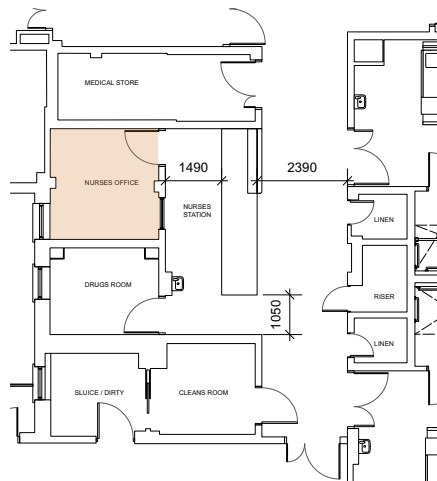
The location of what was the dayroom (now the only four bed bay) is highlighted in the lower diagram, with the dotted line indicating the boundary of the ward. The upper diagram describes the footprint of the former dayroom, with the remaining space an external terrace.



→ SEA-VIEWS

Fig. 5-12. Location of ward meetings

The location of the office room behind the nurse's station that is commonly used for clinical meetings. This room is approximately 2.8m x 2.9m and 8.3 sq.m. As seen from the diagram on the right, the door to this room is directly adjacent the desk of the nurse station and so can cause a bottle neck of the narrow circulation behind it.



previously open meetings are to be kept behind closed doors for only senior members of staff. The conversation between Rachel and Steph implies that a divide has developed not only in decision making but overall communication; as Sailer and Thomas write 'highly partitioned and cellularised environment might cause frustration and inefficiencies if it accommodates an organization requiring speedy information exchange'.<sup>372</sup> Furthermore, Rachel simply states that she believes this to be 'a product of not having the space'<sup>373</sup>, with the implication that the hospice building is forcing changes to care practices that do not offer any benefit.

It is clear from the discussion with Rachel and Steph, that whilst losing the dayroom was detrimental for clinical responsibilities, it also impacted the staff's experience of the hospice in other less formal ways. An instance of this is Rachel and Steph's perception of the clinical nature of the building and the ward environments - 'losing that [the dayroom], has just made it even more clinical because it's all patient bays'.<sup>374</sup> Rachel and Steph describe that now missing from the hospice since the loss of the dayroom was a 'space where the staff can get together and be...talk about their day or talk about things that are challenging or a little bit about their social life, what weightwatchers are doing'.<sup>375</sup> A recent renovation project within the hospice saw, amongst other works, a basement conference room, previously used as the hospice's education room hosting staff development days and courses, become a public facing café and a small storage room directly adjacent to the café become the dedicated staff room. The new staff room is small in size at 7.3 sq.m and only able to accommodate a few staff members at once, see Fig.5-13. This combined with the loss of the dayroom, measuring 36 sq.m, Rachel and Steph stress the sub-conscious impact they feel this reduction of staff space has had on staff morale - '[it] is just telling your staff that they're not important'.<sup>376</sup> They are both aware that the introduction of a café is critical to economically help the hospice 'drive revenue...[and] create income'<sup>377</sup> owing to the bigger picture of funding hospice care, however it is implied that the space was also expected to be a space for staff to use as described above. Rachel disputed the realities of the expectation of the café to be used in this manner for staff, 'not if you're clinical staff really [and] you're sat next to a family'.<sup>378</sup> In proximity of potentially

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372 Kerstin Sailer and Matt Thomas, 'Socio-Spatial Perspectives on Open-Plan Versus Cellular Offices', *Journal of Managerial Psychology*, 36.4 (2021), 382-99, p.385

373 G, 'C&V Hospice Interview 5', ed. by Bellamy, 2019) p.9

374 Ibid. p.12

375 Ibid. p.22

376 Ibid. p.23

377 Ibid.

378 Ibid. p.22

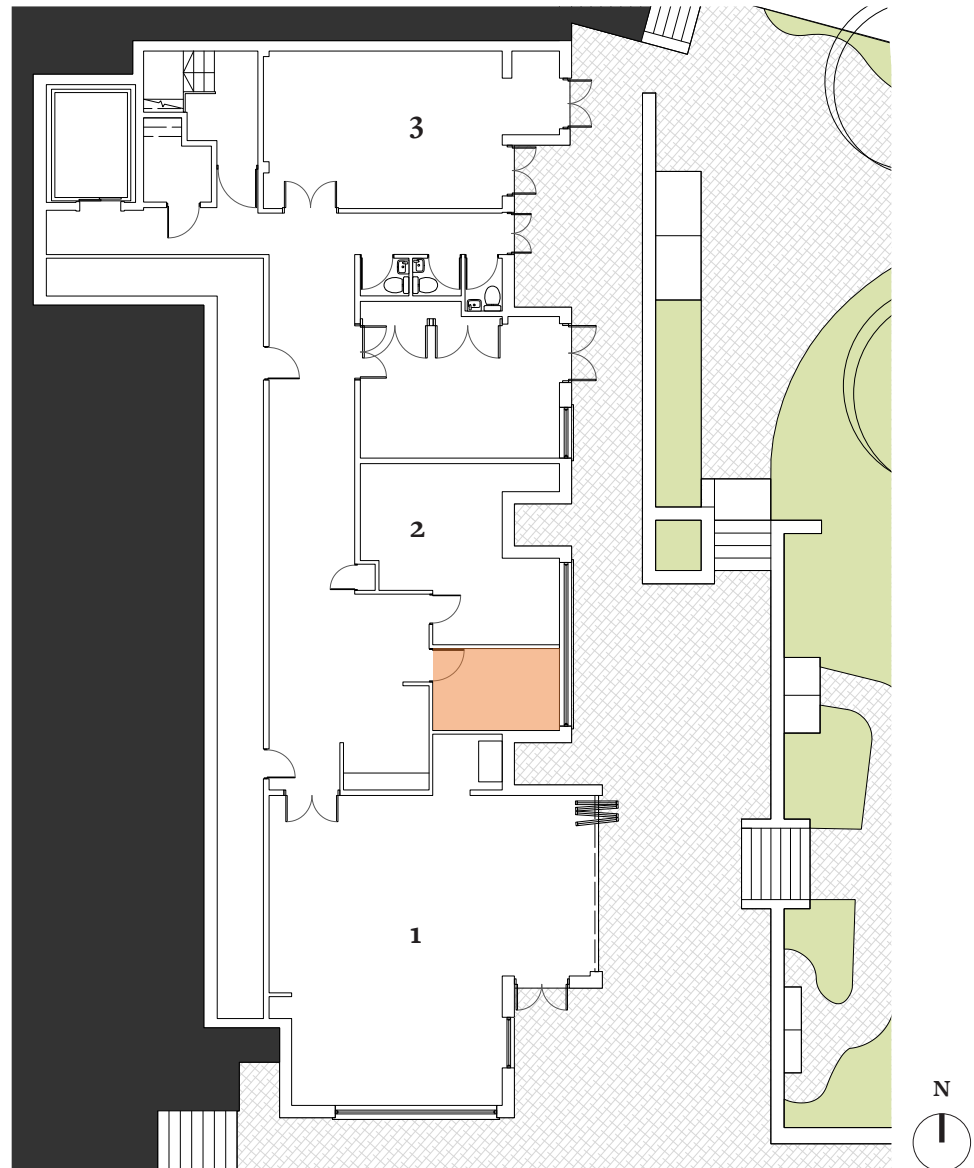


Fig. 5-13. Location of the staff room

1:200 plan of the basement floor of Cliff Villa, the staff room is shown in orange - note it's relative size to the other spaces here, such as the cafe [1], the offices [2] and even the plant room [3].

both patients and their visitors, the shared café space diminishes the boundaries of when staff (especially clinical) are on shift and on a break, reducing the opportunity for meaningful respite where there is a potential to be interrupted. Steph acknowledges that the hospice during her time there has changed as 'a reaction and result of how palliative care is changing'<sup>379</sup> but as Rachels concludes the overall financial pressures on healthcare demonstrates at the staff level 'it's an example of everything getting squeezed, and the thing that gets squeezed the most are the people delivering the care'.<sup>380</sup>

Despite broader hospice management prescribing the future direction of the hospice in its services - and therefore environment - it appears there have been occurrences where members of staff have directly influenced the environment in response to their needs. An example of this is a small room of 11 sq.m, located next to a patient room at the north end of the ward that was previously the Ward Sister's office, see Fig.5-14. Steph described that the office space is only required for management days, and that her current office has the capacity to accommodate the Ward Sister for this time, thus freeing it up to become a multi-purpose room that was nicknamed the cwtch. This was described as having two major functions; firstly, acting as a discreet and private space in which confidential issues could be discussed away from the open ward corridor or shared patient bedrooms and secondly as breakaway type space for staff when:

...they need some concentration, they need to do something that they shouldn't really be interrupted, then they have no space to do that because we've gone paper light and it's all digital, computers on wheels and they're in the middle of the corridor or a ward writing, well, you get disturbed all the time there, so we needed to create a quiet space that they could go and not get interrupted so there is one little computer in there and uhm also, there's no space for the staff to just go and take 5 and reflect, you know if you've had a really challenging day...<sup>381</sup>

There are family rooms on the wards<sup>382</sup> that provide seating and drinking facilities, but as Steph

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379 Ibid. p.19

380 Ibid. p.23

381 Ibid.p.24

382 The family rooms on the wards are a space that has moved numerous times within the footprint of the hospice building. As will be discussed in more depth in Chapter 6, on pg.253, purpose-built visitor accommodation was moved due to infrequent use because the rooms were perceived to be too far away from the patient rooms. Their subsequent locations were moved again, with Colleen referencing that they received feedback from visitors via comment cards, though the reason why was not made explicit by Colleen to the researcher, it was inferred this was due to the suitability of the accommodation itself.



Fig. 5-14. Location of the 'cwtch'

This was re-purposed from a general staff area to a multi-functional office space. Note that it is, relative to the size of the ward, quite detached from the main nurse's station and is very close to a patient bedroom,

pointed out 'you'd be in the middle of having an intense conversation and someone would come in and make a cup of tea amongst the relatives'<sup>383</sup> – the nursing team's decision to create a multi-purpose room for the use of primarily staff on the ward that is distinctly separate from the communal family room is the type of observation drawn from first-hand experience of the nuanced activities that take place there. Adding further weight to the breakaway nature of the room, Steph delicately raised the issue of security during the night, as there is only skeleton staff<sup>384</sup> and the basement café is not linked to the emergency bell this is felt to introduce an element of perceived vulnerability (additionally noted by Mike and Rob) not only for patients but staff who are disconnected from the wards but furthermore exposed during the night hours to the gardens and public park beyond the boundary of the hospice. Perhaps sub-consciously referencing her previous comment about the nature of hospice being squeezed, Steph told me that this is 'an example of how we've looked at a room and thought okay, what's the most we can get out of this room'.<sup>385</sup>

The notion of being squeezed, the perception of exerted pressure or compression as a form of environmental press, is picked up again in further discussion prompted by the models on the table of the interview setting. Rachel, upon picking up the model, exclaimed that she was 'really struck by the number of rooms, like boxy rooms... there's no, there's not much openness at all is there'.<sup>386</sup> Despite clinical care of patients being the primary function of the hospice, there are many separate teams of staff working in the hospice building to manage clinical care but to also facilitate the myriad of other services that are now based within the walls of the hospice. The architectural model of the ward floor offered Rachel and Steph a new perspective to the nature of the environment in which they work, at a managerial and administrative level:

...there isn't space for people to get away, or even work together so I'm thinking not about clinical staff but non-clinical staff we're all boxed off, so there's no interconnectedness between the people, the teams! so you know, the clinical managers will be in one little office, the admin managers in another, so there's nothing that will bring those people together in a natural way...<sup>387</sup>

Though some teams in the hospice operate separately, many teams are interdependent and

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383 G, 'C&V Hospice Interview 5', ed. by Bellamy, 2019)p.24

384 The night shift is made up of approximately six members of staff who cover the ground and first floor wards, with a security guard who mans the reception – a much reduced number in comparison to the day shift.

385 G, 'C&V Hospice Interview 5', ed. by Bellamy, 2019) p.25

386 Ibid. p.5

387 Ibid. p.22

work collaboratively, for example hospice management and facilities. The use of office spaces appears to be in constant flux with members of staff regularly changing office space. Mike and Rob previously alluded to the maintenance related difficulties in reacting to fast paced change, and here Rachel offers another perspective on the staff experience:

...[the] thing is you're chopping walls about and moving things but in that you're moving people all the time from their environment and so that's the other output of that process and then that the output of that is historical 'oh where's...' or 'which office are they in now...' <sup>388</sup>

It is worth noting that the word 'chopping' raises perceptions of decisive and quick changes made with little consideration of their consequences. These historic associations may well be informal elements of staff relationships that re-assert themselves over time; but this highlights the pace at which the hospice building has needed to manoeuvre itself to accommodate changing staff hierarchies, roles and teams. The fragmentation of the office spaces degrades the opportunity for internal communication, especially across a building of five floors with offices spread throughout. There are of course limitations to the way in which the existing building of the case study setting can facilitate change, both owing to the physical structure of the building and financial restraints. Yet, despite acknowledging that most changes have been led by broader shifts in hospice care, Rachel and Steph feel that the hospice environment has changed extensively throughout their career - 'it's a constant trying to make best use of the spaces that we've got...but we go round and round in circles'.<sup>389</sup> As raised in the previous research encounters with Kelly and Louise, there is an implied sentiment that much of the change made to the building have been reactive instead of proactive. Moreover, that this change has been sequestered by hierarchies within the hospice:

...the decision-makers in these processes are often senior clinical people, which is great...but without the understanding of architecture, building, what that does, the space you know, all that I don't know anything about! So, I think sometimes you think, well what's just the most practical solution, to this building that's crammed full of stuff and it's this, this and this and people just make decisions based on the information and the knowledge they've got... <sup>390</sup>

Here Rachel and Steph recognise that despite their own and others expertise of the building's

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388 Ibid. p.13

389 Ibid. p.14

390 Ibid. p.13



function as a place of care, there is a limit to which clinicians can inform meaningful change to the hospice building. The change they can exert is one that is bound to the limits of a scale of both their responsibility in their job roles but also the scale of space within the hospice building that they can manage or influence, for example the cwtch was a singular room but further change would require further input from perhaps the maintenance team or even external contractors.

Reflecting on the above quote, holistically understanding the individual components of a building is the basis of an architect or architectural designer's role and their education and practice offers expertise in spatial organisation and layout. For example, referring to the change of the dayroom to a four-bed patient bay, 'there was no consideration or understanding for thinking about the implications for taking away that space would be for patients or if there was it very short-term'.<sup>391</sup> In this sense, architects/designers consulted to help with a hospice building may be able to suggest radical ideas to improve overall spatial adjacencies or to improve the positive experience of a specific area of the building and to fully understand the implications of any interventions. When moving to a finer grain level of detail, the staff overall may offer more expertise than architects or designers. Steph described an example of this, that during a recent refurbishment:

...there wasn't anywhere to put like the gloves and the pinnies...they hadn't put many of them up with where they should be at point of care sort of thing because they don't look - they wanted to create this lovely kind of environment, homely you know, smooth lines...but we are a clinical environment at the end of the day so...<sup>392</sup>

We might observe that whoever was responsible for the overall design of the changes above, focused on the implementation of an aesthetic over that of the basic requirements of the inhabitants of the space. Furthermore, this highlights the need for a greater dialogue between architects and expert users of the environment being designed, with Bellamy, Clark and Anstey calling for 'collaboration and opportunities for co-production to facilitate and promote this; for action from a multidisciplinary care team that recognises the strengths of each profession'.<sup>393</sup> There is space for design, but as the above highlights, a balance must be struck between the aspirations for environments and supporting the fundamental requirements needed for care.

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<sup>391</sup> Ibid. p.12

<sup>392</sup> Ibid. p.18

<sup>393</sup> Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969, p.5

The boundaries made by walls and beds are crucial to the roles of clinical staff, to help patients, move, whether that is in their bed or to assist them with bathing or needing the toilet. Both Rachel and Steph describe that many of the patient bedrooms are inhibited by the lack of clear space available to them to safely manage this physical aspect of care. The physical dimensions, the smallest patient bedroom measures 3x2.6m, and some other beds occupy alcoves approximately 2m wide, see Fig.5-15. The patient bedrooms at the case study setting are further impeded by the need for additional medical equipment within patient rooms alongside standard furniture such as an armchair for visiting family and friends and a bedside cabinet with lockable storage for drugs – with Rachel commenting that together ‘in terms of manual handling that’s really hard’.<sup>394</sup> There are no definitive space standards either prescribed or regulated for hospices (as may be found for other building typologies such as housing<sup>395</sup>) but there are guidance notes available that outline the necessary space for manual handling around standard sized hospital beds that could be applied to a hospice setting.<sup>396</sup> However, in the case study setting, as an existing building these are not always able to be met due to the constraints of the layout. As Steph describes, ‘getting equipment to the other side of the bed, trying to get someone from the bed to the chair here, using equipment is really tight for the staff’<sup>397</sup> and in some instances, if certain equipment is needed it excludes certain rooms on the wards that are not able to safely accommodate them. This physicality of healthcare practice was further highlighted by the recent refurbishment of the spa bathroom – to be discussed in more detail in Chapter 6 - whereby a toilet was installed immediately adjacent to a wall leaving no clear access either side for personal assistance. The installation of this was therefore abortive and required to be made good with implications on time and cost. The experiences of Rachel and Steph as described above, are those of contrasts. They inhabit places in between the clinical and non-clinical, the physical and the administrative. To some extent, Steph as Clinical Nursing Manager is a vital gatekeeper between the broader nursing and healthcare staff and the more senior teams above. Though certain decisions are made that come from higher up, there is to a certain extent a level of control Steph has managed to carve out over the finer details of the ward spaces, recognising the day to day needs of her team and finding workarounds to ensure that the needs of the staff are met.

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394 G, 'C&V Hospice Interview 5', ed. by Bellamy, 2019) p.16

395 Though not nationally prescribed, the London Housing Design Guide describes minimum space standards for different types of residential accommodation. These have been adopted by local authorities both within and outside London, and also by a number of housing associations that operate nationally.

396 NHS Estates, 'Ward Layouts with Single Rooms and Space for Flexibility', (London: TSO, 2005) & NHS Wales Shared Services Partnership, 'Whbn 04-01- Welsh Health Building Note: Adult in-Patient Facilities', NHS Wales, 2014)

397 G, 'C&V Hospice Interview 5', ed. by Bellamy, 2019) p.17



Fig. 5-15. Manoeuvrable spaces

The clear spaces around beds are highlighted in the diagrams of various sizes of patient bedrooms on this page in orange. The more constrained the clear space the darker the orange colour. The red dotted areas indicate areas where furniture may be placed, such as visitor chairs or other medical equipment. Clearly visible here then are the 'squeezed' spaces that Rachel and Steph refer to. However, it should be noted that these diagrams obviously depict static positions, and that if more medical equipment is required or furniture is required to be moved these spaces have the potential to be further 'squeezed'.

## Fergus

The final research encounter of the professional users of the hospice building is one of the most clinically senior yet least audible at the hospice, Fergus, a specialist palliative care consultant. As one of the consulting physicians, Fergus' clinical role is shared between statutory and voluntary sectors, being the case study setting and the local acute hospital. The reality of Fergus' relationship with the hospice in comparison to the other sampled users, is much more sporadic and fleeting in nature, see Fig.5-16. The combination of his part-time occupation of the building and the time pressure of his job role was, in the first instance, an obstacle to accessing meaningful time to undertake the interview. Due to the difficulties in organising a formal meeting with him during his working hours at the hospice, the interview took place spontaneously during his lunch break on a day that I happened to be visiting the hospice for another purpose. Borrowing the use of the office (set up for hot-desking) shared by the members of the senior clinical team, we began our discussion - as a symptom of the time pressure on Fergus, our conversation lasted just under an hour. However, this contrasted with the original length of time that Fergus had said he was able to set aside, around the twenty minutes of his lunch break. Despite being interrupted numerous times by phone calls he stayed to continue the conversation, demonstrating that the space to reflect on the hospice was a valuable exercise to Fergus.

Fergus' presence in the hospice building is much more transient, more akin to that of a visitor, though one with seniority and unchallenged access. In contrast to the ways in which we have seen other members of staff engage with the hospice building, Fergus admitted that he has:

...never given a huge amount of thought to all the sort of, the behind-the-scenes stuff that needs to happen, like the sluice, and the plumbing and where the store cupboards are, and the mortuary and how the patients get to the mortuary and what it's like for the funeral directors to pick them up from there...<sup>398</sup>

Fergus' job role is wholly focused on direct patient care and administration, and as the above demonstrates he has a surface-level engagement with the environment around him. His role does not necessitate a day-to-day experience in the hospice but is instead one that drops in and out. This therefore has had an impact on his perception of the way in which the hospice building exists and performs. For example, his perception of the patient bedrooms in contrast to the acute hospital

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398 Participant H, 'C&V Hospice Interview 6', ed. by Annie Bellamy, 2019) p.9

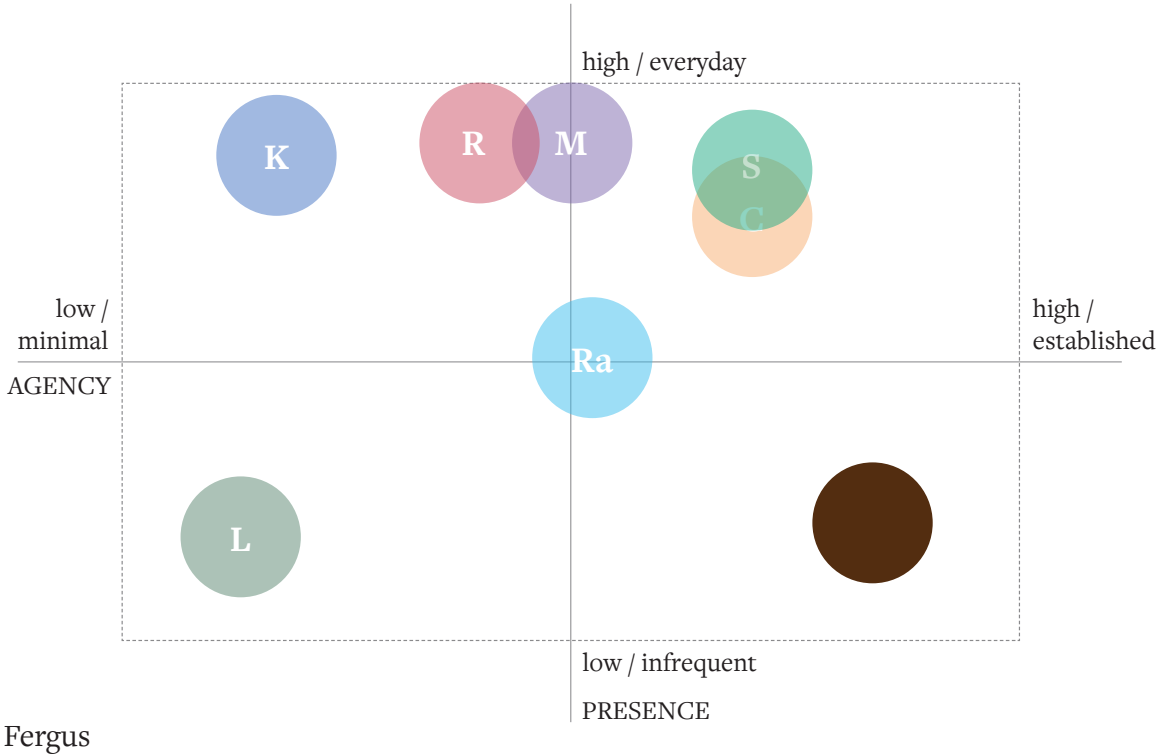


Fig. 5–16. Fergus' engagement with the hospice building

setting, his other place of work, is that they '[are] just colossal, you've got so much space there, the families can be there, the patient with complex needs you need to bring in ventilators or feeding machines or anything like that, it never feels cluttered in there'.<sup>399</sup> However, this is in direct contrast to the experiences of the previous stories of Kelly and Rachel, who as part of the housekeeping and nursing teams stressed that the bedrooms can be cramped and hard to safely manoeuvre within. This difference in perception of the hospice as a working environment is further deepened by Rachel and Steph's previous observation that they feel that decision makers are often senior clinicians with little bodily experience of being in the hospice. Both Fergus' and the observations of the other interviewees might highlight a potential imbalance and bias toward a hierarchical structure that could negatively impact the way the environment is viewed as future changes are considered. An overarching theme of the discussion with Fergus was his impression of the growing over-medicalisation and clinical influence of the process of death and dying. In synergy with the central topic of Gawande's *Being Mortal* - he acknowledged that:

...it's very easy for healthcare professionals to view dying as a medical event, whereas most people don't see it as a medical event or if they do, they're missing something. I think that dying is more a social, societal, family, spiritual, however you want to look at it, it's more than just a medical nursing led thing...<sup>400</sup>

As he describes this in more depth, it is inferred that an outcome of the increasing clinical nature at a broader level is trickling down and having influence over the physical environments of hospices, for example Fergus' earlier quote regarding the normalisation of medical technology such as ventilators and feeding machines. Though Fergus personally acknowledges this change, he describes some of the ongoing debates and confusion about the environments in which specialist palliative care should be delivered:

...[should] the hospice be more like a hospital and be able to do more acute things, the other way of looking at it is that maybe hospitals should be nicer environments which are more conducive to healing, and have a more holistic approach to them...<sup>401</sup>

The above, at first glance seems to highlight the tension and conceptual differences between the hospital and the hospice, however it is felt that this additionally emphasises the polarities of clinical space and how design is to an extent shaped by care practices as determined by clinical authorities.

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<sup>399</sup> Ibid. p.2

<sup>400</sup> Ibid. p.5

<sup>401</sup> Ibid. p.4

Furthermore, this poses a contentious issue; of the role of architects and designers in interacting with care practices, and the potential lost value when evaluated from a solely clinical perspective. From our conversation it is inferred that Fergus had never reflected on the environment in which he and his colleagues were working and that his patients were inhabiting. The quality of this research encounter felt like a reflective exercise for Fergus, as he commented on the case study setting's unique position adjacent to the sea that:

...the location of the building and the view, a lot of the staff will talk about how the view is therapeutic to patients, and I'm sure it brings a lot of calm to the patients, relatives and the staff having that view...I'm sure having a view is important, having a sense of something greater than ourselves...<sup>402</sup>

Whilst he does not engage with the built environment of the workplace day-to-day like other members of staff, his appreciation of what surroundings can offer holistically becomes clearer as the discussion continues. Fergus describes the case study setting as set apart from the five or six hospices he has previously worked at stating that he thinks that it is:

...really important that there is some sense of - this is a special building - and I think it definitely has an effect on patients, relatives and staff that this isn't just a run-of-the-mill hospital [sic] building...<sup>403</sup>

The discussion with Fergus, though brief in comparison to the other stories of the hospice, brings to light an impasse for the development of hospice buildings – the co-production of healthcare spaces between healthcare and architectural professionals. Fergus himself does not mention being personally involved in any renovation works or changes to the case study setting. However, from the other research encounters it is inferred that critical decision making is often guided by senior members of staff with limited engagement with the day-to-day experiences of the environment. Notwithstanding, this limited engagement could also be perceived as offering the benefit of critical distance and wider frames of reference. Like the previous voices we have heard from, such as Kelly, Colleen and Mike, each team brings insights of the hospice workplace that are unique to their role and how they function within it that others may not consider and therefore contribute to a rounded understanding of the needs and requirements of the building. It is critical to note that during the interview with Fergus, death is referred to in an almost abstract conceptual manner – seemingly skirting around referring to the act, and the patients themselves as dying. This furthermore

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402 Ibid. p.2

403 Ibid. p.4



highlights the importance of the growing discourse on the over-medicalisation of death and dying; and the disparity between discussions on a national level regarding the conceptual approach to care and the way in which these influence's how architects and designers are briefed.

## Building Observation

The previous research encounters have described, and analysed interviews and discussions held with various members of staff at the case study setting, hearing the experiences of individuals as part of a variety of teams within the hospice organisation. This final encounter presents the formal observation of the case study setting as a designed built environment; one that was undertaken by the researcher across two months following the in-depth interviews. This observation marks a return to the hospice building in a manner that contrasts to the first visit documented at the beginning of this chapter. During these dedicated visits, the researcher was more familiar with the hospice building itself, having visited four times prior for the interview sessions lasting a maximum of two hours located in office spaces away from the clinical environment of the wards. The researcher was additionally more familiar to the members of staff interviewed prior and who had attended the introductory session. Here the observation sessions were able to develop upon themes highlighted during the previous research encounters, providing ways in which to focus the observation sessions – to ensure that the actions and behaviours of the inhabitants are not recorded. Inhabiting several key locations, the building observation focused on the functional use of space, the sensory environment of the hospice building and the way in which elements of the built environment are interacted and engaged with, see Fig.5-17. It is worth noting that the first official return to the case study setting for the building observation will be discussed in further detail in Chapter 7, as it highlights the issues around undertaking observational research in a sensitive area of healthcare practice. The account of the building observations returns to a first-person narrative as the account of the 'first visit' reflecting the experience of the researcher in the case study setting.

## Reflection

During my visits to the hospice for the interviews I had attempted to be as inconspicuous as possible to avoid drawing attention to myself as an external presence, or feeling I was an imposter in a sensitive environment. Much like I had felt during my personal experience in the communal areas of the hospice where Jen, (the researcher's mother) died. Now, to observe the building I had

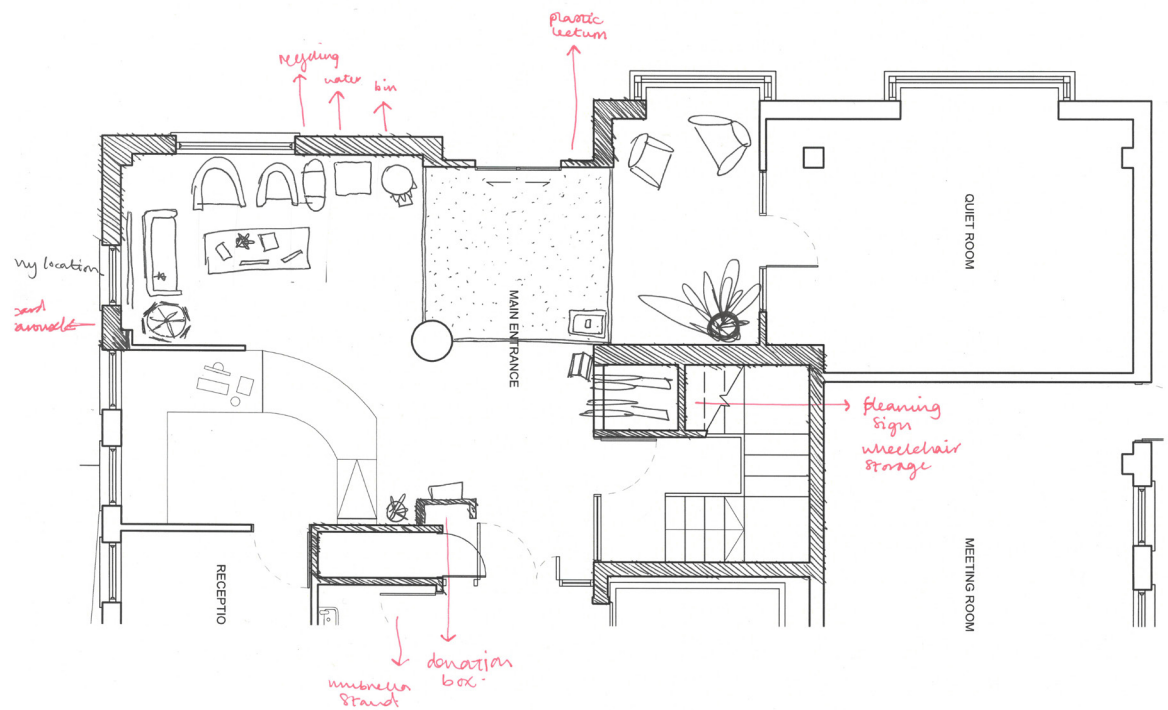


Fig. 5-17. Sketch observations

Drawn during the Building Observation of the reception area of Cliff Villa. The researcher here used the blank plans to note small observations on the inhabitation of the areas at the time of observation, noting the layouts of furniture and aspects such as changes to floor materials.

put myself within the heart of the environment. Arriving in the reception for the first formal visit, I was met with wariness about not only who I was, but what I was there to do. This was overcome with further explanation and the support of my research supervisor who is known to the hospice management team. With my first steps into the hospice tinged with a feeling of suspicion, I became overtly aware of the notion of what it was that I was about to set out to do. I was entering a sensitive environment inhabited by members of the public, the workplace of the hospice staff members that I had to ensure I was not recording in any manner – but I was returning to the hospice ward environment that I had not experienced since Jen had died.

### Data collection

Beginning with the reception, I spent my observation time marking the inhabitation of the reception space, noting where furniture was located, the makeshift wheelchair store in an existing recess in the wall, and how a pillar disrupted the sightlines of the receptionist, obscuring views of those entering, see Fig.5-17. It struck me how the atmosphere of this area was remarkably different to the rest of the hospice building almost like the lobby of a hotel or office, a definite reflection of clinical versus non-clinical space. The reception appeared to represent a gateway between the external and internal experiences. Sitting on the stiff sofa, I could feel a connection to the outside, the sound of birdsong, the hum of passing traffic. With west-facing windows, it was comfortably warm and bright from the afternoon sunlight despite the November chill. As people entered and left the hospice, the opening doors brought gusts of fresh air, a welcome burst of ventilation that contrasts to the ward environments that feel contrastingly airless perhaps due to restricted opening of windows and the need for mechanical ventilation to control thermal comfort. The reception, a deceptively large space in comparison to others in the hospice building at 39 sq.m with seating for up to six people, was during the observation period never busy or full. Leading directly onto the ground floor ward there was little buffer or transition space between the meeting of the public and private realms – with the threshold solely marked by a set of access controlled double doors. Adjacent to this threshold, there was set of stairs behind another access-controlled door, which offered a route to the first-floor ward environment, and beyond this leading to the separate staircase that led to the second floor where the staff changing rooms were located – a long route by which to change in and out of their uniforms.

I spent most of my time observing the hospice, sat close to the centre of the ward footprint, tucked into the side of the nurse's station; here I became immersed in the sensory experience of the building. One of the most noticeable traits of the building was its sound - there was a mechanical score to the hospice, the heating system creaking and crackling, the air conditioning gurgling and bubbling overhead, the noise of the trolleys and cabinets being constantly moved, the noise of the nurse call button going off and penetrating every corner of the ward (even in the corridor beyond the ward itself), the beeping of machines in the rooms, HCA's (healthcare assistants) singing as they go about their job, the laughing and conversation between the nursing staff. It is constant and loud, not dissimilar to the wards of a hospital or an accident and emergency department. The soundscape of the ward environment may provide an alternative sensory reassurance to patients of life beyond the room, a relationship which is vital for social well-being as 'hearing creates a sense of connection and solidarity'.<sup>404</sup> However, I wondered how this would feel during moments when a patient attempts to rest, but also to a member of staff going about their daily role, being constantly bombarded by audio distractions. There were many layers of conversation, from quiet discussions to loud shouting, which created a dense soundscape within the spatial constraints of the corridor.

Turning to another important yet often overlooked sense, the 'smell-scape'<sup>405</sup> of the ward is overpowering, as Pallasmaa writes 'we need only eight molecules of substance to trigger an impulse of smell in a nerve ending...the most persistent memory of any space is often its smell'.<sup>406</sup> I noted the different smells I could identify, bodily fluids such as traces of faeces, vomit, urine, the smell of food, and cleaning products, see Fig.5-18. This was prevalent in all spaces during the observation, despite it being clear that this was not registered by the members of staff, made clear when a key member of staff told me they could not smell what I noticed, emphasising the normalisation of the sensory aspects of their everyday environment. This was most noticeable during my observation of the lower ground floor, that housed the mortuary. Entering the floor from the staircase a strong chemical smell of a garage or machinery. As I sat in various locations around the hospice, it became clear that the smell was directly linked to the ventilation of the building.

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404 Pallasmaa, *The Eyes of the Skin : Architecture and the Senses* (Chichester; Hoboken, NJ: Wiley-Academy ; John Wiley & Sons, 2005) p.54

405 Victoria Henshaw, 'Urban Smellscapes : Understanding and Designing City Smell Environments', (2013) p.5

406 Pallasmaa, *The Eyes of the Skin : Architecture and the Senses* (Chichester; Hoboken, NJ: Wiley-Academy ; John Wiley & Sons, 2005) p.58

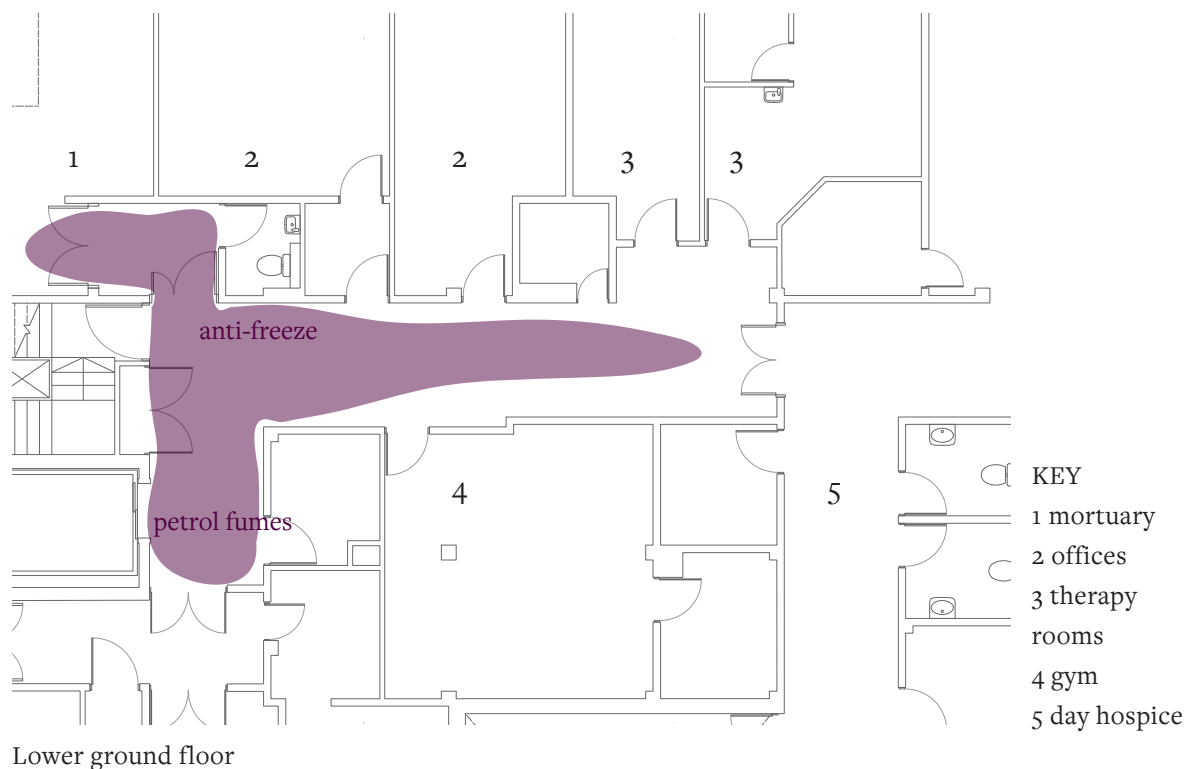
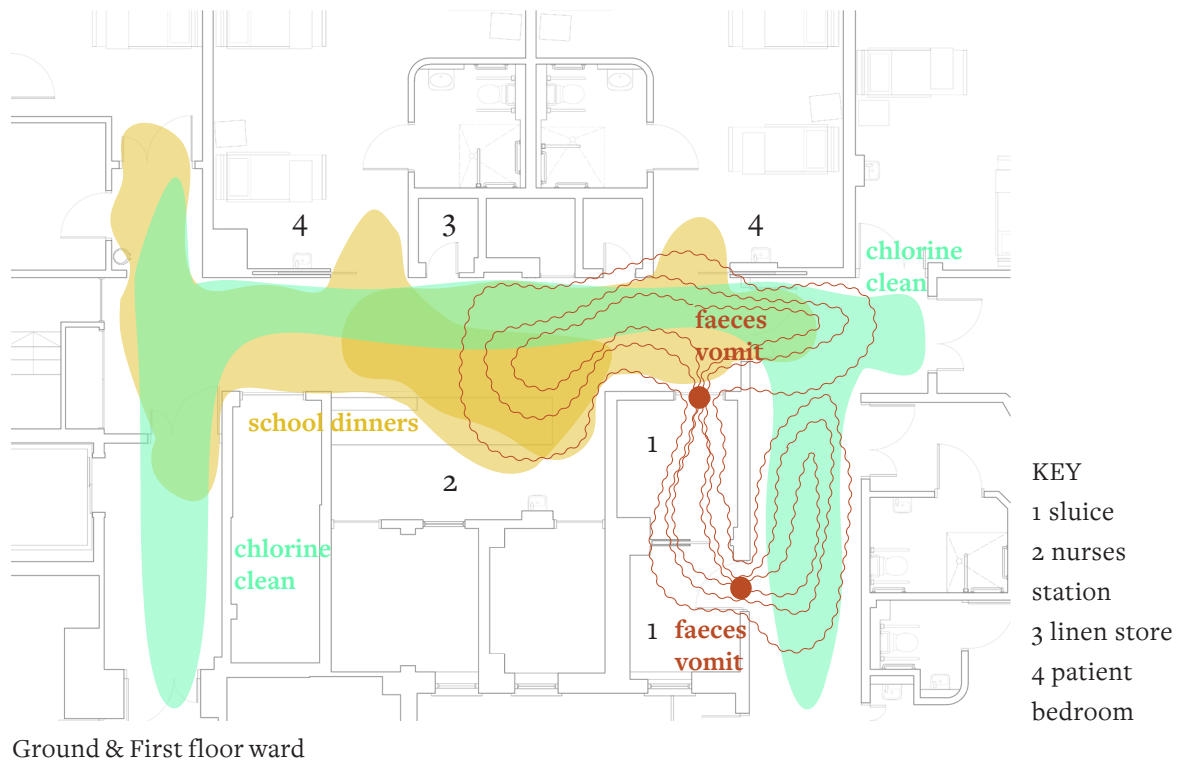


Fig. 5-18. Visualising smell-scapes

On the ward spaces, the diagram highlights that there is a myriad of smells that are encountered. The smells of the lower ground floor differed, in that the petrol fumes were from gardening equipment left in the corridor, and therefore an incidental event - however this demonstrates the overlapping sensory qualities of these areas.

Architectural theorist Juhani Pallasmaa considers that contemporary architecture holds vision as the most dominant sense often overriding our ability to tap into other qualities of space.<sup>407</sup> Throughout my observations in the hospice, it became clear that vision was extremely important. The quality of light on the main ward and corridor was jarring; lit by thin fluorescent lighting - the type historically seen in offices - that up-lit small halos at regular intervals on the wall. Their repetitive pattern and bright but dull light in conjunction with a lack of windows, felt disorientating with no connection to the outside world. These light fittings provide most of the light on the main ward corridor as there are no windows. In the early morning session, I observed the building, as the night shift was handing over to the day shift, I saw that the lights were dimmed, like that of a reading light on an airplane, to mimic the passing of day and night. Beneficial, I thought to create a calmer environment for patients - but I wondered on the impact this low light has for those working, is it enough to safely undertake their role? As the official handover was completed, morning was officially marked by an almost ceremonial raising of the lights, I was shocked to see just how dark the lights had been. From my chair at the nurse's station, I could see glimpses of the morning sun that the patient bedrooms get from their windows, but as these wrap around the inner corridor, this light mostly dissipates before it can reach any deeper to the functional and practical areas. A sense of connection to the natural world beyond, as I witnessed in the reception area, and to an extent in the basement café, is limited by the depth of the plan, that is the distance from the back of the room to the windows.

This feeling of depth is almost palpable. On each visit, sub-consciously, I could feel the weight of the building upon my shoulders as I sat. I could liken it to a feeling of compression, or burden - of a space with no respite to breathe. Perhaps this is intensified by the quality of the surface material, a suspended ceiling masking the structure and services beyond. As Edwin Heathcote muses 'the ceiling has become something better ignored, a surface to reflect light back down into the room'.<sup>408</sup> Yet the matt finish of the ceiling tiles did not reflect that much, but rather absorbed light and emphasised the flat nature of the tile itself and the quality of light. This reminded me of my own experience in the hospice, the hallmark gridded and pockmarked texture of the ceiling tiles being the last view that Jen was likely to see. As Heathcote further contemplates '...if the floor anchors us on the Earth, the ceiling allows our spirits to aspire to the sky'<sup>409</sup> - this affects those thoroughly embedded in the hospice building as a backdrop to the everyday. The nurse's station is not merely

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407 Ibid. p.18

408 Heathcote, *The Meaning of Home* (London: Frances Lincoln, 2012) p.162

409 Ibid. pg 163

a point of contact between insiders (members of staff) and the outsiders (patients, visitors) – but seemingly an anchor keeping the care team together. The main rooms, medical store, drugs room, linen cupboard all revolve around the desk. This offered a practical unification, drawing together all the key areas needed for the clinical care on the ward, but also served as a social hub, a point where information could be shared or discussed. The station itself is formed by a long linear desk, waist high, with space for two computers, with a taller section adjacent to the wall, protected from view on the corridor. The station desk itself appears very much as a formal 'front' with computers and files lined up. I felt as if the desk element represented an invisible boundary, indicating a sense of clinical authority, that it is very much a place of 'work' and that those there should not be disturbed. This contrasted with the front desk in the reception, which despite having a similar taller section, was visible and more open.

I saw across each of my sessions in the C&V hospice, the variety of functions that the hospice building must accommodate day-to-day, almost as if it were stretching at its seams to provide space for all the different types of interactions and groups of inhabitants. Knowing from my previous interviews that the main corridor within the ward was a critical area of activity - I witnessed just how this circulation route expanded beyond itself to act as a multi-functional space that extends the boundaries of patient bedrooms and the nurse's station and associated storage rooms, see Fig.5-20. In each session as I sat tucked away from the corridor, I observed this route being used as not only circulation, but a meeting place, a social hub, storage facility.

On each observation visit there were various pieces of medical equipment and cleaning equipment 'parked' in the spare space where the bedrooms could not accommodate them. As the adjacent space to the patient bedrooms, the corridor additionally doubled as a servery, the food trolley needing to be plugged in to maintain its heat, was constrained to the available plug sockets, leading to several collisions at the threshold of a double door and the difficulties in accessing the rooms behind - see Fig.5-19. Occasionally visitor phone calls or conversations between the staff and visitors would spill out onto the hallway or gather around a doorway, seeking the protection of the threshold – but at the same time causing obstructions to the corridor's main function. Outside the boundary of the ward of the ground floor, during one observation, I noted that there was a certain recess, see Fig.5-20, where the doorways to a set of offices had created a natural stopping point, whether for conversations or as a place to stop. I was not sure if this was intentional, but its generosity for informal breakaways gave breathing space to the circulation.



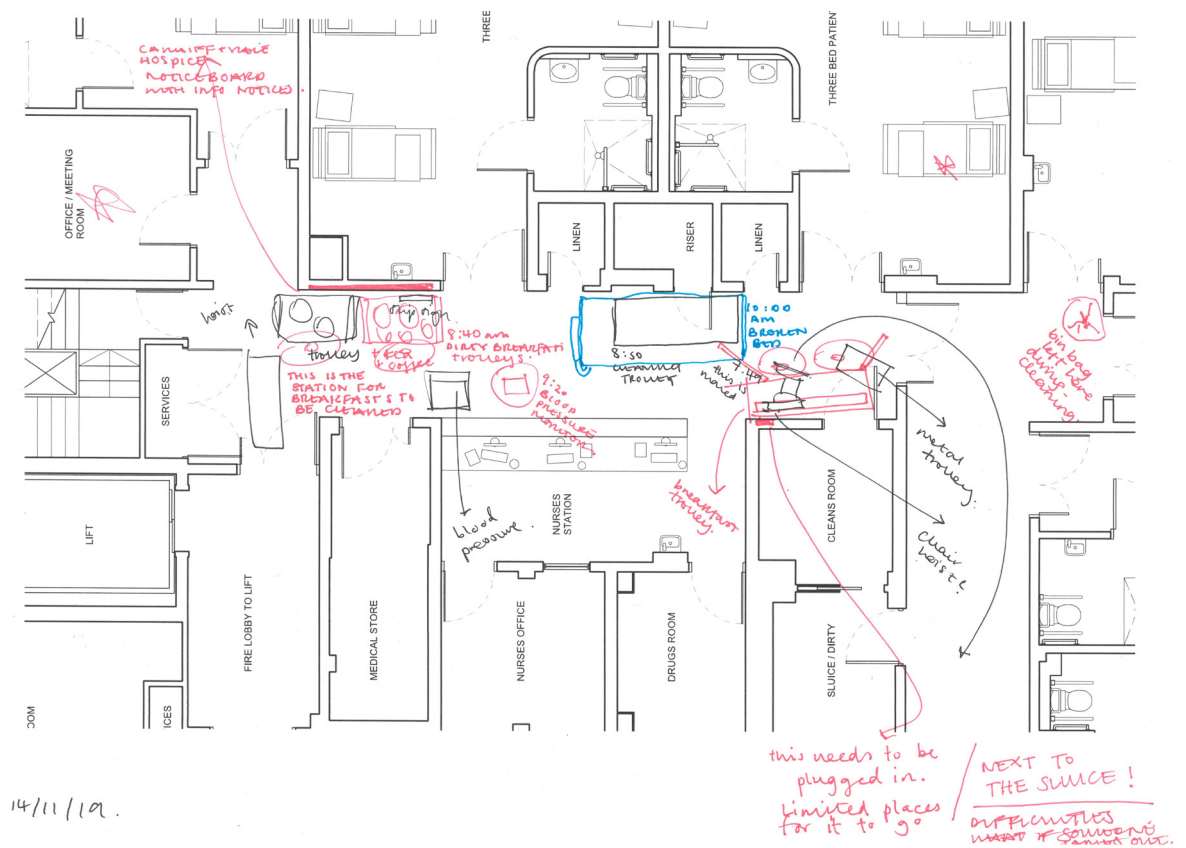


Fig. 5-19. Sketch observations, the corridor

Field note sketches from observation of the ward environment. The sketch demonstrates the clustering of activities that takes place in and around the main corridor adjacent to the nurse's station, and the patient bedrooms. There is often an overlapping of equipment that impacts on the functional use of rooms around this area, for example the linen cupboards adjacent to the sluice that often had cleaning trolleys and the servery trolley parked in front of them.

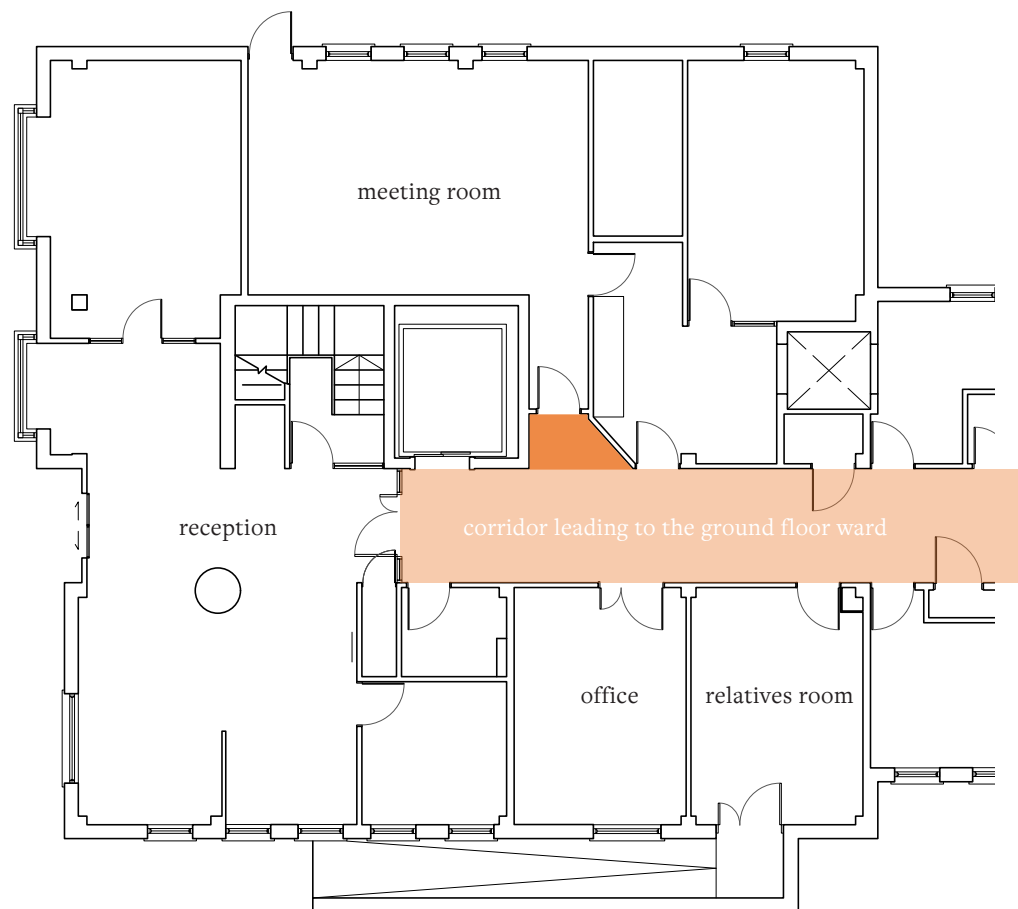


Fig. 5–20. Appropriated spaces

The main corridor from the reception, accessed through a fob-controlled door, leads to the ground floor ward. Highlighted in dark orange is a small recess that leads to a meeting room, this was observed in use as an informal 'meeting' place for those passing, or as a quiet space away from the hustle and bustle of the ward further to the right.

I noted on a few occasions of observation the way in which the hospice building was physically engaged with – in particular, the linen cupboard on the main corridor opposite the nurse's station. These cupboards stored the clean linen, and had narrow doors, that looked heavy and appeared to be on fire closers.<sup>410</sup> These were high-intensity areas, used multiple times during each observation session, each time with difficulty as the member of staff used their own body weight to prop open the door to quickly grab what was needed from inside. I could see clearly how the building here acts as an obstacle in way of their needs and requirements rather than offering easement. Engaging with the physical building itself is not the only way I observed obstacles – sat next to the nurse's station I spent several sessions puzzled by the numbering on the walls that indicated the number of the patient bedroom. Marked by decorative glass signs – these never matched the number spoken – eventually it became clear that these didn't align, see Fig.5-21. This highlighted a division between the workplace and the care environment, a feeling of 'us' and 'them'.

Reflecting on my time, from my memories of the atmosphere and my notes rapidly jotted down on how the building is used, there was a clear contrast between the front and back of house. But where really was the back? Geographically, it was the wards, protected from the more obviously public reception - though the wards were often used as a shortcut down to the day therapy unit. Yet this back was not the place where the staff could retreat to, as the connotation refers – this was the front line of care. Time spent in the café on the basement floor, re-enforced feelings described in the previous interviews with Rachel and Steph of blurred boundaries between staff and visitors. The observation sessions, despite being in a completely different hospice building to my own experience, were oddly similar. The sensory landscapes were both overwhelming and encompassed similar clinical features, institutional lighting, distracting and constant sounds and smells that remind you of the physical nature of care. A visit to a hospice in Denmark in contrast did not have any of these sensory qualities. To what extent is this then a cultural problem, that there may be a certain disregard for air quality and good ventilation? The impact of COVID-19 highlighted the lack of cultural awareness of ventilation to buildings, for not only stopping the spread of airborne pathogens but contributing to the turnover of fresh air for well-being. I wonder how much of this, now, is to be an expected by-product of the growing clinical needs of those in in-patient care? But targeted and intentional architectural design could go a long way, not to eradicating this, but lessening its impact on not only patients but the staff who inhabit the hospice building day in day out.

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<sup>410</sup> A mechanism often attached to doors to mechanically close doors after they have been opened, thus ensuring that the door's fire safety rating is upheld.

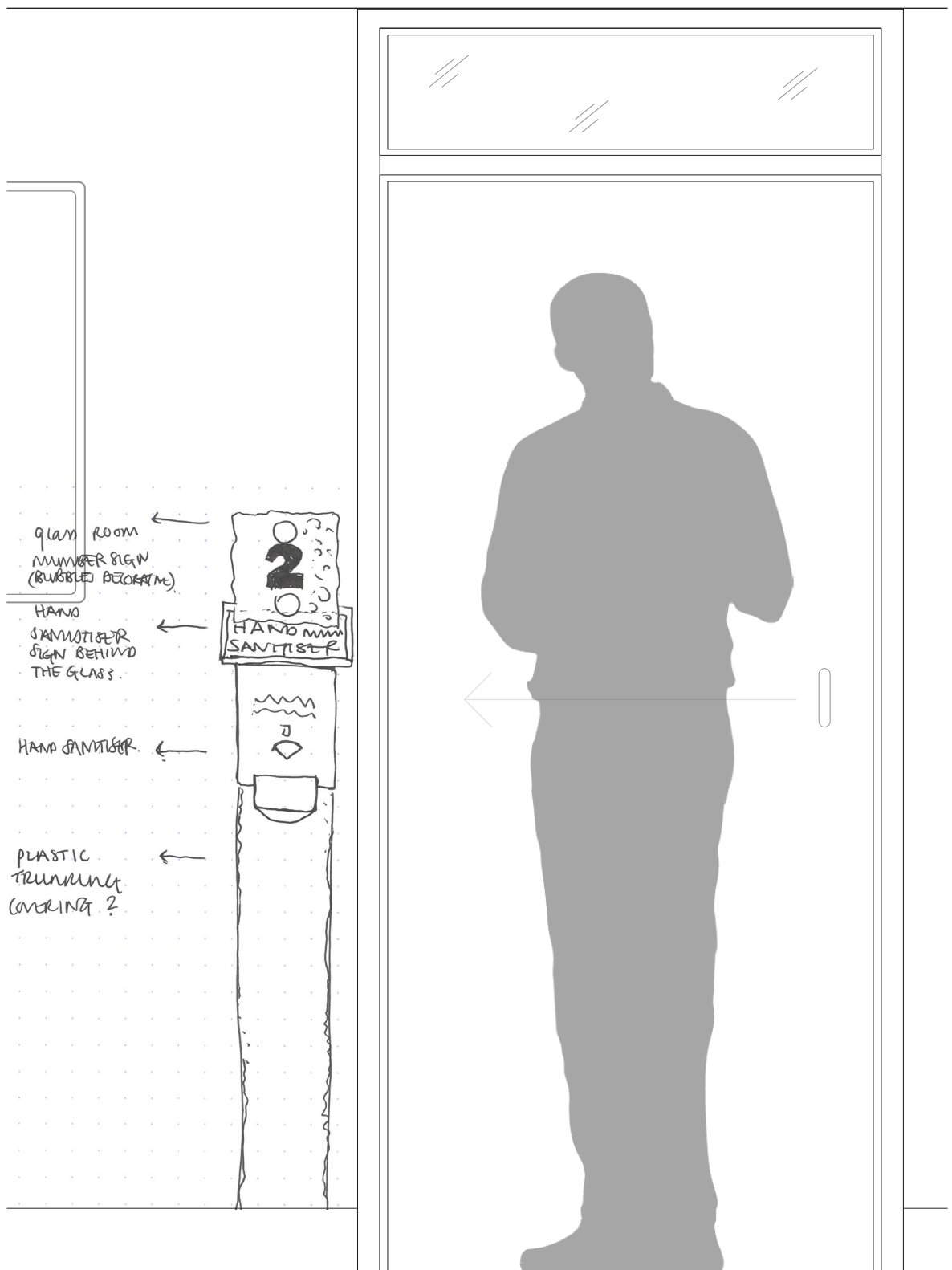


Fig. 5-21. Inhabitation of walls

A sketch drawn during the Building Observation of the decorative glass room numbers - not just the sign itself but the layers of other paraphernalia, such as the sign for the hand sanitiser, the hand sanitiser itself, and the plastic trunking on the wall underneath. Though the room number is visible on the glass panel, there is no other room number on the sliding door itself, leading to further confusion.

## Chapter reflections

This chapter has explored the hospice building via research encounters with various individuals who inhabit the C&V hospice as a place of work. The in-depth interviews revealed several critical findings regarding how the building is engaged with across a range of staff members whose non-clinical voices in the architectural consideration of the hospice as a workplace may often be overlooked. Interpreting the way in which the different research participants could be conceptualised as embedded versus the physical time spent in the hospice environment, we may begin to understand the everyday expertise of the hospice staff in contrast to the assumed clinical authority. For example, looking at Fig.5-23, and in combination with the data collected we might consider that, Fergus, a senior clinical consultant, spends relatively little time in the hospice environment and is solely focused on patient care. Thus, in comparison to Kelly, Mike, Rob, and Steph from housekeeping, maintenance and the nursing teams who inhabit the building every day, his perception of the environment is skewed in contrast to his experience of working in the local acute hospital and relatively short stints inhabiting the building more as an expert visitor. The experiences highlighted by the interviews with the housekeeping, maintenance, and nursing teams, supported by the building observation demonstrates a demanding physical engagement within which the members of staff must operate. For example, Kelly's manoeuvrings around the sluice, Rachel, and Steph's description of moving patients against walls, HCA's using their own body weight to prop open a door all highlight the notion of being physically squeezed within the constraints of the building. This physical bodily engagement with the hospice building demonstrates a radically different mode of the hospice building, in creating obstacles to the roles and responsibilities of all staff. Reflecting on the interviews and the above, there is the emerging distinction of upstairs downstairs.<sup>411</sup> A dichotomy between those whose work serves to maintain and upkeep the fabric of the building itself in support of its broader function – and those whose work focuses on the function of in-patient care.

Stereotypical assumptions about the roles of housekeeping and maintenance may dismiss these as purely supportive – yet it was clear from interviews, with Mike in particular, that their closeness with the case study setting allowed opportunities to affect small, focused interventions of care. This emphasises the necessity to recognise atypical providers of care, and the broad nature of which

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<sup>411</sup> This references the popular 1970's British drama television show that documented the lives of the servants who lived 'downstairs' and the wealthy family who lived 'upstairs' – and has subsequently become a colloquialism that represents the divide between those who serve and maintain domestic environments and those who enjoy them.

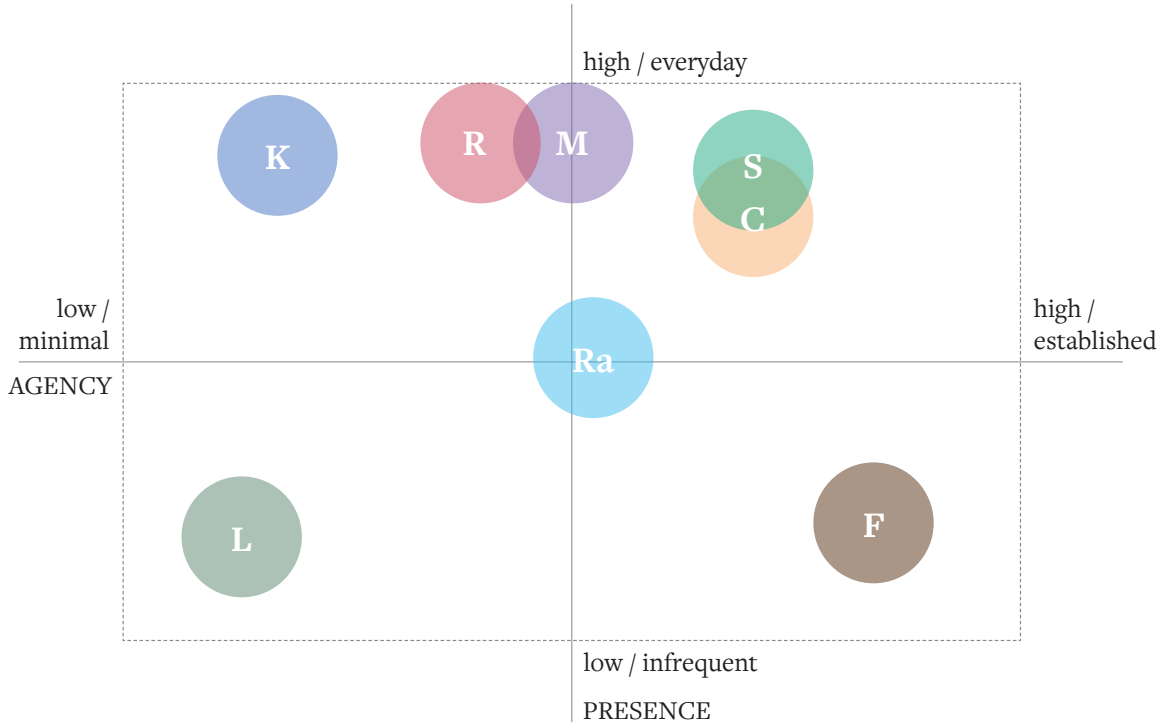


Fig. 5–22. The collated engagement with the hospice building

The diagram above collates all the placing of the interview participants within a framework looking at their relative agency against time spent in the hospice environment. There is a clear clustering to the top right, indicating those who have close knowledge of the hospice building but with varying degrees of agency. Fergus is an outlier, with contrastingly little day to day presence but with perceived high agency perhaps due to their senior clinical status.

care can be given or developed other than overtly clinical forms or practices. Davis, in summarising Denis and Pontille advocates that maintenance can be seen as a form of care in and of itself, as 'maintenance is attuned to the fragilities of materiality but also because, in directly engaging with them, it seeks to stabilise and strengthen, to make good and continue.'<sup>412</sup> It is commonly described that hospice buildings should care for their inhabitants, and this may typically refer to the practices of end of life or respite care taking place within the explicitly clinical areas. The interviews with the downstairs voices, however, highlights hidden expertise, such as care of the building fabric or environments of dwelling which offer meaningful opportunities for co-production that could contribute to the development of hospice environments that challenge the clinical atmospheres.

The interviews especially presented the varying degrees of agency that different members of staff hold with regards to design and change within the hospice building. A common theme of the interviews was the perception that senior clinical voices are dominant within the decision making of the environment, despite a relative lack of presence in contrast to other members of staff who inhabit the building more closely. The interview with Colleen, the facilities manager, additionally highlighted the tensions of perceived and actual agency. There may be opportunities to affect change, but these are constrained by higher levels of authority. Steph's intervention of re-naming and re-purposing the Ward Sister's office on the wards to the cwtch demonstrates a restricted form of agency, that is not physical, but conceptual and linguistic, to change behaviours where the fabric of the building cannot accommodate further space. Many of these obstacles are a result of the constraints of the existing building – however, Rachel and Steph's interview presented an example of where architectural design introduced new obstacles - that is the storage of gloves and pinnies (aprons) being placed away and hidden to reduce the clinical appearance of the patient bedroom. Despite only having the narrative of Rachel and Steph with regards to this, it emphasises the critical expertise of the members of staff and role that architectural design and planning can influence, and or disrupt their experience. We may consider that perhaps drawn on a two-dimensional plan drawing it could be easy to tinker and move singular elements or let the notion of home-like drive decision-making, lacking the reality of how care is delivered.

It is acknowledged that the critical constraints to the experience of space at the C&V hospice is dictated by the existing building fabric, and what is reasonable to achieve given the financial restrictions of the hospice as a charitable entity. The physical capability to affect change is

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<sup>412</sup> Juliet Davis, 'Social Housing Maintenance and the Ethics of Care', in Festival of Maintenance (Liverpool, 2019)



therefore limited to smaller scale interventions; and this serves to highlight the changing nature of hospice care nationally and the growing balance of patient care versus the need for administrative space that supports the other types of palliative care services that are based outside the hospice. The extent to which the staff can be observed to be empowered, defined by Schneider and others as being able to take control of their environment and 'being participative without being opportunistic'<sup>413</sup> is in tension with financial constraints and traditional structures of hierarchy in care. A key reflection from this chapter is design as a reactive rather than proactive process and the prevalence of tinkering – of which will be discussed in depth in the following chapter.

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413 Tatjana Schneider and others, Spatial Agency: How? (n.d) <<https://www.spatialagency.net/database/how/>> [accessed 5th May]

# Practice Note 3

## Precedents and publicity

This third practice note returns to a first person narrative to discuss the researcher's experience of a visit to a hospice building lauded as an exemplar by the architectural media. Offering the opportunity to witness the phenomenological environment in-person, the act of visiting the building highlights that the images we see in the press are not the building, but rather it is made up of the objects and spaces within that we can only truly understand by critically engaging with the users.

This practice note marks a return to a first-person narrative - much like the walking tours and building observation – and includes elements of personal subjective commentary owing to the nature of the activity.

During the first year of my doctoral research, I was on holiday in Copenhagen with my partner and organised a visit to the Urban Hospice by NORD Architects, an in-patient hospice that has garnered critical acclaim by the architectural profession. (For further discussion refer to Chapter 3.) Having seen the architectural press venerate the design of the Urban Hospice with its eye-catching golden bronze-zinc alloy cladding I was excited to experience the place itself. From my personal experience as an architectural student, designer, and educator I am aware of the insight of ‘being’ in a place. The desktop study, as a form of analysis, is typically undertaken via laptop and phone screens and encourages the privileging of visual material over critical understanding of spatial arrangements, materiality, form, and volume. Furthermore, it silences the experience of the phenomenological and sensory environment, such as light, shadow, temperature, sounds and smells. If desktop studies of works of architecture are not employed with rigour, they risk being compromised by personal taste and experience.

On the first morning in Copenhagen, making my way to the hospice, I turned off a busy main road full of cars, trams, and bikes to a wide peaceful tree-lined suburban street. Approaching its location, I had assumed that the hospice I had seen in the press, so golden and bright, would be more conspicuous. Years of weathering, however had patinated and muted the original reflective shine of the cladding to a shade of deep mossy green. The effect of this ageing made the hospice appear as it had always been on the street. A lack of signage and car parking to the front of the building felt distinctly un-institutional. We pushed open the heavy timber doors to the reception area, where we were greeted with coffee and biscuits in the main communal space whilst we waited for my contact, Peter, to arrive.

Warming from the cold outside, we took in the atmosphere of the hospice, interrupted only by a music therapist arriving and sitting down to play the piano nearby. There wasn’t anything obvious in the main communal space that would signal this was a hospice building, full of beautiful furniture and noticeably non-clinical materials. This was a stark contrast to the other hospices I had visited in the UK, with use of infection control approved materials and fluorescent lighting being so prevalent in the UK. The Urban Hospice inside is white, a common signifier of clinical spaces but nothing else gives away the buildings true function.

1 of 1000  
top global  
websites  
&  
360,000  
daily users<sup>3</sup>

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site visits to dezeen  
53,500,000, 2017<sup>1</sup>  
61,000,000, 2020<sup>2</sup>



A note on process, method & ethics:

This activity employs several common exercises and methods within architectural education and practice - the precedent study and the fieldtrip. Learning from the work of others, which can be categorised by many different elements, form, function, location etc, is a 'a proven method of acquiring knowledge and insight'.<sup>[6]</sup> Desktop studies can generate a degree of knowledge regarding buildings through the in-depth study of architectural drawings, but done without meaningful critique may risk becoming a simple 'scrap-booking' of aesthetics that dulls the lived experience of the building. This mode of precedent study has been amplified by the nature of the architectural press and resources, such as Dezeen, ArchDaily and Pinterest presenting easily accessible visual material with little regard for understanding context.

The information on the following pages has been collated from various fieldnotes taken on the day of the visit and (subjective) memories of the spaces. Touring the building with Peter, the contact at the hospice, I was able to take written notes capturing important pieces of information and keywords, in addition to photographs. The shorthand notes from the tour of the hospice building were compiled sitting in the communal area once finished, taking

time to reflect on the experience and documenting more detailed observations, thoughts, and analysis of the experience. All data collected from the visit was then re-visited during the writing of the thesis, further reflecting, and analysing the experience to uncover relevant findings.

Whilst it was not proposed that I would be interviewing or interacting with staff, other than the contact Peter, or patients or visitors, the visit to the Urban Hospice - in comparison to other hospices in the UK visited as part of this doctoral study - occurred with virtual ease. In organising the visit to the hospice, which was arranged via my institutional email, there was no requirement for ethical approval or background check. Furthermore, there was complete freedom of photography in and around the hospice, excluding obvious areas where there were patients or members of staff. We might consider this openness as being a result of several reasons, firstly the open cultural attitude toward death and dying of the Danish society, and secondly that the architectural attention that the Urban Hospice has received means they are willing to exhibit the building as an exemplar for the hospice typology.



The courtyard garden is an unexpected oasis. Being in the urban centre of Copenhagen the hospice has no idyllic scenery to take advantage of. Somehow it feels like it gets the best of both worlds, protected outside space, the rustle of trees and plants against the backdrop of a faint city soundscape. I feel calm yet connected to the place.



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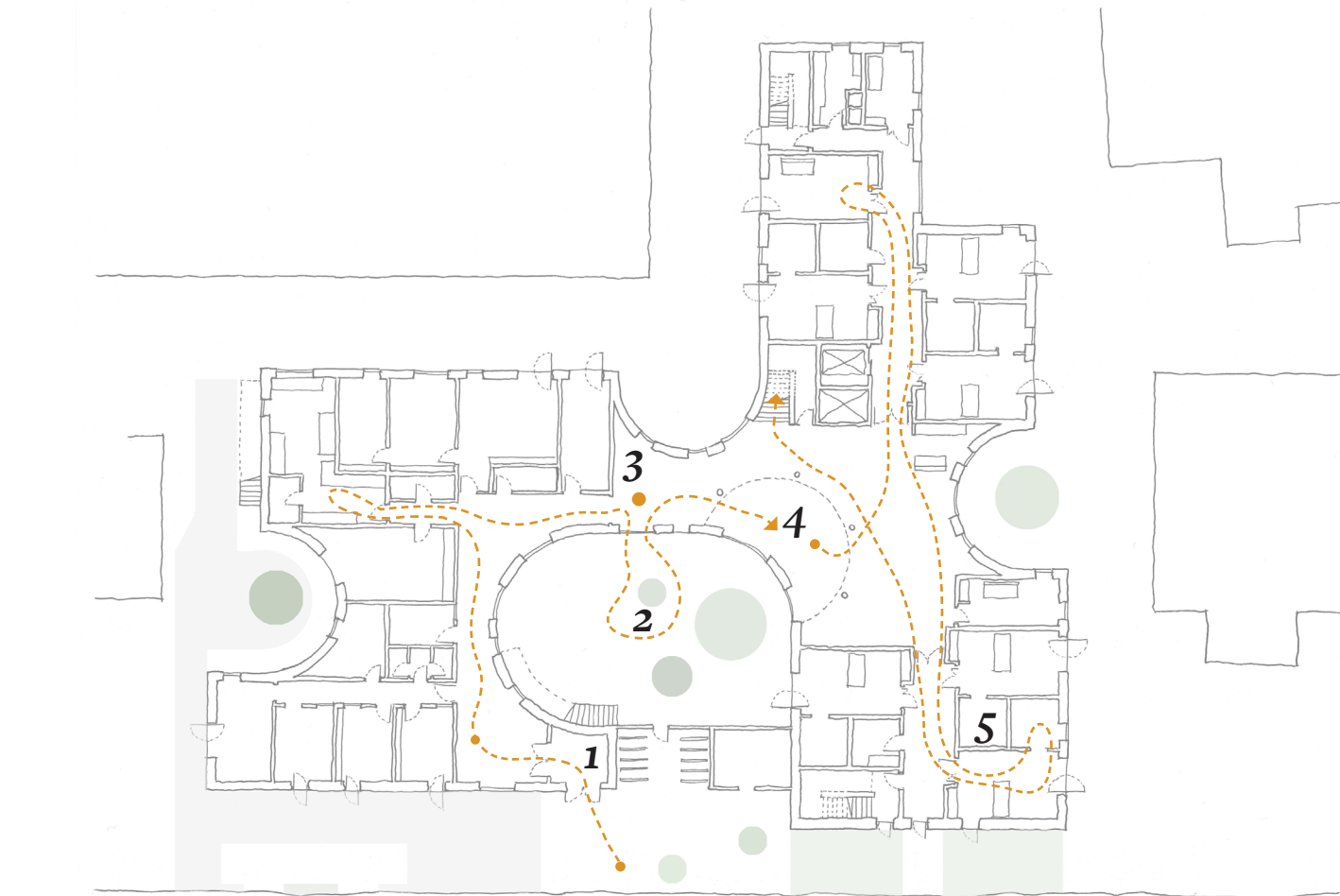
“many people choose to die out here, even I would like to die here”<sup>5</sup>

Peter spoke passionately about the metaphorical journey that everyone goes through in inhabiting this building, the passage from life to death, and made special reference to the front door. It's a powerful threshold for someone who is used to a culture that shies away from any exposure to death. I thought how uncomfortable I might have felt if someone there and then would have been taken out - but it hit me how undignified it was that I felt that disgust - and how this unified passageway was so much more dignified.

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### 3 Curiosity

“ Along the corridor, I was stopped by an inquisitive man holding a coffee, looking at me with an inquisitive smile. Dressed so casually I mistook him for a visitor, until it transpired during our conversation that he was in fact a Senior Consultant. He seemed to find it intriguing that I was here only for the building, but conceded that it was a lovely place. He explained that he thought all hospices in the UK must be like this and couldn't understand my interest in it. On his way to listen to the resident music therapist playing piano in the communal living room he told me how the building has come to be a place for everyone to use, staff lunches, birthday parties, therapy sessions... ”



### 4 The heart of it all



### 5 Generosity

Bathrooms aren't where I would think generosity comes into play; but seeing the bathrooms here I remember laughing to myself. It was bigger than my bedroom at home! And definitely bigger than any hospice bathroom I had seen. It made me reflect on space standards in the UK, so rigidly defined by minimums and yet here is an example of minimums that are met but with generosity of space so as to provide comfort and dignity for not only the patient but the staff and volunteers also.



“you come in through this door ... and this is how you leave”<sup>4</sup>



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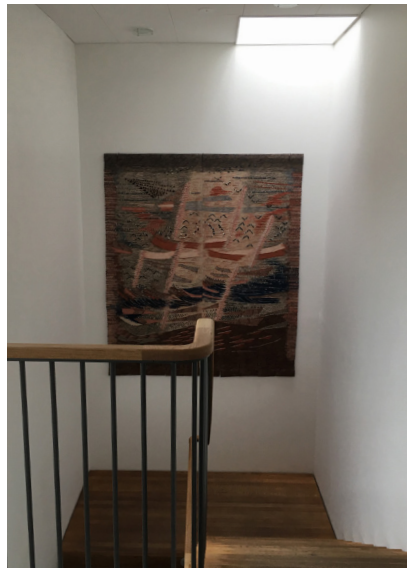




The once reflective golden cladding has weathered down to a muted and rich mossy green recording the age of the building.

## 2 Consequences

Peter noted that the cladding, a hard fought for element of the building, had unintended & unwanted consequences. He described that when they moved in the metal cladding severely restricted mobile phone and wi-fi coverage causing patients to feel isolated from their friends and family during non-visiting hours. They eventually installed boosters on the roof to a lot of expense.



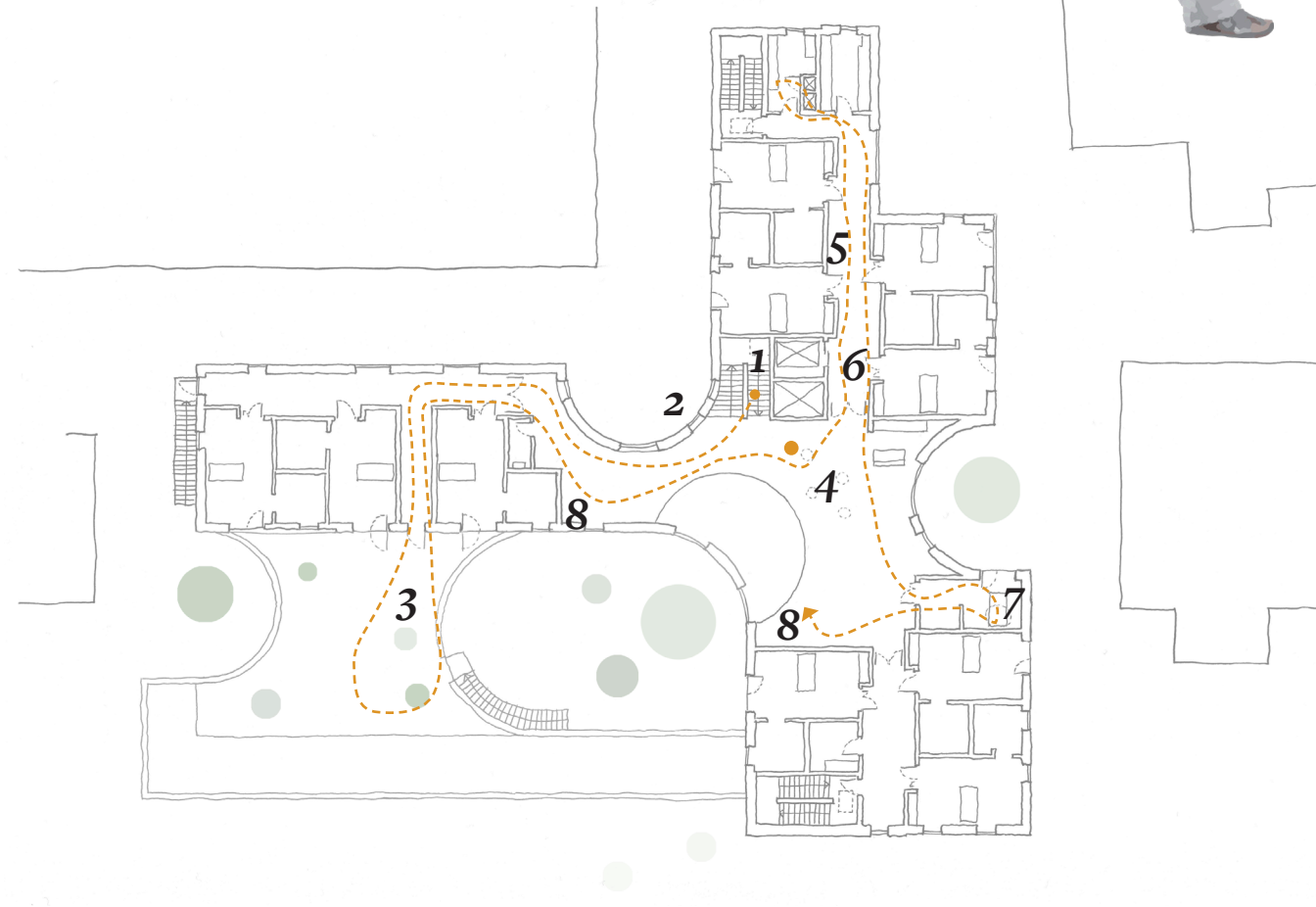
The more I experienced the hospice, the more quality and qualities of space felt overwhelming. The solid timber floor felt solid, none of that strange non-slip yet smooth veneer finish, door, soft curtains softly swaying from the open windows kept them free to be looked through. The subtle variations in light and shadow, all made me feel a closeness, a comfort of something familiar but not generic.

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Despite the open Danish attitude to death and dying, Peter explained that they recently put bamboo in front of the fence on the terrace as new neighbours opposite didn't feel comfortable seeing patients in their beds outside...

## 3 Fitting in



## 8 Variety



I spotted it out of the corner of my eyes everywhere we explored in the hospice, spaces for sitting, spaces for being, and there were none the same. There were private spaces tucked away behind screens of plants and spaces where the furniture itself created privacy - and there were plenty of places to also be communal, to share space with family or friends, spaces to be within the sphere of life in the hospice without being the focus and spaces to be in the heart of life! Choice, variety, options all made the building feel like you could fit in, not the other way round.

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“ I encounter a nurse carrying an armful of packages and medical paraphernalia . She seemed stand-offish and initially asked if I needed directions; but softened slightly when I mentioned the building. Peter had previously described the transition the staff made to a new normal and that despite the collaborative design process adapting to new processes and routines was always going to be difficult. This nurse however was brutally honest, and told me that the corridors are too long, there's only one medical room thats too far from the bedrooms and the sluices are also far away meaning they have to carry lots of dirty laundry in the corridors. She sounded weary, and I wondered if I had caught her on a bad day, but the honesty of day to day life ” was bracing.

## 4 Points of view

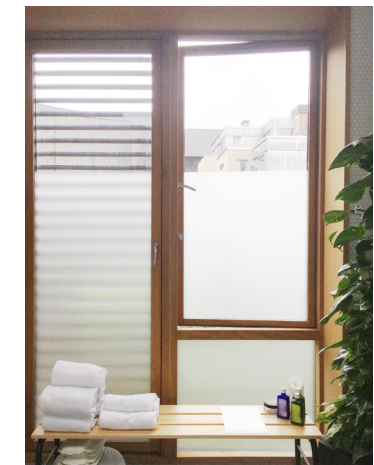
Walking past the bedrooms with Peter, he must have sensed my hesitation about the bedroom doors, solid and with no vision panel as I am so used to seeing in the UK. He described that the patient board who had been consulted during the design expressed a dislike for how vision panels made them feel watched over. This tied in with the hospices wish to do away with the aggressive flickering neon lights so often found in hospitals, instead choosing to introduce uplighters along circulation routes and outside bedrooms so that staff can navigate safely during all times of day and so that patients rooms are not flooded with artificial light when the doors are opened. Peter noted that this has contributed to more positive relationships between staff and patients that is built on trust and routine.



## 5 Comforts



## 7 Perspective



Peter spoke a lot about 'closeness' and sensation and tactility for those at the end of life and not just visually. The bathroom captured this for me, the room wasn't about a dominance of the visual, but the experience of light, the different lengths of gaze, the warmth of the sun coming from above...



## 6 Visitors (of all kinds)



The visit was a surprising one. On one hand, it was an extremely positive experience to be within the hospice that has been so praised by the architectural community for its response to, and handling of the end stages of life. Having seen so many two-dimensional images of the plans and the spaces, hearing the day-to-day sounds of the space, the materials used, brought the building quite literally to life. Elements of the plan that I had previously assumed were leftover spaces from the drawings, I could see had been inhabited with chairs and tables to create smaller intimate spaces. If constrained to a desktop study this would have been an element of the architectural space lost on those interested in building. Not visible on the plan therefore was the intent to provide a variety of spaces that could be inhabited in different ways between staff and service users as opportunities for living.

My expectations for the visiting the hospice were perhaps naïve, influenced by the glimmering press photographs that presented the hospice as the go-to exemplar of best practice for a contemporary in-patient hospice building. However, the visit offered much more than just the experience of the spaces from the photographs. The conversation before beginning the tour with Peter outlined the approach to death and dying of the Danish society and culture, and how this was reflected in certain aspects of the architecture itself, such as the single front entrance, used by everyone and for all purposes, including the ambulance service and funeral directors. The tour itself, of different provisions within the hospice building, again highlighted aspects hard to garner over a screen, the generosity of the patient bedroom and bathrooms layouts, the short and long-distance views available from the windows, and attention to natural materials throughout. Post-tour as Peter was called off on other business, I was given permission to explore more and take photographs of anything I had missed. It was during this short reconnaissance that perhaps the most important event of the visit occurred, that being two informal encounters with two clinical members of staff who willingly spoke about their thoughts and experiences of the building. One described the untapped potential of the communal space as being more than just a place for eating meals, but sharing patients, visitors, and staff events. The second, spoke about their opinion of the hospice as their new workplace and their frustration with the spatial layout of key clinical spaces in relation to the bedrooms, that being they were too far away from each other.

The unabridged truths from the two members of staff significantly shaped my visit to the hospice and how I was able to reflect on the buildings function. From the short snippets of lived experience I was able to learn much more about the building in use and its life than what is feasible from the curated images of the architectural media, and to some extent the guided tour by Peter. Hearing directly from the staff, how the environment impacts on their ability to care was transformative, not only for my holistic understanding of the hospice as a building typology but the potential impact and value of co-production on the environments of caregivers. The Urban Hospice has been lauded by the architectural media for its innovative approach, with primacy given to its aesthetic. Visiting the hospice in-person myself highlighted that missing from this coverage was the voice of those using the building every day, and a discussion on how pragmatically the building works from the perspective of caregiving best practice.

Like hearing that UK hospice providers visit other hospices to learn about best practice in healthcare - the experience of visiting the Urban Hospice stressed the importance of this practice also for architects and designers. Architecture and design is inherently a subjective field; and finds influence from a wide variety of factors - personal taste, social background, political understanding, cultural values, amongst many others. To make sense of and learn from the design decisions and strategies we have a responsibility toward our clients and the end users of the buildings we design for to truly learn from precedent, to go beyond a simple



search picking the nicest images or referencing overused and generic projects without considering the true impact on the lived experience.

Pulling this information together additionally gave me an opportunity to reflect on the implications for my work but also the broader scope of this within architectural practice. I was fortunate to be able to visit the Urban Hospice on a personal holiday that tied in all the associated costs of travelling. However, there is little capacity in the standard RIBA Plan of Work for this type of scoping or research activity within the lifetime of a typical project; especially not one that would incur considerable additional costs without perceivable or tangible outputs by the clients. This type of activity is further compounded by the constraints presented by the COVID-19 pandemic. The experience of the visit that I had was only made possible by the informal encounters and the willingness of the hospice to show me round with such freedom. The pandemic has effectively reduced visitation to healthcare facilities to only emergency or essential reasons - meaning that in-person visits for research such as this would be unlikely to take place. Though this is part of a broader discussion around the facilitation of in-person research as the pandemic comes under control it highlights the difficulties faced by practitioners in accessing precedents in more depth than desktop methods.

As the physical world shut down due to lockdown restrictions and social distancing, we may consider a positive from the COVID-19 pandemic as the emergence of online accessibility, location was no longer a barrier to meeting others and has forged new networks of sharing and learning. Perhaps we are not able to visit places in person, but the nature in which collaboration can happen has shifted and could allow for more systematic and consistent platform of sharing.

## Endnotes

- 1 dezeen, "Unstoppable" Dezeen Had Its Best-Ever Year in 2017 with 53 Million Visits (2018) <"Unstoppable" Dezeen had its best-ever year in 2017 with 53 million visits> [accessed 20th February]
- 2 dezeen, Record Traffic and Six Awards Helped Make 2020 Dezeen's Best-Ever Year (2021) <<https://www.dezeen.com/2021/01/05/record-traffic-2020-dezeen-best-year/>> [accessed 19th February]
- 3 ArchDaily, Archdaily, One of the 1,000 Most Visited Websites on the Internet (2020) <<https://www.archdaily.com/tag/internet>> [accessed 20th February]
- 4 Jesper Grud Rasmussen, Interview with Annie Bellamy, (Copenhagen, 12 September 2018)
- 5 Ibid.
- 6 Jack Breen, '11 Designerly Enquiry', in Ways to Study: Design Research and Typology (OpenCourseWare: TU Delft, 2020) pg.96

# 6

## Hospice as a designed environment

This chapter marks a shift into a designerly reflection of the C&V hospice as an environment that is subject to spatial planning and design. Here we will present a summary of the historical changes that the building has seen and discuss in detail three recent design changes of varying scales spatially determined from small to medium to large. The scales have been defined by the researcher in relation to length of time required to complete and holistic impact on staff and patients. These interventions will be considered with regards to the role of architectural design but additionally the influence and role of staff members. Supplementing each of the interventions we considered the available and appropriate guidance regarding design and best practice.

## An 'archaeology' of the case study setting

Since it was built the case study setting has seen numerous changes to its built environment, visibly demonstrating the piecemeal and reactive development as described by various staff members in the previous chapter. Through the development history we can observe has been subject to incremental change, or tinkering. This being the act of making 'small changes to something, especially in an attempt to repair or improve it'<sup>414</sup> which Mol and others describe with regards to care practices as 'all things are (and have to be) tinkered with persistently'.<sup>415</sup> The steady stream of refurbishment and renovation projects were driven by needs to improve the functionality of the hospice building to ensure it can match changing medical standards and models of care. We know from the previous chapter that members of staff have had a bearing on the design of the hospice building in an informal manner, through small interventions that will be discussed later.

This data has been collected as part of a desktop study using information shared by architects direct to the researcher, public information and via publicly accessible information from the Planning Register of the local authority Department of Planning and Building Control, see Fig.6-1. It must be noted, however, that for multiple reasons the following is not an exhaustive history of all the changes made to the C&V hospice. Firstly, the online platform, the Planning Portal was only established in 2002, with online applications available from 2003, with anything prior made via a paper format. A concerted effort was made to digitise previous applications, however not all were successfully transferred to the online system with many applications listed lacking the original application documents. Secondly, the grounds for which planning applications are required typically cover changes made that affect the external character of the building, therefore precluding small changes made to internal layouts. As evidenced in the interviews in the previous chapter the hospice building has seen many small scale and informal changes to the use of space that have not been officially drawn, though may be recorded in other forms, such as invoices or accounts. Furthermore, when the researcher was provided with the current plans of the case study setting by a member of hospice staff it was found during the fieldwork that these were out of date, with numerous changes that were not recorded on the drawings referring to spaces that no longer existed. Additionally owing to the relative age of the hospice there are several historical planning

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414 Cambridge University Press, *Tinkering* (Cambridge: Cambridge University Press, 2021) <<https://dictionary.cambridge.org/dictionary/english/tinker?q=tinkering>> [accessed 25th August]

415 n.a, *Care in Practice: On Tinking in Clinics, Homes and Farms* (Columbia University Press, N.D) <<http://cup.columbia.edu/book/care-in-practice/9783837614473>> [accessed 25th August]

Year	Type	Proposal
2017	FUL	Re-positioning of 4 no. condenser units and the installation of 4 no. additional condenser units
2017	TCA	Fell silver birch within the [REDACTED] conservation area
2016	TCA	Remove cherry tree and crown lift atlas blue cedar tree
2016	TCA	Remove eucalyptus
2012	FUL	New proposed glazing to ground floor balcony to form internal space & proposed first floor glazing with extension to roof
2003	FUL	Construction of first floor extension - building over existing single storey dining room/kitchen block to provide overnight rooms for patients family members. (plus internal alterations to ground floor rooms.)
2000	FUL	Replanning of part of workshop lower basement area to form office for education department
1999	FUL	Retrospective application to resite compressor, proposal to increase height of existing laundry trolley store by 700mm
1995	TCA	To remove row of cupressus leylandii along southern boundary
1995	FUL	1) Extension onto day room balconies (2 floors) for patients' smoking areas; 2) extension onto dining room roof for meeting room and office
1991	FUL	Extension of existing approval to include 3 toilets on lower basement level, laundry store externally at basement level
1985	FUL	Conversion of existing nursing home to provide six flats
1982	LBC	Demolition (of Courtlands)
1982	FUL	38 bed hospice and day centre with ancillary accommodation

*Key to planning application types*

*FUL Full Planning Application*

*TCA Notification of proposed works to trees in conservation areas*

*LBC Listed Building Consent*

Fig. 6-1. Timeline of planning applications at the case study setting

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Fig.6-2. Original drawings of

the case study setting

These drawings were used to supplement a subsequent planning application made by another architect.

applications that were drafted by hand, therefore there may be a level of detail that was lost during the digitisation that contributed to a loss of detailed understanding of the building fabric. As such the researcher has made best efforts to uncover as much information as possible regarding the changes made but there may be elements that are missed or not available.

Six years after the hospice building opened, the first planning application was lodged in 1991 for the 'extension of existing approval to include 3 toilets on lower basement level, laundry store externally at basement level'.<sup>416</sup> A relatively minor change, this filled a recess to the garden level façade to provide additional space for further sanitary provision. No application history exists for this, but we can see that this was lodged on behalf of the case study setting by agent David Hanson Associates of Bristol, a now defunct architectural practice offering estate and management services. The first major change to the building fabric occurred in 1995 when the same agent applied for permission to partially infill the balconies to the ground and first floor day rooms with glazed smoking shelters for use by patients and staff, and to build a first-floor extension over what was then the dining room to provide further office and meeting space.<sup>417</sup> Only the infill to the balconies were constructed, see Fig.6-3, as noted in a letter from David Hanson Associates to the planning officer, the case study setting at the time could not afford to do both. The addition of a protected smoking area adjacent to the communal day room would have made a considerable difference to the experience of the building. This is the first example that indicates the hospice responding to the changing cultural needs of the users at the time and the constraints of operating within limited financial means.

Following this, in 2000, BHP Harwood Architects applied for permission to reconfigure the workshop area used as the hub for the maintenance team, located on the lower ground floor to create an additional office. This work was relatively minor but owing to its impact on the elevation and the hospices location in a Conservation Area required the formality of planning approval. From the plans available, see Fig.6-4, we can observe that this marked perhaps the first change made to the design of the hospice environment to combine divisions in space and consolidate the office spaces available as the role of the hospice grew. Shortly after this, another planning application was made by Gerald Latter Associates to construct a first-floor extension over the dining room area to provide overnight facilities for visitors and to reconfigure internal layouts on the ground floor,

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[REDACTED]

417

[REDACTED]

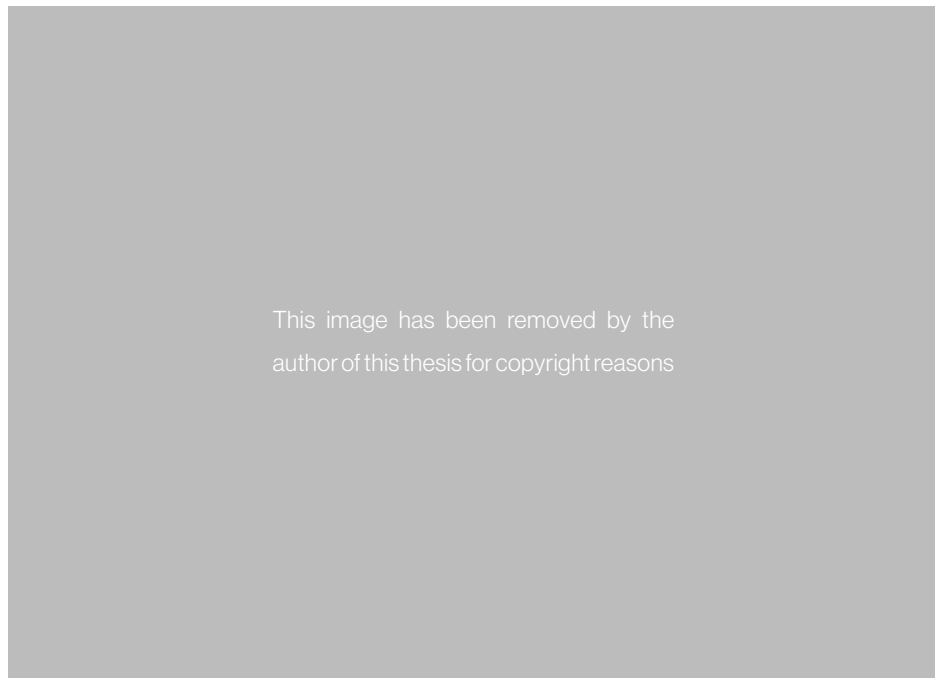


Fig. 6-3. The balcony infills

The orange dotted line indicates the infill to the balconies that prior wrapped around the dayrooms of the ground and first floor.

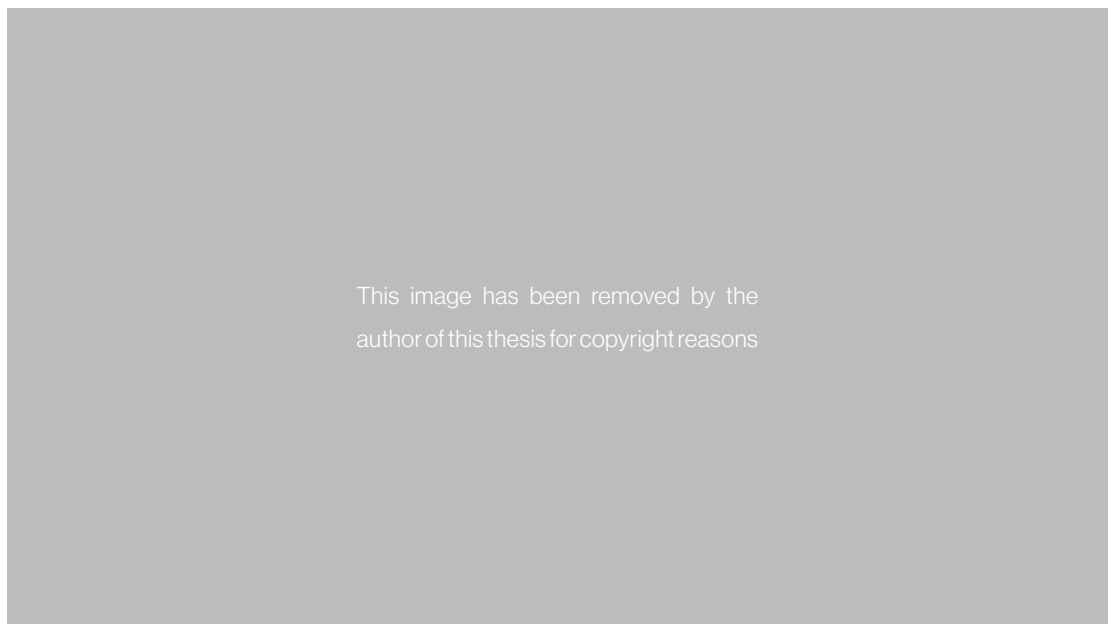


Fig. 6-4. Sub-division of space

The image on the left indicates the workshop area with associated toilet versus the amended layout that has removed the toilet area and sub-divided the space into additional offices.





Fig. 6-5. Reconfiguration of the ground floor wing

As part of the planning application for the first floor extension, the reconfiguration of the ground floor. Highlighted in orange, on the top image are the spaces that were previously designated for the staff, the image below shows how this space was eroded to make way for other office spaces.

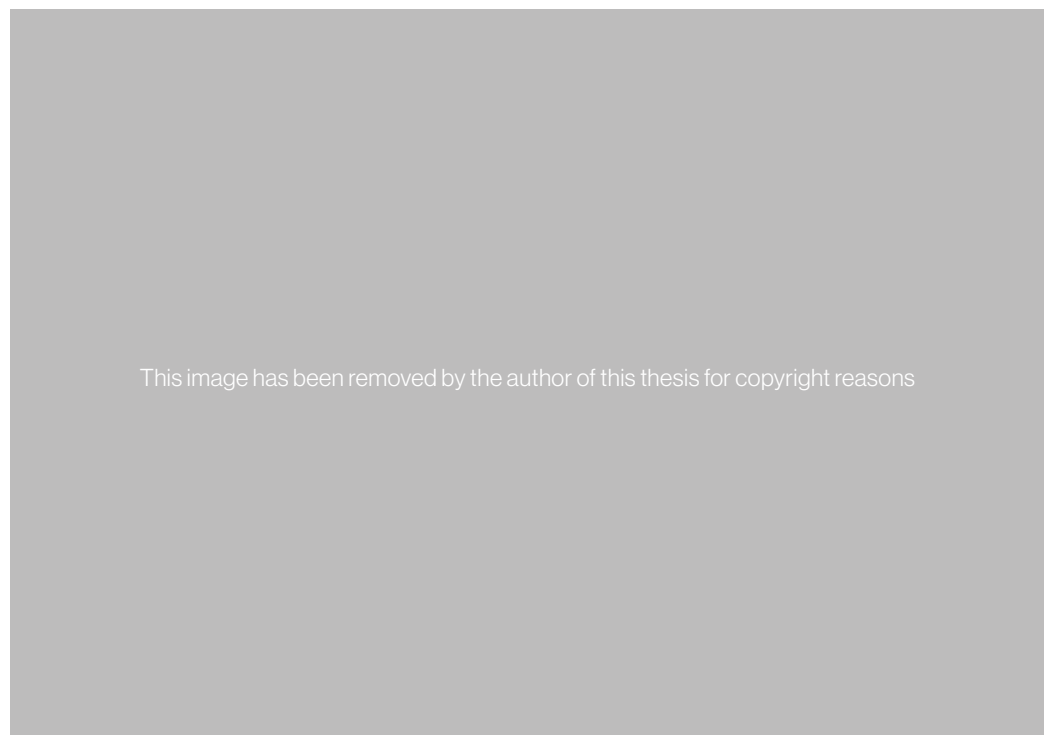
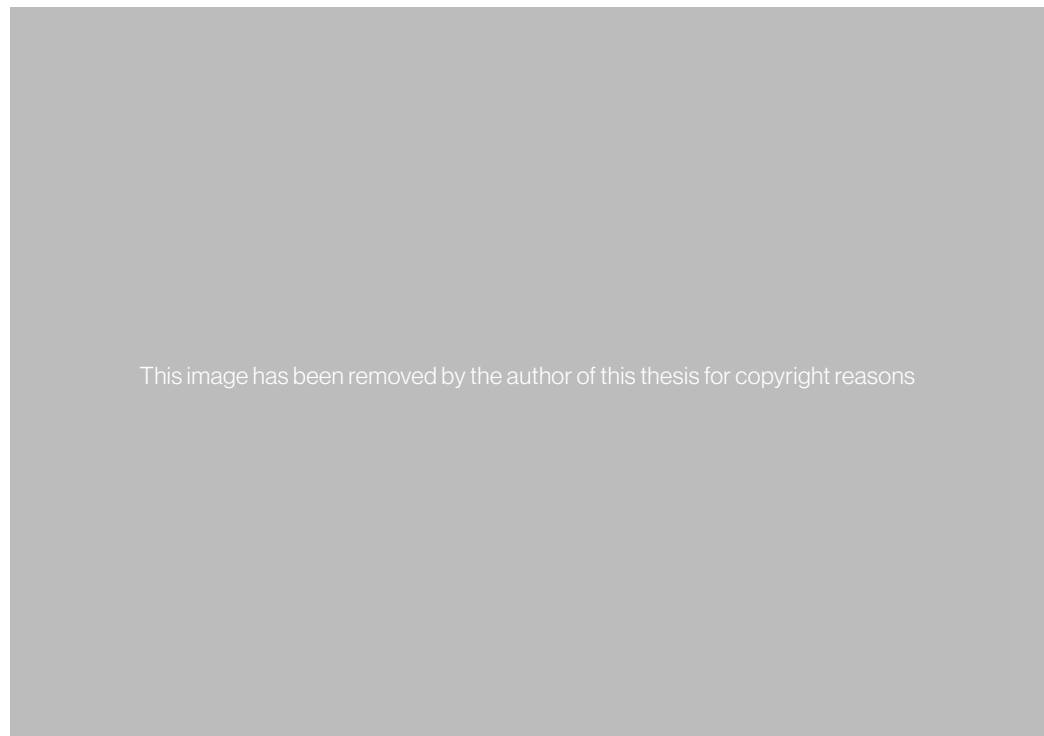


Fig. 6-6. The family area

This drawing, submitted in conjunction with Fig.6-5, the image on top shows the existing single storey wing and the image below describes the new addition of family and visitors spaces, which include bedrooms, a lounge and bathrooms. The dotted line indicates the previous building envelope line.

see Fig.6-5 & 6. With the same aspirations as the project that had been granted permission eight years prior, this required a new and separate planning application as permission typically only lasts for five years in Wales, dependant on conditions. This project was facilitated by a grant from the National Lottery Fund following the lack of funding that caused the project to be put on hold prior, thus demonstrating inconsistency and delay between needs being identified and the feasibility of construction. This project reveals a particularly important moment in the design history of the C&V hospice. Not only did it significantly increase the visual presence of the building with regards to size and height; it also provided new space for functions within the hospice building that it had not been able to accommodate before, a suite of rooms to primarily serve visitors. However, the rooms are no longer used for their original purpose but are instead now offices, as it was observed that visitors did not feel comfortable using them due to the physical distance separating the rooms from the patient bedrooms. Speaking about this project, a key member of staff used this as an example of the unintended consequences of design changes – of how changes will be received and utilised in the day-to-day experience of the hospice. We cannot speculate on whether feedback on the proposals were sought from stakeholders during the design process – but this does emphasise the delicate balance and potential disparities between architectural drawings and the building in use. It is also worth noting that the second item from this application, re-configuration of the ground floor area demonstrates an erosion of dedicated staff space, dividing part of the staff dining area off to become an additional office space.

The next major modification to the building was an application to subsume the balconies to the ground floor and first floor day rooms, thus converting them from exterior to interior spaces. As the C&V hospice is part of a wider national end of life care charity, this was made via an application made directly by a member of staff, a chartered surveyor, based in the central headquarters of the charity. The approved design was delivered a year later as part of a wider refurbishment to the internal layout of the hospice, including the renovation of the day rooms into four bed bays, the creation of new en-suites to patient bedrooms, a new accessible bathroom and various other room changes. This renovation project saw collaboration with an architectural practice, JDDK, recognised as having a specialisation in the design of in-patient hospices who produced the information necessary for the works. Described by the architects as: 'a 'fast-track project the brief

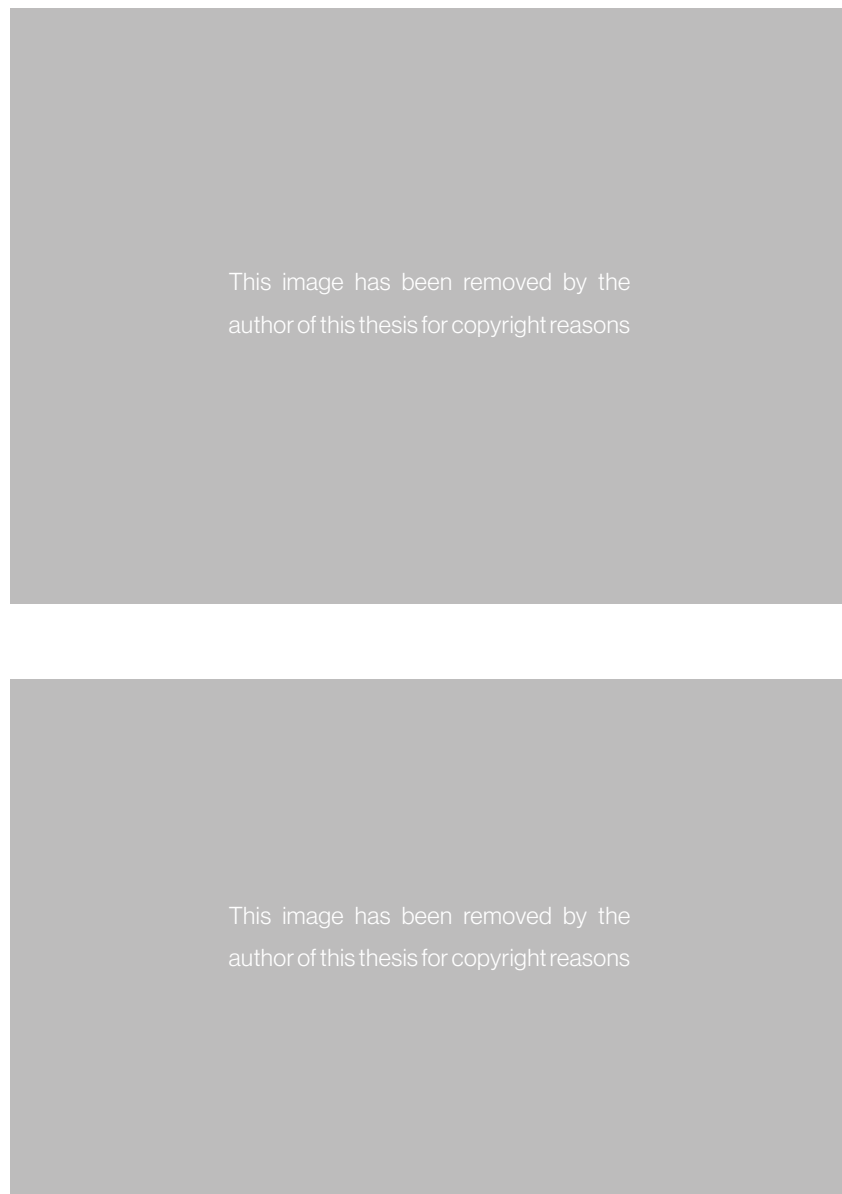


Fig. 6-7. Conversion of the dayroom to a four bed ward

As part of the 2012 application, these drawings indicate the loss of the dayroom and external terrace to form a new bedroom that could fit four patient beds.

of which was essentially to address patient dignity<sup>418</sup> this project saw the transformation of the day room to a four-bed patient room, a critical change to the hospice building as discussed in the previous chapter. Whilst this project included major works both externally and internally, the project offered the hospice building an opportunity to consolidate work, thereby reducing further potential disruption caused by other smaller works. Not only did this project update the services offered for patient care, but it modernised the environment itself, with hospice users commenting to a local newspaper that it felt more like a hotel than a hospice.<sup>419</sup>

Since the works undertaken in 2012 no further planning applications have been made in association with design or building work to the hospice building. However, there have been two further major projects delivered that did not require any formal planning permissions though may have involved an application to Building Control, which does not have a searchable database. In 2016 the hospice's day-therapy unit on the lower ground floor was renovated following a grant from a local charitable foundation; that sought to reconfigure and upgrade the area of the lower ground floor for complementary therapies and patients from the wider community. This involved minor reconfiguration to internal walls and redecoration works. Following this, 2019 saw the completion of several packages of works, at a large scale the change of use of a room previously used as the education centre to a public café, on a small-scale conversion of patient bedrooms to spa bathrooms and essential maintenance to the fabric and services of the hospice building. The incorporation of changes listed above, in conjunction with the building falling within a Conservation Area would typically constitute a planning application however neither this project or the 2012 project involved an architect or designer that lodged an application and as such there are no official drawings or documents available to support this study. This package of works was funded jointly by a charitable grant and a legacy donation.

Considering the above, the hospice worked in collaboration with architects where necessary, for example where major changes required a formal planning application owing to the needs of producing architectural drawings to represent the proposals to the local planning authority. This

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418 JDDK Architects, 'Autumn 2012', 2012) p.6 & the concept of 'dignity' is a critical term within care practices and is often referred to when discussing patient needs. The Cambridge Dictionary defines dignity as 'the importance and value that a person has' but has multiple other definitions based on particular contexts of patient care. For example, as stated by 'Steph' and 'Rachel' the refurbishment of the dayroom to a four-bed bay and the works to other patient bedrooms changing storage rooms to sanitary facilities was based on the concept of dignity as being access to 'single rooms and en-suite toilets'. This singular interpretation may prevent a holistic understanding of the implications and consequences of this focus, on dignity whether experienced by patients, staff or visitors.

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has perhaps been required more than usual as the building sits within the local conservation area placing additional constraints on the work that can be carried out that affects the external appearance of the building. Only on one occasion was the work carried out by the charity itself, the 2003 application lodged by a chartered surveyor, it is not clear why this was done though it may have represented a financial saving and potential expedited process. We can see that the smaller informal changes made to the interior of the hospice that did and do not require planning permission have primarily been the domain of the members of staff, facilities, and maintenance teams who request, and action change internally in response to the changing demands of their roles. However, we can also see that these changes have also been periodically appended to the planning applications, where there was no requirement to do so – and so we may observe that this perhaps occurred to combine as much work into one package thus reducing potential disruption and combining the delivery.

A key observation from the history is the clear documentation of the influence of finances on the approach to architectural design. Referring here to the 1995 planning application with two items, only one of which was affordable at the time, with the proposal being delivered some years later with the benefit of external funding. Financial constraints were identified in the previous chapter as contributing toward a reactive approach to building work, as the sporadic and unpredictable nature of charitable donations and bequests may not align with current or expected needs of the hospice building. It is also critical to mention that within the context of the C&V hospice, donations, and bequests, as a stream of funding have occasionally come with conditions attached. These conditions often specify uses for the funding such as purposes that make a visible difference to areas of patient care and make visible the contribution of/to the donor. This is perhaps common amongst third sector organisations largely reliant on public funding and as highlighted in Chapter Two there is a national shortfall of funding available to hospices across the United Kingdom, including Wales. Therefore, the financial viability of undertaking any type of refurbishment or constructions works could not only limit the aspirations for design works but also restrict the potential for strategic and long-term planning and development.

## Design interventions

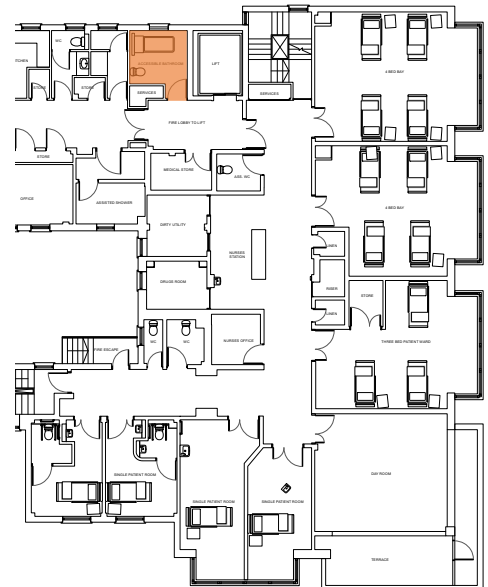
Having explored the formal design history of the case study setting, we now move to discuss a selection of design changes that were mentioned in the interview analysis of Chapter 5. These examples are of varying scales, from small to medium to large changes made. Small, the renovation of a patient bedroom to a spa bathroom on the ground-floor and first-floor wards, has been defined here as a change that can be actioned in a relatively short period of time, perhaps requiring some physical interventions such as demolition of 'stud' or timber frame walls or moving of services and having little impact on the experience of staff and patients. The phased replacement of windows to patient bedrooms on the east elevation represents the medium scale. Though others within the construction industry may view this as a small intervention and a few days' work. Within the hospice environment this becomes more onerous, involving multiple phases of work and involves the planned closures of multiple bedrooms reducing the number of patients the hospice can admit. The large, the renovation of much of the basement level to form a new café open to hospice users and the public, taking the place of the former education and development room for staff. The project for each scale will be described using data from the in-depth interviews and the implications regarding design and the involvement of designers evaluated.

### S - the spa bathroom

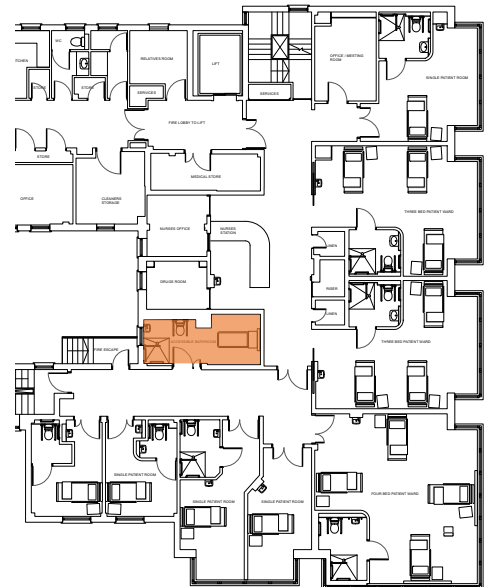
As part of the amenities available for their patients, on both the ground and first floor wards, the hospice has provided space for an accessible bathroom that accommodates walk-in showers and a freestanding bathtub that do not fit in the en-suite bathrooms of the patient bedrooms. These two bathrooms have occupied multiple locations within the hospice building, as various renovation projects have shifted services around the ward spaces, see Fig.6-8. In a major internal refurbishment in 2012, the accessible bathroom was moved central to the ward space occupying what was previously two separate toilets for visitors and the Sister's Office. As one half of the most recent renovation project in 2019 saw the accessible bathroom converted into a new sluice, and the accessible bathroom (referred to as a spa bathroom) re-located again to what was previously a patient bedroom. The pattern of work over the years, as highlighted previously has been defined by the availability of finances, and might be likened to a jigsaw, a perpetual reconfiguration of spaces that aims to keep the hospice building aligned with the current needs of the patients. As 'Colleen' explained:



[1] 7.6s q.m



[2] 12 sq.m



[3] 15 sq.m

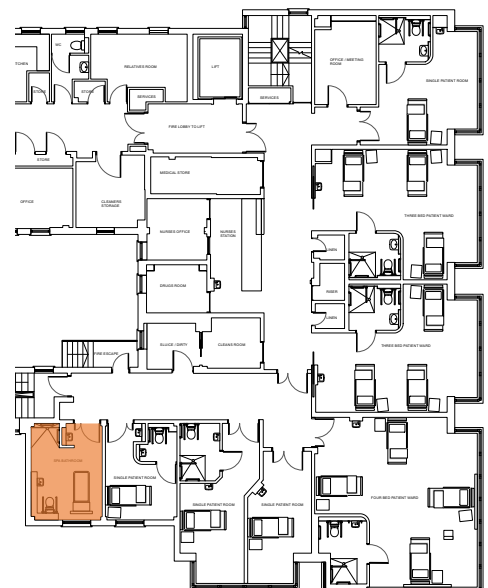


Fig. 6–8. Location's of the spa bathroom  
Shown in chronological order, from top to bottom, the plans demonstrate how the bathroom has grown in size over time.

...we never dreamt of a spa bathroom, that was sort of, further on when we had another injection of money, uhm and there was actually, oh wow if we did move the sluice, then, and moving the sluice gave one of the bedrooms that didn't have an en-suite that facility, which was fantastic. so that was a win. and yes, we lost a bedroom, but it was causing more issue than not...<sup>420</sup>

Though this latest move of the bathroom resulted in the loss of two patient bedrooms, and the subsequent statutory funding, this was a risk balanced against the reality that that bedroom was constrained in size and the furthest distance from the nurse's station making observation more difficult. The renovation was funded by a legacy donation and though other critical maintenance works were undertaken at the same time; the spa bathroom highlights the desire for donated money to be seen as contributing to elements of the hospice building that directly benefit the patients rather than indirectly. Furthermore, an informal encounter with a member of the nursing team highlighted the potential for new specialist equipment that would assist with bathing patients at a higher level relative to the nurses than a traditional bath that would be lower to the ground, thus making the spa bathroom even more accessible to patients with complex needs. However, this specific piece of equipment would not fit within the existing en-suite shower rooms. We may speculate that this could result in the en-suites of patient bedrooms becoming redundant, bar use by able-bodied patients and visitors, if the spa bathroom became a preferential option owing to improved comfort and dignity levels, thus contributing further to the pattern of renewal.

The works undertaken to converting the former patient bedroom to the spa bathroom, included partial demolition of a non-load-bearing wall, the installation of new services and drainage for the sanitaryware and decoration of the room as appropriate for a wet environment that will require multiple members of staff and pieces of equipment to assist with the safe manual handling of patients in and out of the bath and shower and when using the toilet. The work was assisted by a project manager from an external firm of chartered surveyor, who helped to source light fittings that could fit around the existing services in the room. The design of the bathroom was also subject to a collaborative design process, with 'Steph' and 'Rachel' confirming that they were involved in early conversations to ensure the room met the necessary spatial requirements needed by the nursing team to safely move patients - 'we got the pieces of equipment in before we put the bath in to make sure there was enough space to access for the nurses and that sort of thing'<sup>421</sup>. Following

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420 Participant A, 'C&V Hospice Interview 2', ed. by Bellamy, 2019), p.10

421 G, 'C&V Hospice Interview 5', ed. by Bellamy, 2019), p.18



Fig. 6–9. Ergonomic requirements of Part M

The diagrams outlining the 'minimum' dimensions needed for an accessible WC as defined by Part M of the UK Building Regulations. Note in 'Diagram18' the closeness of the drop-down rail adjacent to the toilet itself.

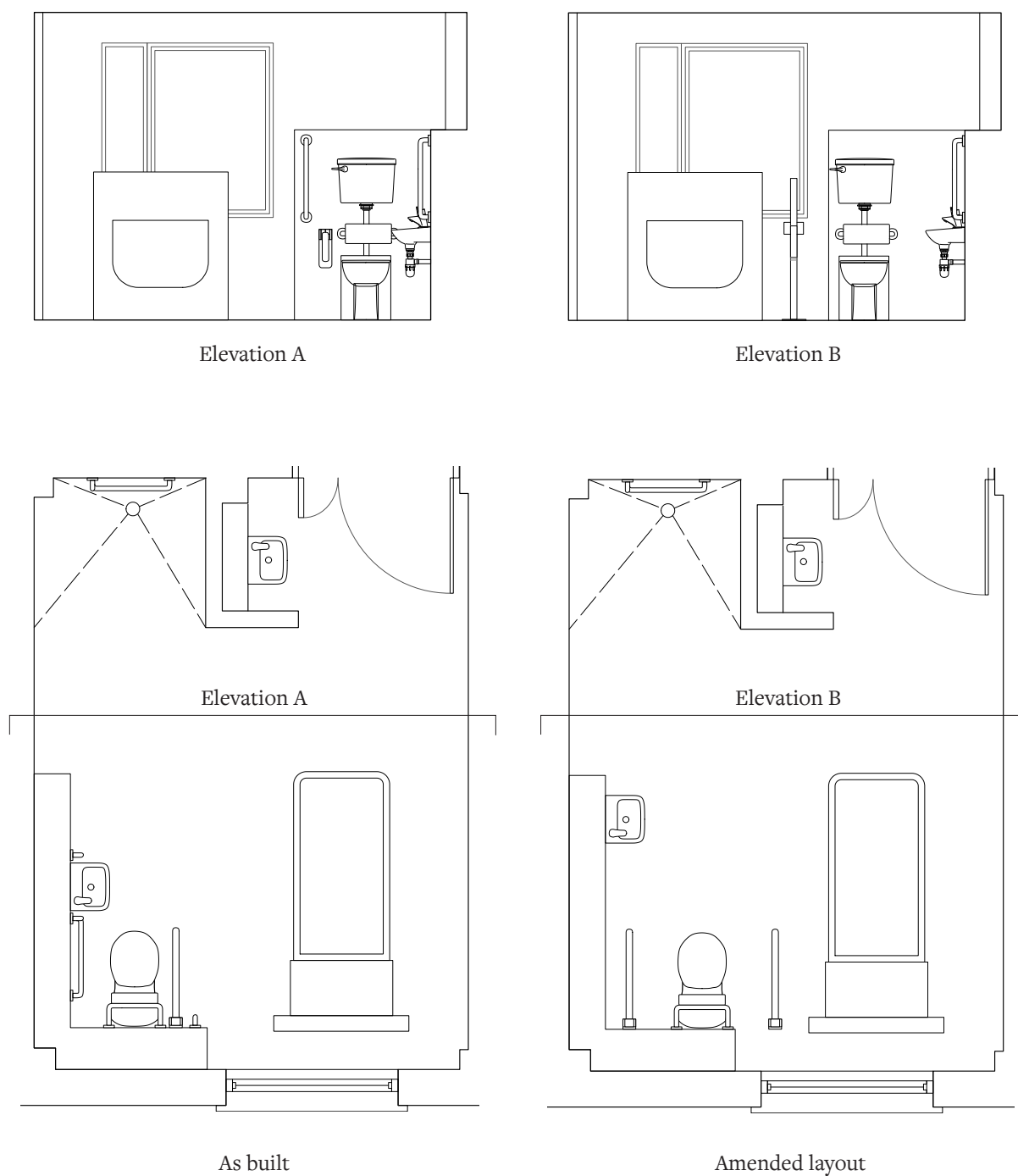


Fig. 6-10. The layout of the renovated spa bathroom

The plan and elevations of the 'spa bathroom' here illustrate the Part M configuration originally installed, and the subsequent changes made to ensure enough space for the WC and hand basin.

this consultation, construction work took place for which it is noted that an architect or designer was not involved. Once works were completed, however a critical error was noticed by 'Steph', that resulted in abortive and remedial works necessary to additional costs. Describing the piece of equipment used by staff to assist moving patients to the toilet:

... so the toilets are up against the wall here so getting a steady in for a patient, which is a piece of equipment sort of a patient stands up on sits down and wheel them in and ideally you should have a nurse each side, well you can't get a nurse that side of the wall... so yeah they're leaning over, so we've had that problem here because when they first put this...because like I said you can't get a nurse to stand there at the side, it should be accessible...<sup>422</sup>

The design as discussed by the nursing team had specified clear space either side of the toilet to allow for members of staff to safely assist the patient on and off the steady. However, as built, it emerged that the contractors had instead configured the layout of the space in accordance with UK Building Regulations 'Approved Document M: Access to and use of buildings' that outlines the dimensions for accessible toilets, see Fig.6-9, not considering the requirements as highlighted by the nursing team. The requirements for the layout were to ensure safety for both the patient and staff members to have adequate support, with Steph commenting:

...which is why we asked for the sink to go there so we could get the piece of equipment in but then when I came back after holiday it was there [the wrong place] and I thought hmm how's that happened that's not where we decided to put it and then 'well oh well yes but actually the regulations are'...<sup>423</sup>

The remedial works involved moving the toilet away from the corner of the wall and necessitated the construction of a free-standing drop down grab rail planted in the floor, see Fig.6-10. This misunderstanding regarding the definition of 'accessible' in the hospice setting - between that which is defined by government guidance<sup>424</sup> versus a physical understanding from practical experience – emphasises two key points at contrasting scales. Firstly, the confusion regarding the concept and definition of accessibility can be linked to a lack of clarity of the classification and status of hospice buildings. As neither a hospital or domestic setting, the guidance available for hospice organisations

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<sup>422</sup> Ibid., p.17

<sup>423</sup> Ibid., p.18

<sup>424</sup> It should be noted that this guidance is not mandated, and that the information provided in the Approved Building Documents outline statutory guidance on how to meet the requirements of Building Regulations.

to follow sits in a grey area, often being classed as private hospitals or nursing/care homes – neither of which truly represent the spatial needs of hospices. Furthermore, as hospice buildings are commonly the responsibility of third-sector organisations they are additionally not obliged to follow specific NHS guidance on the built environment, such as such as HTM's (Health Technical Memoranda) or HBN's (Health Building Note). A recorded conversation with an architectural practitioner who specialises in hospices mentioned that they sometimes refer to this, if asked, regarding sanitaryware or piped gases, and occasionally refer to a document produced by the NHS that discusses ward and bed layouts. Within the architectural and construction industry, Part M of the Approved Building Documents are perhaps the most known and referred to specifications that outlines the minimum requirements for accessibility for various aspects of domestic buildings<sup>425</sup>, such as WC's, ramps, and staircases and so on. However, there is a growing discourse around Part M as reductionist tool that 'objectifies the disabled body as, primarily, comprising a physiology with impaired mobility, in which a wheelchair is required to facilitate movement, mobility, and access'<sup>426</sup> and does not adequately consider other types of disability. Furthermore, we might observe that the production of guidelines in this manner may 'reduce the human body to a source of an abstracted system of proportions'<sup>427</sup> and lead to the regulations as a set of minimums being misrepresented as ideals.<sup>428</sup>

Additionally, we may observe in addition to the above a lack of formal architectural drawing, such as a package of internal room elevations or 'setting out' drawings, could have contributed even further to the confusion surrounding the desired outcomes of the project. A set of considered drawings are a valuable tool in the design process, often going through multiple stages of review and revision until all parties agree upon and are confident that the design meets all requirements. Furthermore, working drawings within professional procurement routes are often legally binding contractual documents outlining the specification of what is to be constructed. Without full access to the communication and decision-making by the contractors the abortive work is not the sole responsibility of the contractors – and perhaps lacked formal management from either the client themselves and/or the acting project manager as the client representative. Rather

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425 The Building Regulation documents consist of two parts, one for domestic dwellings, and buildings other than dwellings. The hospice would be considered a building other than a dwelling.

426 Rob Imrie, 'The Role of the Building Regulations in Achieving Housing Quality', *Environment and Planning B: Planning and Design*, 31.3 (2004), 419-37, p.423

427 Ann Heylighen, Caroline Van Doren, and Peter-Willem Vermeersch. "Enriching our understanding of architecture through disability experience." *Open House International*, 38-1 (2013) 7-19, 17

428 Imrie, 'The Role of the Building Regulations in Achieving Housing Quality', *Environment and Planning B: Planning and Design*, 31.3 (2004), 419-37, p.423

this incident serves to stress the significance of methods that ensure clear communication. A similar misunderstanding was described by 'Rebecca' during the scoping visit to the North Wales Health Board hospice, whereby another hospice during the renovation of their counselling rooms requested discrete emergency cords/push buttons to be installed adjacent to the light switches. Instead, bright red boxes were installed in the middle of an empty wall, with the hospice covering the costs of the remedial works to make good the wall and move the boxes to the desired location. If we consider both arguments raised above, it is not suggested that the introduction of architects into the process of design of the spa bathroom would have completely removed the possibility for errors to be made. However, collaboration with an architect would have offered opportunities to record needs and offer a method of assurance regarding design changes providing clear direction to contractors and others, such as statutory authorities.

### M - the windows

The medium scale, as mentioned in two of the in-depth interviews in the previous chapter is the planned renovation of several windows within the patient bedrooms to the east elevation of the case study setting. Several windows on this elevation had been replaced the previous year and funding had recently been made available to complete the renovation. The windows on the elevation to be replaced are made of a dark brown aluminium frame with secondary glazing in place, that offers additional insulative properties and airtightness. Facing the sea, exposed to the potentially harsh conditions of sea air and high winds, 'Mike' and 'Rob', the maintenance team spoke of how the seals have degraded to the point that there are drafts of cold air unable to be counteracted by heating. The original design of the windows, see Fig.6-11, is of two panes, one fixed to the bottom of the window and an opening casement to the top. The panes are separated by a thick transom<sup>429</sup> that forms the structural frame to the opening part of the window that cuts 'across it all right where the bed is, and people are sitting'.<sup>430</sup> The replacement windows were to still consist of two panes due to the costs, both material and construction related of reducing this to one single pane.

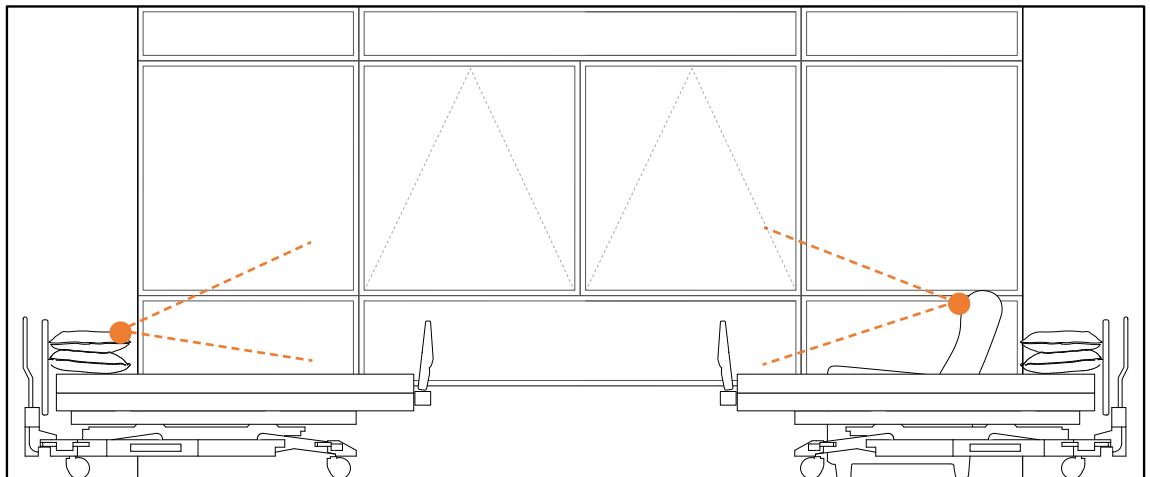
Outside of the remit of the work possible to be undertaken by the maintenance team, external window specialists were hired to fulfil survey, design, and installation services. 'Mike' and 'Rob' described the process of procurement as a process initially involving a 'big chain' of members of

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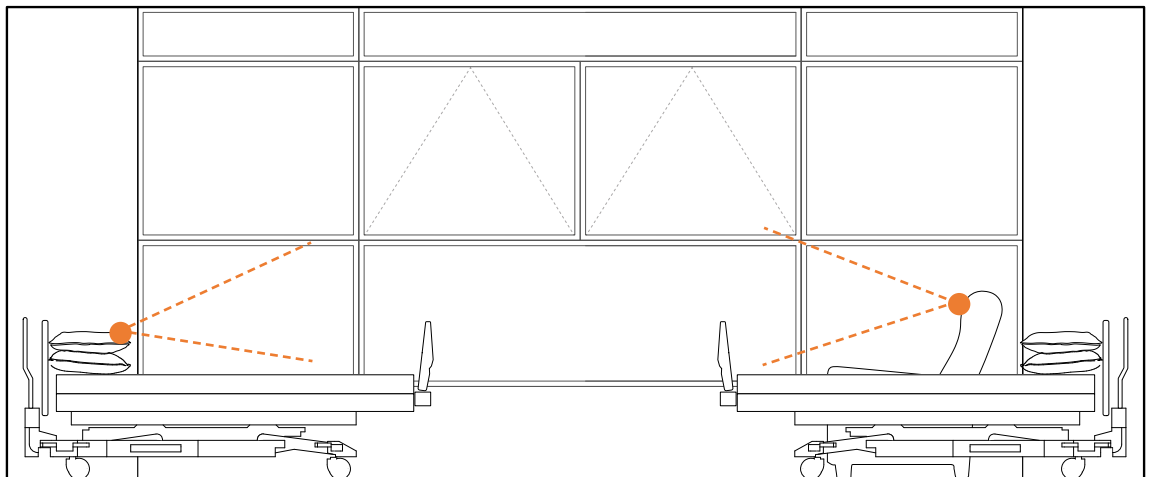
429 A transom is the architectural term for the horizontal structural member that divides a window.

430 E, 'C&V Hospice Interview 4', ed. by Bellamy, 2019) p.25





Existing window design



Potential new design

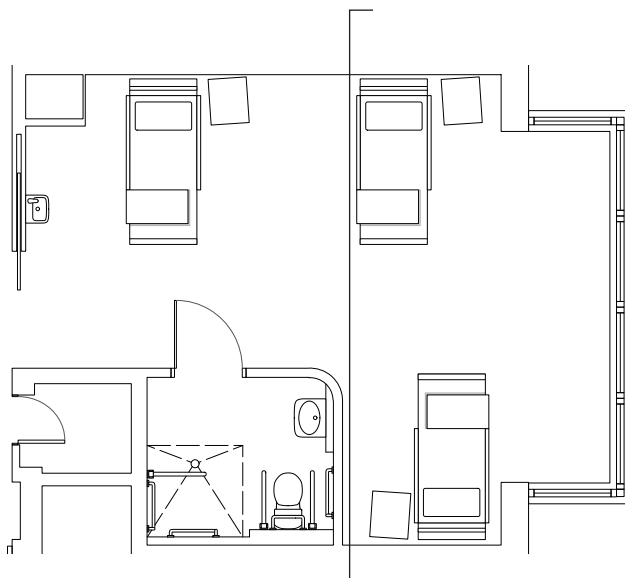


Fig. 6-11. Configuration of the bedroom

windows

The elevation of a typical three bed patient bedroom and the window bay. As described by Mike, the transom of the existing windows cuts directly into the middle of the sightlines of someone sitting or lying down. The potential new design, shown here shifted up by 300mm allows a clear view out.

staff, including an in-house project manager from the Estates division, and the regional manager, before the Facilities Manager made an official bid for the funds required:

...so then it passed then to us, so we will get the contractors out we will show em, say what it is, design wise, you are restricted, there's not an awful lot you can do it is, it's a bay with two sides, you know, so yeah we would source all that we would then chase up, get the estimates, we get the estimates in and we would pass it down to Colleen and Colleen will go through the proper channels...<sup>431</sup>

Once approved, the organisation and project programme are managed on the ground, 'in-hospice' by 'Mike' and 'Rob' themselves. Despite being only a relatively small material change to the building's fabric, we can observe that the replacement of the windows offered the opportunity for additional work to be undertaken that is extremely difficult to schedule in the hospice setting. Though a small material change relative to the size of the building, this work requires meticulous planning given the incredibly sensitive nature of undertaking building work in such a specialised environment of care and the need to plan for the closing of patient bedrooms. 'Mike's' knowledge of the hospice enables himself and 'Rob' to propose realistic schedules that takes advantage of the building work. As 'Mike' stated 'it's very rare that we get the opportunity to go into the multi-room bays to do any work'.<sup>432</sup> With 'Rob' further confirming that 'we use that time, don't we, to get as much of it done as possible'<sup>433</sup> which includes for example, deep cleaning and re-painting. Not only does 'Mike' and 'Rob's' insider knowledge impel these opportunities to upkeep problematic areas, but they also influence the project programmes to make time for the above and to allow for the unknowns of either the building or the context of the hospice at the time. 'Mike' explained that external contractors typically state timescales for completion of work that would be expected of a normal domestic or commercial project but has found that these timescales do not align with the realities of undertaking building work in the hospice and may potentially cause additional financial costs. For example, explaining the timescale behind the windows 'Mike' stated 'so whereas there say the contractor can do it in three days, forget that, we're saying six, because Sunday, by Sunday morning that room will be completely finished'.<sup>434</sup> Here 'Mike' and 'Rob' demonstrate further a duty of care, as described in Chapter 5 using their knowledge to minimise disruption to not only the building but for patients and staff.

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431 Ibid. p.27

432 Ibid. p.27

433 Ibid. p.28

434 Ibid. p.27

Following the first phase of window replacements, and amid the second phase replacement programme - a chance encounter played a critical role in the design of the windows. Standing outside one of the rooms, 'Mike' had noticed that the middle transom in the new windows, 'that bar unbeknown to us is higher, it's only 10cm but it makes all the difference'.<sup>435</sup> The windows as replaced during the first phase had not been designed and manufactured to match the existing, rather the difference to the transom offered a marginally clearer sightline from the patients bed and chairs out to the view beyond. 'Mike' subsequently communicated this finding with 'Steph', the Clinical Nurse Manager to discuss potential changes to capitalise on the brief lead time before they were manufactured. The exchange between 'Mike' and 'Steph' drew out their respective expertise for the everyday use of the windows:

...we can't drop the bar down because the window is on hinges and it has to open out, so the weight would be too much, so I said do the opposite, take the bar up, so you could take the bar, so just imagine the bar is there [standing up and pointing out on the wall] and in room X and you could go there [gesturing much higher up the wall] you could go 30cm, now bear in mind rooms X-X have got air-con so there's no need to open the windows and if they did open they only open that much [gesturing a few cm's] so all they got to do is get the shortest nurse we got here if she manage to reach then we can gain...<sup>436</sup>

Despite being a completely chance observation, 'Steph' described that this change now means that as a patient or visitor 'you'll see straight out and not into a bar, that dark brown that's right in their eye-line if they're sitting in the bed or a chair so that's good'.<sup>437</sup> 'Mike's' action to take the issue immediately to the nursing team - 'you have a chat with nursing and have their opinion'<sup>438</sup> - further demonstrates the growing disposition for collaborative decision making between the clinical and non-clinical teams highlighted in the previous chapter. It additionally emphasises the relationship between 'Mike' and 'Rob' and their working environment and care displayed towards it, as the design of the new windows was the responsibility of the external contractor and there was no formal requirement for the change to be requested.

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<sup>435</sup> Ibid. p.25

<sup>436</sup> It is worth noting that the possibility of re-designing the windows to remove the need for a transom was quashed by the financial implications of replacing the windows with full panes of glass or with thinner profiles. These, however, are elements of design that are defined from the outset of a project brief and are unlikely to change when a project is already underway.

<sup>437</sup> G, 'C&V Hospice Interview 5', ed. by Bellamy, 2019), p.29

<sup>438</sup> E, 'C&V Hospice Interview 4', ed. by Bellamy, 2019) p.25

## L - the café

The large and final scale of design interventions to be discussed presents the other element of the most recent building project that the case study setting has undertaken completed mid 2019. The cafe project saw the first major change to the scope of facilities within the hospice building since the conversion of the day rooms to four bed patient bedrooms. What was previously used as the education and development room for staff on the lower ground level was converted into a café open to both hospice users and members of the public, making the most of existing access to the terrace level and garden, see Fig.6-12. As mentioned in the first section of this chapter, though incorporating both 'change of use'<sup>439</sup> and material changes to the elevation, this project did not apply for planning permission. The decision to convert part of the building to a café could be observed as being driven both by financial reasons, to broaden the standing of the hospice in its local community and address changing expectations of patients and visitors. Despite the education room being used as a setting for paid courses, the café offered an opportunity for a new type of funding stream. As 'Rachel', the practice development facilitator explained,

...the messaging around the cafe is we need to drive revenue; we need to create income...you know we've changed as a result of palliative care...well that in itself is being something it's messaging is uhm a result of the culture of healthcare and the economy...<sup>440</sup>

The café opens to the terrace and garden beyond which is accessible from the public park adjacent. With this connection we may observe it was hoped that the café would draw in members of the wider public for both engagement and financial purposes. It is a similar model as used by the North Wales hospice visited as part of the scoping visits, that has located a café to the street facing elevation that has been successful in generating a status as a destination to visit. However, the inclusion of a publicly accessible space has come at the cost of conceding space that was previously dedicated to members of staff. The decision to incorporate a café into the C&V hospices' facilities additionally plays into the recognised pattern of the hospice organisation keeping up to date with the anticipated experience of patients and visitors. The loss of the day rooms within the hospice building in 2012 meant that, apart from small family rooms within the wards, there had been no communal or larger space available for patients and visitors to use.

439 Planning Portal, Use Classes (n.d) <<https://www.planningportal.co.uk/permission/common-projects/change-of-use/use-classes>> [accessed 12th April]

440 G, 'C&V Hospice Interview 5', ed. by Bellamy, 2019), p.23

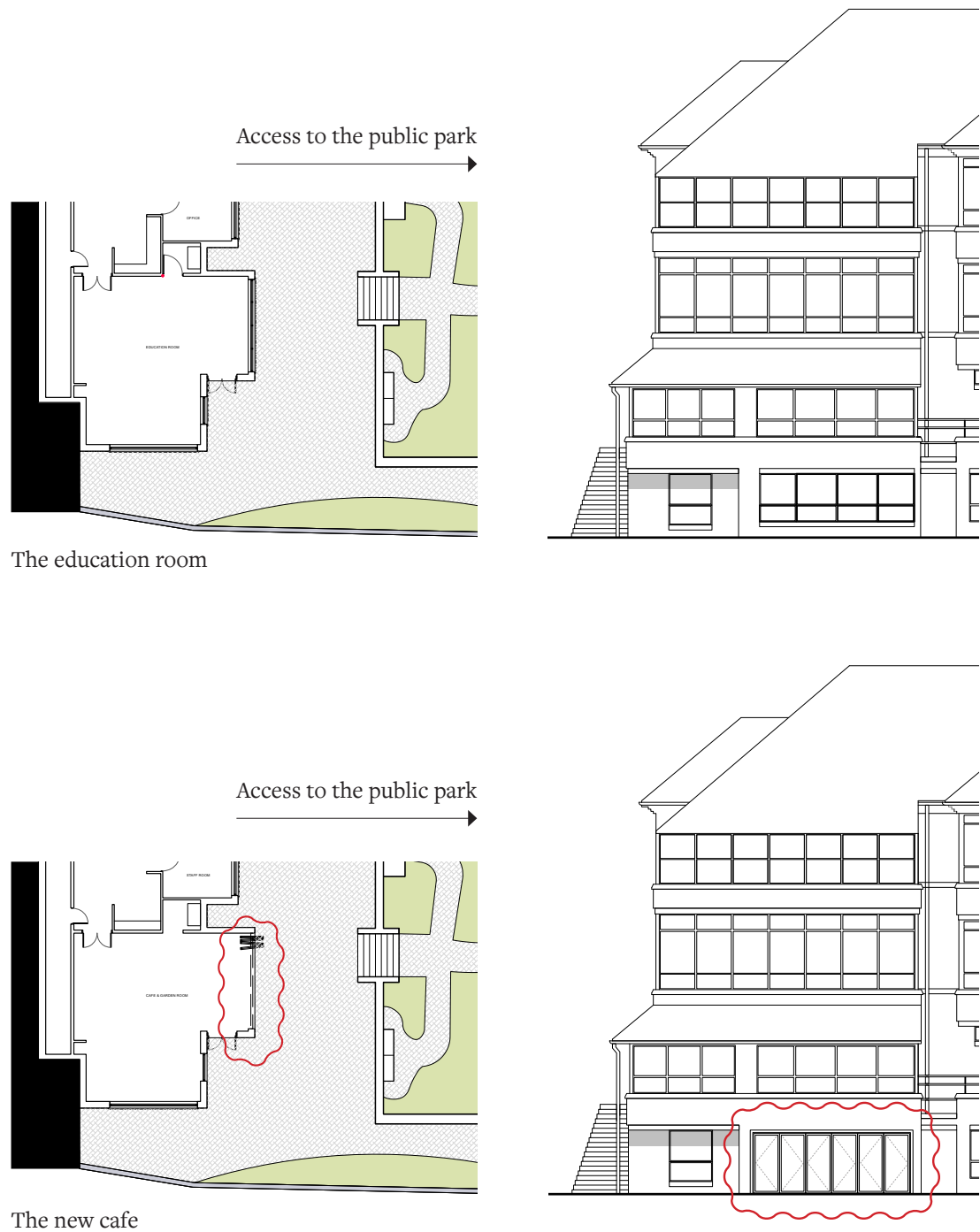


Fig. 6-12. The amended elevation

The plans and elevations above illustrate the change to the facade following the introduction of a cafe. The previous windows have been replaced by bi-folding doors that open out to the terrace, giving use to a previously underused space.

During a visit to the education room as the room was being stripped out and prepared for the renovation, it was mentioned by a key member of staff that there had been very few formal drawings of the proposed café, one of which was from the specialist company that was to design and install the servery. This matches the context under which the spa bathroom was managed, and thus could be seen to contribute to the workload of the Facilities Manager, 'Colleen', who took on supervision of the projects. Adding further weight to her role as discussed in Chapter 5, 'Colleen' was responsible for juggling aspirations for the hospice building environment, financial constraints, and the charge of gaining a range of opinions. As she described for the cafe:

...the colour palette these are the sort of things we're looking at, here's books of what the furniture may look like uhm so we've tried to involve as many as we could, sometimes the group wasn't that big, otherwise you know too many people...especially when we were choosing uhm colours for the furniture for the café - I think I went round about eight people in total and from the nurses they needed to be comfortable, from the kitchen and housekeeping they needed to be able to clean quite easily, maintenance they have to be quite strong, OT [occupational therapy] was well we need some with arms, and some with not...<sup>441</sup>

The collation of inputs from the different groups of members of staff echoes in part, a strategy described in conversation with an architect who specialises in in-patient hospice design; that a nominated client representative would weigh up issues from a committee of representatives of staff members. This approach - that we can see traces of in 'Colleen's' role and actions within the hospice building - may help circumvent situations of 'design by committee'. It is similar in nature to that of the advocate role highlighted in the scoping visit to the North Wales hospice, and the 'commissioning officer' appointed by a hospice in England described by the specialist in-patient architect. However, though some may see this investigative role as part of an architect's exploration of their brief, understanding the context of the to-be designed environment and its inhabitants is time - and therefore financially - intensive and may not be feasible due to geographical location. This will be discussed in further detail in the following chapter.

Like the previous interventions, architects were not involved in the renovation of the education room and the design of the café. Though, as this project was undertaken simultaneously to the

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<sup>441</sup> Participant A, 'C&V Hospice Interview 2', ed. by Bellamy, 2019), p.19

spa bathroom a firm of external chartered surveyors were employed who acted in the capacity of project manager. Critically however, an informal conversation that took place with a key member of staff prior to the formal research activities highlighted surprise when it was asked if architects were involved in any capacity during the project, with reference to the scale of the project being not of interest to an architect or within the remit of their professional services. A confusion regarding the professional role of the architect and the services and or expertise they can bring is perhaps emphasised here by the presence of other construction professionals, such as surveyors and feeds into a growing discourse on the value of architects within the broader construction profession.

Flora Samuel in 'Why Architects Matter' proposes several factors that may have contributed to the decline of the value of architects, with a critical aspect being the 'mismatch between public perceptions of architects and what it is that they actually do or believe that they are doing'<sup>442</sup> clearly demonstrated by the response detailed above. We might draw a link here between the perception of the role of the architect being linked to the process of planning. The hospice has, as documented in the first section of this chapter engaged the services of architects to assist with the production of information necessary to submit for planning consent. However, for the smaller scale projects and interventions these have been managed internally by the associated teams and members of staff, such as maintenance and the Facilities Manager. Therefore, as the café did not require a planning application or major structural changes, we may speculate that it may have been decided that the involvement of architects was an additional extra that plays into what Samuel describes as an 'emergent "culture of amateurism", in which traditional professional roles are questioned'.<sup>443</sup>

## Chapter reflections

Looking at the C&V hospice as a designed environment, we can see that members of staff and architects have varying degrees of agency. The pattern of architectural involvement in design changes appears to mainly correlate with the need for planning permission (with the externally appointed architects acting as the main point of contact for all but one application) and subsequently the scale and nature of the changes to the building. We might consider that the role of the architect in these instances was to predominantly produce the information necessary and liaise with the local planning authority; and that for any changes perceived to be 'smaller', that is not needing

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<sup>442</sup> Samuel, 'Why Architects Matter: Evidencing and Communicating the Value of Architects', (2018) p.23

<sup>443</sup> Ibid. p.16



planning, was managed and organised internally.

However, with the engagement of an architect comes the requirement of additional professional fees, which may make an architectural team a potential casualty of a modest budget. Furthermore, the involvement of architects to facilitate planning applications plays into the growing trend of de-regulation of the planning process within the United Kingdom by 'widening planning freedom'<sup>444</sup> through permitted development rights. Critics have highlighted the potential negative implications of cutting red tape and allowing developers to build with little to no regulation. Though permitted development provides a shortcut to building works, despite popular perceptions building regulations are still a statutory requirement.

There is an inherent quality of co-production evident within the case study setting, not between healthcare and design professionals – but rather between the teams within the hospice building itself, such as, maintenance and nursing. Whether motivated by financial constraints or shared understanding of the day-to-day experiences. However, despite collaborative and multi-disciplinary decision making becoming more normal within the hospice setting for specific and small-scale works, there perhaps remains an imbalance with regards to broader or large-scale works. This is despite the expertise and care existing within the teams, as Mike from the maintenance team explained 'since the time we've been here, we've, you know we've pushed and pushed to have an input of work that we would like to be seen'.<sup>445</sup> Furthermore, the maintenance team, with extensive knowledge of the hospice itself, and the sensitivities of working in this environment can to some extent plan and manage these works more realistically than contractors who 'drop' into the environment. The presence of external contractors within building work poses an additional potential complication, requiring clear communication to ensure that the project is delivered as designed and within strict timeframes. As evidenced by the café and particularly the spa bathroom project, a lack of formal drawings to guide the building work had an adverse impact on the environment, both financially as causing abortive work, and functionally by introducing an additional grab rail element.

Missing from the discussion within this chapter is an additional scale, the XS, extra-small. That is the informal and minor works made to the hospice building by the members of staff themselves, with

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444 Richard Waite, 'Riba Shocked by 'Dangerously Relaxed' Permitted Development Rollout', in *The Architect's Journal*, 2021)

445 E, 'C&V Hospice Interview 4', ed. by Bellamy, 2019) p.16

the maintenance team directed by the requirements and needs as identified by their colleagues. Though this could evidence a sense of care and duty to the environment (for example Mike and the mortuary door), it has on the other hand produced additional responsibilities for members of staff beyond their role, as seen in Colleen's role. These XS changes might include aesthetic elements such as painting, the addition of a new sink, or the moving of a member of staff's office. In the manner of tinkering, though a maintenance schedule might exist for regular and/or planned work these alterations as such are generally not recorded in any official way. For example, it is noted that the as plans that the case study setting provided for the researcher did not reflect the building as it is existed. Conversely, to the XS there is also the XL scale which so far has not been evidenced at the case study setting. This might involve the procurement and delivery of a new build hospice, such as St. David's. It may even more broadly comprise the re-imagined occupation of the case study setting as part of the wider estate of the national end of life care charity it is managed by or the proximity of care facilities within a health board. For example, architects may be engaged to prepare strategic proposals that evaluate the feasibility of their current building stock with regards to finances through investment, that is, refurbishment or divesting by selling or rationalisation.

Considering the case study setting holistically, especially as one that is so old, it is inherently fluctuating in its nature. Like many other healthcare building typologies, change, in response to contemporary patient needs can be slow to action and result in piecemeal fragmented work. As Cohen and Fenster consider the status of architecture as a caring practice 'highlights other aspects of projects that contradict care: capitalist economy, difficulties to build, finance, and sustain projects through volunteers and donations'.<sup>446</sup> Ongoing relationships with architects may contribute to a coherent pattern of change, with insider knowledge of why certain changes were made, as evidenced by the North Wales hospice of whom the architect of the original design had been employed for subsequent changes, though this may be limited by the lifespan of the architectural practice. Indeed, for the case study setting, the architects who originally designed the building and presided over subsequent planning applications no longer exist.

A similar strategy to counter reactive changes may be for architects to assist hospices to develop a 'vision plan' that might lay plans for a series of changes based on various options – though this relies on the hospice itself having a clear direction to move forward. 'Colleen' summarised this is a fundamental limitation that the C&V hospice has come up against, knowing how the hospice is

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446 Shelly Cohen and Tovi Fenster, 'Architecture of Care: Social Architecture and Feminist Ethics', *The Journal of Architecture*, 26.3 (2021), 257-85, p.281

going to need to change to meet the future needs of patients. In discussion with 'Colleen' regarding the future potential of the case study setting, she stated 'there are things you can do, you can knock walls down and do things, but it needs money, I think we've done everything we possibly can'.<sup>447</sup> We can consider that this statement may represent a devaluation of the role of the architect and a lack of knowledge on the services of the architectural profession. 'Colleen', in her capacity as a Facilities' Manager believes that the case study building has no further opportunity to be adapted other than being demolished and re-built. Carl Elefante, former President of the American Association of Architects commonly quoted proposition that 'the greenest building is the one that already exists'.<sup>448</sup> An attitude of starting again from scratch furthermore highlights the critical importance of architect's approach to sustainability and the climate emergency.

To an architect there may be apparent opportunities for adaptation or change based on their expertise to think broadly and openly to generate innovative ideas on the use and function of space. For example, the second floor of the case study setting currently houses several office spaces ranging in size and several defunct rooms associated with the previous Matron's flat – rationalising this area in conjunction with the existing staff changing area might provide flexible open plan office space that could free up other areas within the hospice building to provide either further storage or dedicated staff areas. For architects to do this however, they require the ability to understand the needs of the inhabitants meaningfully and critically, the context of which will be discussed in the following chapter.

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447 Participant A, 'C&V Hospice Interview 1', ed. by Annie Bellamy, 2019), p.5

448 Robert Adam, "The Greenest Building Is the One That Already Exists", in *Architect's Journal*, 2019)

# 7

## Hospice as a field of study

This chapter, as the concluding section to the third and final Part, represents a reflexive turn in the thesis. We will present the numerous and significant challenges faced accessing healthcare environments for academic purposes as a non-healthcare professional and in conducting the fieldwork of this thesis. Before discussing multiple aspects of ethical practice that bear influence upon the way architecture and design can be utilised in both practice-led research, and research as part of post-occupancy and product review of in-patient palliative care environments. It is hoped that the reflective discussion presented in this chapter will highlight constructive insights regarding the obstacles faced as positive lessons for future inter-disciplinary research.

## Accessing the case study setting

### Pathways to permission

The fieldwork was designed to engage with human participants to explore the lived experience of the end users of the hospice building. The researcher had originally aspired to engage with patients and visitors directly, however the final research participants were members of staff of the Cardiff & Vale hospice. By drawing on the knowledge and experience of those providing care the data contributes to the understanding of co-production to generate greater awareness of the needs of the in-patient hospice. Having conducted a previous study in a similar setting the researcher was acutely aware of the potential concerns for gaining the correct permissions for undertaking research in this setting. The process for gaining ethical approval took over a year and involved multiple submissions to a variety of research ethics committee's (REC's) between the researcher's host academic institution and the C&V hospice's own governance committee.

As summarised in Fig.7-1, the process commenced with an application to the REC of the Welsh School of Architecture. At the time of the application, this was a two-page document that only required further in-depth explanation of recruitment processes and methodologies if human participants were identified.<sup>449</sup> This was approved with minimal comment from the Chair of the REC. Following this approval, the case study setting was approached, and it was advised that the researcher should make a direct application to their governance committee and may additionally require NHS Ethics approval, as NHS patients and staff members were proposed research participants. As the researcher's background is non-clinical, advice was sought regarding the NHS Ethics process from their academic school's Research Office. However due to the specificity of the process and it not being a commonly researched area within the school this did not provide further guidance. Simultaneously, applications for the case study setting's governance committee, using a supplied template, and NHS Ethics via IRAS were prepared. Despite uncertainty as to whether NHS Ethics was necessary, the researcher sought the advice of the local NHS ethical review support team that confirmed it as a requisite. To assist in the preparation of the documents the researcher approached a 'critical friend', an academic member of staff from the School of Healthcare Sciences with previous experience of the process.

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449 The process of ethical approval within the School has subsequently been reviewed as part of a university wide project to consolidate and standardise consideration across all subjects. The ethical application document is now nine pages long.

October 2019  
Marie Curie Research  
Review Committee (Phase 2)

Dear Ms Bellamy,

**Project Title: The Architecture of Palliative care: toward a new approach to the project title and design of in-patient hospices.**

**Ethics reference: EC1903-4380 (within school of architecture)**

The above study has been received by the [redacted] Review Committee, in order to consider approval for the observational part of the study.

The following documents were received:

Document	Version	Date
Study Protocol	2.0	21 <sup>st</sup> May 2019
Patient Information Sheet	1.0	21 <sup>st</sup> May 2019
Consent Form	1.0	21 <sup>st</sup> May 2019
Confirmation of sponsor		10 <sup>th</sup> March 2019
Evidence of ethical approval		10 <sup>th</sup> May 2019

I can confirm that the above study documentation has been reviewed in light of the further part of your research entailing an observational study of the hospice, as part of the clinical audit and effectiveness meeting on the 26/10/2019, and a favourable opinion has been agreed and the Organisation will take part in the study.

May I ask this opportunity to remind you that it will be your responsibility to:

February 2019  
APPROVED

JULY 2019  
IRAS APPLICATION  
NO LONGER NECESSARY

[illegible]

The first direct application to the governance committee of the case study setting was rejected, referring to a discrepancy on the approval from the researcher's academic institution. The rejection coincided with an addition to the supervisory team of the researcher, an academic from the School of Healthcare Sciences and a key honorary member of staff of the case study setting. The addition of this supervisor was a formative point in the ethical review process for the project as this person assumed the role of 'gatekeeper'. As an academic member of staff within the School of Healthcare Sciences they had working knowledge of the case study setting as both a link lecturer and as a previous employee working as part of the nursing team. The prior connection to the setting, with ongoing working relationships with key members of staff at the C&V hospice – the 'gatekeeper' was able to assist in mediating between the researcher and the hospice. The role of 'gatekeeper' additionally extended to advocating for the rigour of the non-clinical research proposed and navigating the case study setting's requirements for ethical approval.

Subsequently, the pathway to ethical approval following the gatekeeper's support necessitated a secondary academic application be made to the School of Healthcare Sciences. This application contrasted with the Welsh School of Architecture in its extent and was assessed by a REC - whereas the WSA was only referred to REC if the Chair necessitated it. This application proposed separate workstreams consisting of individual research activities; focus groups/interviews and building observation. These applications were not only form heavy but required several documents to evidence operational aspects of the study. For example, participant information sheets, consent forms and advertisements for participant recruitment. These offered the researcher a chance to exercise their design skills to assist with the visual nature of these documents. Once approved, this application formed the basis of two further successive applications to the case study setting's governance committee, with the first proposing the focus groups, followed by the observation once the first had been approved and undertaken. To undertake the research activities, an official letter of approval was issued by the case study setting's research and governance committee lead. For the first workstream, the focus groups, this was issued shortly after approval. The building observation phase approved by the governance committee in October 2019 however was not issued a formal letter of approval until February 2020. The fieldwork was undertaken based on the study's approval communicated with the governance chair and hospice manager via email and text message (SMS) communication.



## Fitting in?

Throughout the ethical review process, it was apparent that there was a disparity between the researcher's background as an architectural designer and researcher respectively, and the expectations and approaches to research within a healthcare field and setting. The researcher held both insider and outsider positionality to the case study setting – yet it is suggested that they also held an additional position, an 'outside' outsider. Not only was the researcher attempting to enter an independent setting, but they were also doing so from a non-clinical perspective using qualitative methods, a type of study and researcher that the case study setting had not previously encountered. Throughout the ethical review process, and during the fieldwork itself, the researcher was required to 'adapt' themselves to meet tacit expectations of research aligned with typical quantitative studies in clinical settings.

A foremost concern of the researcher that emerged during the process of gaining access was that of navigating the process of ethical review in healthcare settings. As mentioned above, the researcher's background is in architectural practice and research, and though has previous experience of undertaking qualitative research has not before entered such a specialist and protected care setting. Reflections by the researcher highlight that approaching the various institutions related to the governance of care settings was an overwhelming process, that owing to the bio-medical model of ethics often lacked clear and/or misleading direction for those not undertaking physical clinical studies. As such an attempt was made to position themselves as close as possible to the identity of a healthcare researcher to levy a positive view of the architectural research by healthcare professionals. For example, the researcher undertook several training days led by Health and Care Research Wales, NHS Wales on research competency in clinical healthcare settings despite these sessions focusing on clinical research to evidence preparedness for the proposed activities to the case study setting. Further to this the researcher sought support from those with experience in the field from the School of Healthcare Sciences, to firstly assist with understanding the route through the NHS ethics application and secondly as an official member of the supervisory team acting as a mediator between the two disciplines. The supervisor's recognition of the value of the architectural quality of the research in support of principles of care practices was fundamental and offered the researcher an advocate when in conversation with the various REC's.

Following on from the above, a specific act of 'fitting in' for this research related to the language used by the researcher in communicating the intentions and methodologies of the research in the ethical review applications. The original research proposals needed to be 'translated' into language commonly used in clinical/healthcare research:

Ethics application forms for care settings are biased toward medical research, as demonstrated by terms like research "protocols" or "human subject". Such terms make sense to medical researchers but may be less familiar to researchers who do not undertake experiments or test hypotheses and see their work in a more collaborative sense.<sup>450</sup>

As noted in the research diary of the researcher, shown in Fig.7-2, this contributed to the protracted length of the review process as the applications required amendments, review by the researcher's supervisory team, and revisions before the applications could be lodged. The act of re-framing of qualitative social science research activities to fit quantitative healthcare research parameters is a well-known issue. Both the lexicon and vocabulary used by the researcher to describe the fieldwork changed noticeably, in the manner that Sleeboom and others highlight "chatting with patients and children" becomes "interviewing people who are ill and families"; "getting to know the community" becomes "snowball sampling"; and "building relations through mutual understanding and trust" becomes "acquiring access permission based on informed consent".<sup>451</sup> As reflected upon in the research diary of the researcher, language used to describe the architectural nature of the research was softened and reduced. It was recognised prior to the application process that some of the specialist architectural language would need to be amended so the context and purposes were clear to those outside of the profession. This was intensified to re-frame the research to better fit the subconscious bias toward bio-medical standards of ethics. Tutenal and others describe how this has the potential to obstruct the original purposes of the research and asks researchers to 'tailor their proposals to protocols with little relevance to the approach they propose'.<sup>452</sup>

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450 Piet Tutenel and others, 'Conversations between Procedural and Situated Ethics: Learning from Video Research with Children in a Cancer Care Ward', *The Design Journal*, 22.sup1 (2019), 641-54 p.647

451 Margaret Sleeboom-Faulkner and others, 'The Formalization of Social-Science Research Ethics: How Did We Get There?', *HAU: Journal of Ethnographic Theory*, 7 (2017), 71-79

452 Tutenel and others, 'Conversations between Procedural and Situated Ethics: Learning from Video Research with Children in a Cancer Care Ward', *The Design Journal*, 22.sup1 (2019), 641-54 p.648

26th June 2019  
personal diary entry

*I'm in the School of Architecture yet I am doing nothing remotely to do with my topic. Well. Sort of, by association, I guess. I tell him about how I've been working from home as I felt like too much of an imposter to be sitting at my desk in the design office. It's a centre of design and practice in the school yet here I am sitting filling and writing what feels like endless interpretations of ethics applications. I'm using the language of social scientists. Instead of celebrating and using my designer/architectural heritage as a positive it feels like I am trying very hard to not let anyone know that that is what I am. Trying to convince people that I'm more reliable, more approachable, screaming out to say 'I'm more respectable'.*

*But compare the applications, the WSA's is barely two pages and is processed and approved almost with no worry at all. But with those two pages – no wonder they're sceptical of me and cautious about who I am. Would this be a similar case I wonder of an academic studying care coming into look at architectural practice? No, as it would be public to private sector and they wouldn't be acting in a similar fashion. It would be much more removed, separated. There might also be less space for collaboration, in the way that I am not looking to come in and look at the specific way care is given, but rather look at the implications of my industry on the industry of care. Not the way in which it is applied. The same couldn't be said for care practices looking into the practice of architecture.*

*However after a number of site visits, I am in the position of wondering to what degree would my investigation be easier if I were the architect who had been appointed by each hospice? For this type of 'research' conducting steering group meetings with stakeholders would have been easy to organise, or perhaps not easy but they would have been an assumed part of the design process. Perhaps it's the intangibility of 'Research', although with a defined purpose has no tangible outcome to it – whereas the 'research' of an architect, much like Frayling's research with a little 'r' employed to design a refurbishment or new building is inherently more trustworthy to a population of people because they approached them, not the other way round.*

*Would architects hired by a hospice have been required to do an ethics application to look around, to conduct meetings, to meet with stakeholders to discuss the needs of the hospice? Would they have done observations to understand the workings of the hospice and would this have required sign off from the governance committee/board of the hospice?*

Fig. 7-2. Excerpt of a research diary

Kept by the researcher, this particular entry, written after a rejection of ethics discusses the concerns of the researcher about the ethical approval progress, but also the position of attempting to gain access in comparison to architects in practice

## A note on the role of Research Ethics Committees (REC's)

The ESRC defines a REC as 'a multidisciplinary, independent body charged with reviewing research involving human participants to ensure that their dignity, rights and welfare are protected'.<sup>453</sup> Academic institutions such as universities have code of conducts that outline research responsibilities and subject based REC's.<sup>454</sup> Publicly funded institutions, such as the NHS uses IRAS<sup>455</sup> a centralised platform for any research. Independent organisations may also have governance systems that act in a similar manner to REC's. Sleeboom-Faulker and others describe that REC's within the UK have over time adopted and favoured a formal model of review that is characteristically aligned with biomedical research, commonly known as procedural ethics.<sup>456</sup> This model is geared toward research of a clinical nature which has the 'potential to cause harm to participants through known or unanticipated risks of treatment interventions'<sup>457</sup> but often overlooks the subtle nuances of situated ethics in qualitative studies. Though there is no centralised system that governs REC's in the UK, common requirements of REC's include study protocols, information regarding and proof of informed consent, risk assessments, information on data protection and ownership and potentially even national security - which some consider outside the remit of the purposes of ethical review and diminish contemplation of how genuine ethical practice is involved in the design of research.<sup>458</sup> However, the inclusion of these documents does not provide concrete assurance that the participants fully understand the research process but rather provide a mechanism for recording that the formal process has been followed.<sup>459</sup>

There is much literature that explores the current state of research ethics that illustrates a growing emphasis toward an emerging over-bureaucratisation. Academic discourse identifies that the

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453 ESRC, 'Esrc Framework for Research Ethics', 2010) p.40

454 In fact, the researcher, after access had been finalised, sat on the REC of their respective School as a PGR representative. Though involved in discussions regarding process they were not involved in assessing ethics applications that were submitted.

455 Integrated Research Application System,

456 Sleeboom-Faulkner and others, 'The Formalization of Social-Science Research Ethics: How Did We Get There?', HAU: Journal of Ethnographic Theory, 7 (2017), 71-79, p.2

457 Kristian Pollock, 'Procedure Versus Process: Ethical Paradigms and the Conduct of Qualitative Research', BMC Medical Ethics, 13.1 (2012), 25, p.3

458 Sleeboom-Faulkner and others, 'The Formalization of Social-Science Research Ethics: How Did We Get There?', HAU: Journal of Ethnographic Theory, 7 (2017), 71-79 p.5

459 Pollock, 'Procedure Versus Process: Ethical Paradigms and the Conduct of Qualitative Research', BMC Medical Ethics, 13.1 (2012), 25, p.3

current ethical regulation model appears to be 'riddled with problems'<sup>460</sup> providing obstacles to the undertaking of research not following traditional bio-medical routes of hypothesis testing.<sup>461</sup> These obstacles reduce the ethical review process to a tick-box exercise or steers researchers away from situations or contexts that may be seen as too risky. Pollock summarises that:

...concerns are mounting that such mechanisms increase the cost, reduce the quality and restrict the scope of research, especially among vulnerable sections of the population who stand to benefit most from the outcome, e.g., older patients and those with dementia, or who are dying.<sup>462</sup>

As the above demonstrates the obligations now placed on ethical review may have tangible impact on research that sits outside what is considered a standard model – and specifically highlights the field of this study. The need for REC's is undisputable as a preventative approach to protect researchers and research participants from any type of harm. Yet evidence of ethical review does not necessarily determine that research will be ethical.

## Ethical encounters

Having outlined the experience of gaining access for the study, we will now reflect on several encounters experienced by the researcher during the fieldwork, highlighting potential opportunities for situated ethical practice, or 'micro-ethics' based on informed and mindful judgements.<sup>463</sup> The researcher has past personal experience of the in-patient hospice, with their mum Jen, and was subject to comprehensive formal ethical review prior to entering the field which identified areas of potential ethical concern. Yet positionality and process alone are not enough to circumvent the fluid nature of qualitative research based on social science methods such as ethnography. These ensuing encounters are what Guillemin and Gillam describe as 'ethically important moments'<sup>464</sup> within the changeable nature of the field in qualitative studies

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460 Ruth McAreevey and Jenny Muir, 'Research Ethics Committees: Values and Power in Higher Education', *International Journal of Social Research Methodology*, 14.5 (2011), 391-405

461 Sarah Richards and others, *Ethical Research with Children: Untold Narratives and Taboos* (London: Palgrave Macmillan, 2015) & indeed it is recognisable that the tension between the traditional framework of hypothesis testing existed within the realms of architectural research and has been somewhat mediated by the emerging popularity of practice-based, or creative practice research that follows the approach of 'discovery science'.

462 Pollock, 'Procedure Versus Process: Ethical Paradigms and the Conduct of Qualitative Research', *BMC Medical Ethics*, 13.1 (2012), 25, p.1


463 Ibid, p.3

464 Marilyns Guillemin and Lynn Gillam, 'Ethics, Reflexivity, and "Ethically Important Moments" in Research', *Qualitative Inquiry*, 10.2 (2004), 261-80

A key event within the organisation of the fieldwork was an introductory session, held during a staff development day, where the researcher presented both themselves and the proposed research activities. This served several purposes; firstly, to aid recruitment to avoid hierarchical coercion. Secondly, and perhaps most importantly was to lessen any suspicion or apprehension towards the researcher being on site and undertaking building observation. Despite the building being the focus of observation, it was reasonable to expect that members of staff working in the environment during these sessions may feel uneasy about an outsider presence. This was perhaps heightened by external reviews taking place in the hospice shortly before the research began. The presentation communicating the researcher's personal connections created commonality, but more importantly a chance to be seen. We might consider this soft introduction a successful approach to reducing ethical tensions when undertaking non-standard research in clinical settings as several staff members recognised the researcher during the observation sessions.

However, despite its success the introduction session had its limitations as not every member of staff was able to attend the staff development day owing to the nature of shift patterns. Though some staff members recognised the researcher - one such staff member joked that the researcher was a 'spy here to look at us' - there were many that did not and thus the presentation did not completely dispel staff members' anxieties of being watched. This meant that the researcher was required to be agile in responding to the hesitations of members of staff who were unsure of the researcher's presence and purpose; whether answering questions about the architectural perspective of hospice environments or providing reassurance that people were not being observed. However, it is important to note that whilst the researcher was approached by staff members on numerous occasions - this prior introduction to the researcher to members of the public was not feasible. Thus, the readiness of the researcher to be able to answer questions and clearly describe the work was even more critical if a visitor or even patient were to approach the researcher. To assist, posters announcing observational research was currently taking place, were displayed throughout the hospice that welcomed any questions, see Fig.7-3. Consequently, only one member of public approached the researcher during the sessions - however this does not diminish the necessity for clear advertisement and alacrity.

Further ethically important moments that occurred during the fieldwork related to the act of gatekeeping; both from the researcher's supervisor and the case study setting itself. As previously mentioned, a member of the researcher's supervisory team acted as a gatekeeper during the




Welsh School of Architecture  
Ysgol Pensaernïaeth Cymru

## Observational research is taking place today

Annie Bellamy, an Architecture PhD candidate from Cardiff University is studying the hospice building. (Not people or their care.)

She is here today to observe this part of the building, and this means you may see her sitting or walking around.

She will be wearing a large name badge so you can easily identify her.



**Any Questions? Contact Us**

Principal Researcher  
Annie Bellamy, PhD candidate, Welsh School of Architecture,  
[Redacted]

Academic Supervisors  
[Redacted]  
[Redacted]

Fig. 7-3. Poster notifying observation taking place

The poster above was placed in numerous locations (not just the area being observed) in order to ensure that anyone entering the space would be aware of the research taking place. A picture of the researcher themselves was included to humanise their presence but also act as a signpost should anyone want to ask questions.



observation sessions. The supervisor assisted in setting up for the sessions, checking in with the on-duty clinical nurse manager to confirm that it was appropriate for observation to take place in the proposed locations. One such example of this, was a session that was due to take place in the day therapy unit of the hospice, which at the time of observation had a small group meeting in session. Upon the supervisor's enquiries the session turned out to be a private event due to a recent community bereavement. This demonstrates the importance of the gatekeeper, not only in protecting the researcher from harm but the interests of the hospice users and the research project by smoothing the path to progress. Here the supervisor, as gatekeeper, is a key member of staff within the hospice and was privy to information regarding circumstances that the researcher may not have been.

This acceptably changed the course of the observation session of that day, with another less sensitive area of the hospice found. Much like the moments described above, this further highlights the need for the researcher to be agile, and in this case flexible, to be ready to change prepared plans in response to the context of the care setting. Secondly in an acute act of gatekeeping, the researcher during their first formal visit to the hospice environment was met with intense suspicion at the reception. The member of staff on duty was unaware of any such research taking place and did not know who the gatekeeper was. The researcher was subsequently accompanied to the office where they were meeting their supervisor by the member of staff – who once confirmed their identity – was satisfied and returned to the reception. Unknowing of any such research taking place, this was an appropriate reaction to the researcher's arrival to safeguard from an unknown outsider gaining access to the clinical environments. Though this may have been an oversight, this moment serves to emphasise the collaboration between the researcher and the host setting and the communication necessary to reduce conflict.

The last ethically important moment to be considered, occurred during the fieldwork itself, when the researcher was observing one of the ward environments. Here, the researcher was seated adjacent to the nurse's station, tucked in and out of the way of the corridor. From this position, much of the ward was visible, including the thresholds to two patient bedrooms, though further inside the rooms was not visible due to the angle at which the researcher was sitting and the lighting inside the rooms. Shortly after sitting down to undertake an observation session in this location, the researcher noticed a visitor arriving, who was stopped by a nurse leaving the same room they were intending to enter. The ensuing conversation saw the visitor become visibly upset and distressed,

during which the same time the patient alarm inside went off which several staff members rushed to attend. Thus far in the observation sessions, the researcher had heard the patient alarm sound innumerable times; however, an instinct of the researcher sensed something was not right. Rather than waiting to see if the situation would resolve itself – the researcher took the immediate decision to end the observation session and remove themselves from the ward, alerting the nurse manager they were leaving and took down all the posters advertising that observation was currently taking place. The researcher's insider status was influential in this decision, as they were able to recognise qualities of the social atmosphere from their personal experience with Jen, indicating a potentially sensitive event. This was ethically important in two ways. Firstly, that given the sensitive nature of the in-patient hospice setting it was not appropriate for active research, even if people were not the focus. Secondly, that observing this atmosphere may be psychologically triggering for the researcher given their closeness to the setting in a similar circumstance. Therefore, it was wholly appropriate for the researcher to stop the observation to protect both members of the public and themselves by taking the ethical decision to protect people over any potential gain via data collection.

The examples selected above of 'ethically important moments' highlight the way in which this care setting required an alert and responsive mindset of the researcher and dynamic risk assessment – particularly considering their insider status. It is felt that insider knowledge contributed to confidence in explaining the non-typical research practice of an architectural academic in a healthcare environment especially when needing to explain architectural terms to laypersons. As ethically important moments, that posed challenges and obstacles to the research process, the researcher concurs with Tutenel and others that it is these 'uncomfortable moments between different viewpoints, assumptions, and research traditions in themselves [that have] created a space of reflection; which would not have existed without these differences'.<sup>465</sup> These moments situated in and between their insider and outsider status forced the researcher to be acutely aware of their actions and behaviours whilst in the field demanding reflexivity.

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<sup>465</sup> Tutenel and others, 'Conversations between Procedural and Situated Ethics: Learning from Video Research with Children in a Cancer Care Ward', *The Design Journal*, 22.sup1 (2019), 641-54 p.650

## Ethical practice of architecture

'Ethics' can be broadly defined as the study of what is morally right and wrong.<sup>466</sup> Over time this has evolved to become an umbrella term that covers not only morals, but the description of actions, behaviours, and process of gaining necessary approval to undertake research that involves human participants and/or tissue. Furthermore, ethics can be divided into two distinct categories, an informal measure of conduct and formal research ethics that governs academic research. Research ethics, as defined by the Economic and Social Research Council are 'the moral principles and practices guiding research, from its inception through to completion and publication of results and beyond – for example, the curation of data and physical samples, knowledge exchange and impact activities after the research has been published.'<sup>467</sup> The field of study for this thesis, the in-patient hospice, posed numerous ethical challenges for the researcher under both categories of personal and research ethics. This chapter considers the different ways in which ethics was implicated in the process of the research but additionally the way in which it governs broader architectural practice; and how this might impact on not only research, but that which is undertaken in fields and settings in which architectural or design research is uncommon.

## Professional responsibilities

As described in a polemic for the UK-based architectural publication, *The Architectural Review*, Owen Hopkins states that 'it would be hard not to be conscious of the crescendo of articles over recent months and years dealing with the question of architecture's political and social role, and, more broadly the agency of architects'.<sup>468</sup> Aligned with a global shift in social and political movements and global issues - such as Black Lives Matter and the climate emergency - the question of ethics, whether ethical architecture or the ethics of architecture, has over the past decade become a pertinent issue for the profession. This growing awareness aligns with the theoretical position of architecture as a form of care, eminently defined by Tronto and Fisher as being:

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466 n.a, Ethics (Cambridge Dictionary, n.d) <<https://dictionary.cambridge.org/dictionary/english/ethics>> [accessed 6th July]

467 Economic and Social Research Council, Key Terms Glossary (ESCR, n.d) <<https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/useful-resources/key-terms-glossary/>> [accessed 1st July]

468 Owen Hopkins, 'Why Is Ethics Such an Important Issue for Architects?', *The Architectural Review* (2015), <<https://www.architectural-review.com/essays/why-is-ethics-such-an-important-issue-for-architects>> [accessed 5th July 2021]

a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.<sup>469</sup>

With regards to this understanding of care practices, Krasny writes it is 'important to see architecture as an empowering support for everyday living and social reproduction'.<sup>470</sup> Architects, and more broadly the design profession, may be considered the custodians of our built environment, even considering the traditional role of architects as 'master builders' being diminished by ever-growing specialisation in the construction industry and capitalist influences on construction developments. Historically, the architect held a central role, organising multi-disciplinary design teams and leading co-ordination of design and construction information – however as construction projects have grown increasingly complex, so has it 'become increasingly difficult for designers to be responsible for all aspects of design...and act as contract administrator'<sup>471</sup> with this complexity requiring more and more specialists as part of the overall design team.

As a protected and chartered profession there is an expectation that registered architects<sup>472</sup> must uphold a form of 'ethics defined by the code of conducts of the regulating, Architects Registration Board (ARB), and the professional, Royal Institute of British Architects (RIBA), bodies of architects in the United Kingdom. It is worth noting that any practicing architect is mandated by law to uphold current registration with ARB, the regulating body, to protect the consumer; chartered membership of RIBA on the other hand, is an individual choice, as the institution is primarily predicated on representing the interests of architects and driving 'excellence in architecture'.<sup>473</sup> Membership of the two is not mutually exclusive, with approximately 28,000 chartered members of RIBA and 42,000 registered architects with ARB.<sup>474</sup> These codes state that architects must conduct themselves with competence and 'shall act competently, conscientiously and responsibly and are expected to apply

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469 Joan C. Tronto and Berenice Malka Fisher, 'Toward a Feminist Theory of Caring', 1990)

470 Elke Krasny, 'Care', *Solitude Journal*, 1, Collective Care & Response-ability (2020) p.70

471 Sir Michael Latham, 'Constructing the Team: Joint Review of Procurement and Contractual Arrangements in the United Kingdom Construction Industry', (London: HMSO, 1994) p.47

472 Registered architects however are not the only architectural professionals, for instance, architectural assistants are not bound by the same Code of Conducts as they are not qualified, other roles such as technicians will be regulated by their respective institutions and therefore are not guaranteed a coherent code of practice.

473 RIBA, The Royal Institute of British Architects (n.d) <<https://www.architecture.com/about>> [accessed 15th August]

474 Designing Buildings Wiki, Royal Institute of Architects Riba (2021) <[https://www.designingbuildings.co.uk/wiki/Royal\\_Institute\\_of\\_British\\_Architects\\_RIBA](https://www.designingbuildings.co.uk/wiki/Royal_Institute_of_British_Architects_RIBA)> [accessed 10th August] & ARB, Arb Annual Report & Financial Statements for 2020 (ARB, 2020) <<https://arb.org.uk/publications/publications-list/annual-report-2020/>> [accessed 13th August]

reasonable standards of skill, knowledge and care in the performance of all their work.'<sup>475</sup> These code of conducts, despite not explicitly referencing ethics, imply a moral code of responsibility and behaviour. The 2018 findings of RIBA's Ethics and Sustainable Development called for 'determined leadership on ethics and sustainable development...and [to] ensure that a commitment to the public interest, social purpose and sustainable development is a core requirement of Chartered and Chartered practice membership'.<sup>476</sup> Furthermore, as part of RIBA's proposed overhaul of architectural education and continuing professional development, 'The Way Ahead' core competencies have been identified to ensure that the knowledge of RIBA Chartered architect's and students enrolled on RIBA validated courses will be relevant and up to date. One of the first three competencies drafted, shown in Fig.7-4 outlines 'Ethical Practice'.

Whilst the 'Knowledge Schedule' outlines the many parameters that ethical practice refers to, of particular significance is the section 'Duty to Society and the End User' that lists the importance of not only technical aspects such as space standards but social value and responsibility. There are also vital additional items in the schedule, such as learning how to identify genuine ethical issues and resolution via decision-making and advocacy. Whilst architecture and design is not a 'silver bullet' which can solely eradicate or solve complex issues, the process of design and its physical outcomes can play a vital role in influencing positive experiences and change for communities, cultures, and specific population groups. Though not an exclusive motivation for all architects, some see the heart of the profession as being 'the challenge and the responsibility of imagining and nurturing a truly human and sustainable home for us all'.<sup>477</sup> 'Spatial Agency: Other Ways of Doing Architecture' a research project by architects and educators, Jeremy Till and Tatjana Schneider defines ethics in architecture as a characteristic:

in the sense of 'being-for the Other', to 'assume responsibility for the Other'-with the Other being a 'mix of builders, users, occupiers, observers of architecture'. Basically, everyone who is affected by the production, construction and inhabitation of architecture. To have an ethical stance as an architect does not therefore mean to adhere to the 'ethics of the profession', but to acknowledge and work with the desires and needs of these 'others'.<sup>478</sup>

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475 Architects Registration Board, 'The Architects Code: Standards of Professional Conduct and Practice', (ARB, 2017) & Royal Institute of British Architects, 'Riba: Code of Professional Conduct', (RIBA, 2021) p.9

476 RIBA, 'Findings of the Riba Ethics and Sustainable Development Commission', (RIBA, 2018) p.4

477 Jane Collier, 'The Art of Moral Imagination: Ethics in the Practice of Architecture', *Journal of Business Ethics*, 66.2/3 (2006), 307-17

478 Tatjana Schneider and others, *Spatial Agency: Why?* (n.d) <<https://www.spatialagency.net/database/why/professional/>> [accessed 5th May]

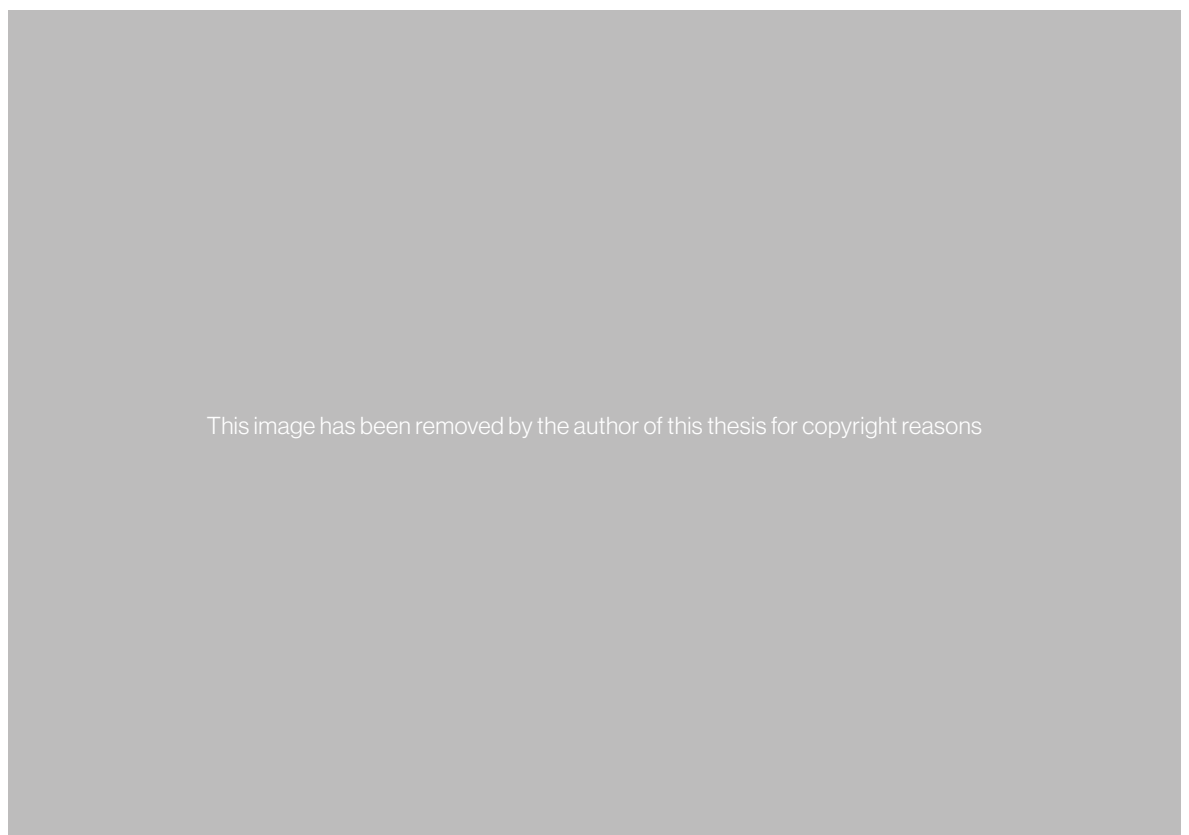


Fig. 7-4. RIBA's Draft Knowledge Schedule, Ethical Practice

The above is a draft document from the Royal Institute of British Architect's proposed mandatory competences to provide assurance that architects have the necessary skills to practice. This knowledge schedule specifically outlines the variety of ways the profession must commit to 'ethical practice'.

Here we may posit that the architectural community has a responsibility to meaningfully consider for whom we are designing for and how the profession can facilitate positive outcomes that are appropriate and responsive. Considering the above, ethical practice of architecture champions the democratisation of design and the built environment to be critically responsive to potential end users and not merely an aesthetic expression of form. Furthermore, this concern of architecture and ethics highlights the importance of empathy - the ability to attune to and understand the requirements of future inhabitants of buildings and spaces. Considering this with regards to both the ethics of architectural practice and an approach to the built environment 'empathy deepens the architect's understanding of user needs and feelings and strengthens the users' appreciation of what it will mean to 'own' their habitation of that space'.<sup>479</sup>

The act of being empathetic requires emotional labour on part of the architect and/or designer in order to place themselves in the context and situation of the brief to which they are responding to – which they 'may not have 'access' to first-hand lived experiences of'.<sup>480</sup> Niall McLaughlin of Niall McLaughlin Architects, the designers of an award-winning residential scheme for those with Alzheimer's, reflects on this projection as a form of intersubjectivity - 'an architect must strive to imagine what it is to be someone else experiencing a place. This intuition is the cornerstone of an architect's role,'<sup>481</sup> see Fig.7-5. Given the specialised field of the in-patient hospice we might consider a degree of empathy is a necessity for an architect responsible for intervening in the built environment. Reflecting on the notion of intersubjectivity, Annemans and others write that 'truly placing oneself in someone else's shoes is hardly possible, being aware of this and making design decisions based on the best available information is.'<sup>482</sup> Though potentially nurtured during architectural education, student exposure is to an extent shaped by the outlook of their respective studio and attitudes of the studio leaders. Though studios are governed by module and programme Learning Outcome's set at university level, many programmes are supported by external architectural practitioners acting as tutors. As such there is a debate regarding the extent to which these are observed. As empathetic design is not an explicitly taught skill there are no guarantees that this will be used in design projects.

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479 Collier, 'The Art of Moral Imagination: Ethics in the Practice of Architecture', *Journal of Business Ethics*, 66.2/3 (2006), 307-17

480 Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969

481 Niall McLaughlin Architects, 'Alzheimer's Respite Centre', *Bartlett Design Research Folios* (2016) p.15

482 Annemans and others, 'Informing Hospital Design through Research on Patient Experience', *The Design Journal*, 20.sup1 (2017), S2389-S96, p.S2389



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Fig. 7-5. Research methods for the Alzheimers Respite Centre, Niall McLaughlin Architects, 2009  
The images shown on the page are examples of the extensive activities undertaken by Niall McLaughlin Architects with the community and residents of the alzheimers respite centre they designed. This included walking tours, periods of observation, photo-elicitation, 1:1 model making.

## The relationship between research and design practices

As previously discussed, within broader architectural practice there are standards for, and a growing movement toward the role of ethics as informal contracts for moral responsibility. To further understand a position of ethics for this thesis we must reflect on the nature of how architectural research is conducted and the challenges that are raised by this. Research can be defined as 'a detailed study of a subject, especially in order to discover (new) information or to reach a (new) understanding'.<sup>483</sup> However, Christopher Frayling, a prominent academic in the field of design and previous dean of the Royal College of Art, in 'Research in Art and Design' confers that research has 'two basic definitions, one with a little r and one with big R'.<sup>484</sup> Research with a 'little r' may be observed occurring frequently in the day-to-day practice of architects. Architects 'research' their client and their needs, the site and its context, technical products, and systems, and spend time 'researching' spatial organisations and layouts to understand the best approach for the project. Furthermore, 'research' may be used as a post-rationalisation of the design process as a sign of acclaim for their work to demonstrate a specialist knowledge of an area. The term may also be cited in reference to collections of, or specific projects, sometimes referred to as creative practice in architecture that "tell the back story" of key works in order to begin to explicate key aspects of that practice.<sup>485</sup> Whereas academic research with a big 'R' is held to standards of recognised originality, significance, and rigour via such processes as peer-review assessment and REF, the Research Excellence Framework.<sup>486</sup> The aforementioned references may have more in common with informal inquiry or investigation contrasting with academic research that contributes to the development of innovation in products or processes and as such may not be acknowledged to be forms of research that necessitate ethical awareness.<sup>487</sup>

Research with a little 'r' may also be seen occurring within architectural education as students engage with research-like activities to assist them in understanding their design briefs. This may

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483 n.a, Research (Cambridge Dictionary, n.d) <<https://dictionary.cambridge.org/dictionary/english/research>> [accessed 4th July]

484 Christopher Frayling, 'Royal College of Art Research Papers 1993/4: Research in Art and Design', (London: Royal College of Art, 1993), p.1

485 Richard Blythe and Leon Schaik, 'What If Design Practice Matters?', 2013), pp. 53-70, p.61

486 REF, What Is the Ref? (n.d) <<https://www.ref.ac.uk/about/what-is-the-ref/>> [accessed 16th August ] & this is process of expert review undertaken by four UK higher education funding bodies that assesses the research produced institutions of higher education in order to ensure parity of quality and impact.

487 Frayling, 'Royal College of Art Research Papers 1993/4: Research in Art and Design', (London: Royal College of Art, 1993) p.1

include photography of public spaces, attempting to engage with users, built interventions in the public realm. It is more common to see these activities and ethical applications for fieldwork undertaken for dissertation modules; yet ethical applications for design studio work are less common and are usually seen as a one-time tick-box exercise to fulfil requirements for research specific modules. Describing ethical review in higher education, McAreavey and Muir describe that students typically 'do ethics at a particular point in time and so do not feel the need to reconsider it throughout the research process and so may actually neglect to address ongoing ethical issues within the research'.<sup>488</sup> Note the language used here - 'do' - implies a singular action that is completed. Anecdotally, the researcher has observed research behaviours in design studios which raised ethical questions for the author. Though there is debate regarding how you teach ethical awareness; Sleeboom-Faulkner and others suggest that students could be coached via activities such as role-play to imagine situations in the field that assists them in developing skills to improvise and adapt skilfully.<sup>489</sup>

There is a need for architectural research both with a big and little 'R' especially for built environments and subsequent building types that serve care purposes to ensure efficiency of function and quality of experience. Depending on the projects aims and objectives, architectural research can be qualitative in nature, with aspirations to understand 'architectural atmosphere' that is the phenomenological qualities of space that contribute to qualities of lived experience. Aspects of architectural atmosphere such as light, texture and other sensory features call for a physical presence in the setting, as this material cannot be engaged with meaningfully via desktop methods, see Practice Note 3 on site visits. As discussed by Stephen Kieran in the Journal of Architectural Education,

[r]esearch brings science to our art. Responses to place and program provide intuition to guide form. Research provides information and insight that enhances the performance of our intuitions...to move the art of architecture forward, however, we need to supplement intuition with science...We need a deep research ethic to guide the art of intuition.<sup>490</sup>

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488 McAreavey and Muir, 'Research Ethics Committees: Values and Power in Higher Education', *International Journal of Social Research Methodology*, 14.5 (2011), 391-405, p.400

489 Sleeboom-Faulkner and others, 'The Formalization of Social-Science Research Ethics: How Did We Get There?', *HAU: Journal of Ethnographic Theory*, 7 (2017), 71-79, p.4

490 Stephen Kieran, 'Research in Design: Planning Doing Monitoring Learning', *Journal of Architectural Education*, 61.1 (2007), 27-31, p.31

The research ethic referred to above, this thesis judges not only to be the rigorous application of research practice but also in application and consideration of ethics itself. As ethnography is a commonly used method in qualitative studies in architecture to study the socio-geographic context of the built environment this raises questions of how architectural researchers can purposively access fields that are not their own, and to what extent their own experience can bear influence on this.<sup>491</sup>

### Researcher positionality

This thesis adopts an uncommon perspective, as the researcher has direct personal experience of the environment being studied. Therefore, the research was undertaken with what is commonly referred to as insider and outsider status, referring to the 'degree in which a researcher is located either within or outside a group being researched, because of her or his common lived experience or status as a member of that group'.<sup>492</sup> The researcher can be considered an insider with regards to knowing the environment specifically as a visitor, who spent approximately a week in a hospice as her mother died. It is important to note that this means that the insider knowledge is of sharing a common lived experience of the hospice building and not of being or having been a member of the staff, or a patient of the hospice. Motivated to undertake the study owing to their personal experience, the dual positionality of the researcher had both positive and negative consequences on the research process. Detangling the insider-outsider status of the researcher herewith is important for multiple reasons; firstly, to discern the potential for harm to the researcher themselves and secondly to interpret the way in which this duality influenced the research process itself.

The potential risks faced by researchers is an emerging area of discourse within the broader conversations regarding a holistic approach to ethics in qualitative research. The Quality Inquiry into the *Risk to Well-Being of Researchers in Qualitative Research* published in 2007 by Cardiff University acknowledged that there is an increasing awareness of not only physical but emotional harm to researchers and sought to provide 'practical recommendations to reduce research-related harm'.<sup>493</sup>

Reflecting on the emotional labour of qualitative studies Emerald and Carpenter comment that:

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491 Cranz, *Ethnography for Designers*, (2016), p.5

492 Susan Gair, 'Feeling Their Stories: Contemplating Empathy, Insider/Outsider Positionings, and Enriching Qualitative Research', *Qualitative Health Research*, 22.1 (2011), 134-43, p.137

493 Michael Bloor and others, 'Quality (Ncrm) Commissioned Inquiry into the Risk to Well-Being of Researchers in Qualitative Research', (Cardiff: Cardiff University 2007) & Michael Bloor and others, 'Unprepared for the Worst: Risks of Harm for Qualitative Researchers', *Methodological Innovations Online*, 5.1 (2010), 45-55, p.46

[r]esearchers are familiar with ethics applications that endeavor to ensure the safety of their participants, but only recently have they been urged to examine the short and long-term effects of research on themselves and consider the risks to their own safety and well-being.<sup>494</sup>

In the case of this research, the in-patient hospice could pose potential psychological risks to an 'outsider' researcher coming into the field owing to the sensitive nature of patient care, however, the researcher of this thesis also has insider status. Their experience of the in-patient hospice as a daughter and family member meant that they were not neutral or value-free entering the study. This insider status helped them, to an extent, anticipate the environment of the scoping studies and the case study setting, by drawing on the similarities of the hospice typology despite it being a completely new setting. Despite this, additional learning was required before undertaking the case study fieldwork to achieve a balance between practical knowledge of the hospice and their personal experience and to minimise any risk of bias from the personal experience. Drawing on personal experience however has not historically been seen favourably by traditional academia which 'instead encourages defined space between the 'researcher' and the 'field', asserting that the removal of the subjectivity of the researchers' own positionality is evidence of rigour that protects against bias.'<sup>495</sup>

Despite legitimate concerns of subjectivity and bias, qualitative studies can draw advantages from insider status. Breen, summarising Bonner and Tolhorst, states that these include 'superior understanding of the group's culture; the ability to interact naturally with its group and its members; and a previously established and, therefore greater, relational intimacy with the group'.<sup>496</sup> The researcher's insider status of personal connection to the hospice environment, presented to staff members prior to data collection taking place enabled the researcher to minimise their formal academic 'researcher' presence and gain 'more rapid and more complete acceptance by their participants'.<sup>497</sup> Furthermore, insider status was advantageous in quelling concerns and suspicion of the 'outsider' architectural discipline that deals with a wholly different mode of inquiry, methodology

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494 Elke Emerald and Lorelei Carpenter, 'Vulnerability and Emotions in Research: Risks, Dilemmas, and Doubts', *Qualitative Inquiry*, 21.8 (2015), 741-50, p.741

495 Bellamy, 'The Insider Vs the Outsider: Architectural Investigations of Palliative Care Environments as Both Researcher and Daughter', in AHRA Young Researchers Symposium (Newcastle University 2020)

496 Lauren Breen, 'The Researcher 'in the Middle?: Negotiating the Insider/Outsider Dichotomy', *ECU Publications*, 19 (2007) p.163

497 Sonya Dwyer and Jennifer Buckle, 'The Space Between: On Being an Insider-Outsider in Qualitative Research', *Int J Qual Meth*, 8 (2009), p.58

and language as typically seen in bio-medical research. For example, using qualitative rather than quantitative methods and the use of linguistic terms pertaining to social sciences in contrast to overtly medical terms of reference.

The positive influence of insider experience is noted on the fieldwork and the data collection, whereby the commonality of previously being in a hospice environment was beneficial to undertaking the in-depth interviews with members of staff. The familiarity or 'common wounds'<sup>498</sup> additionally offered the second phase of research, Building Observation, the benefit of recognising everyday 'insider meanings'<sup>499</sup> that may be missed by those with outsider status. However, this distinctive status posed significant concern for the researcher's own well-being. A previous study conducted by the researcher occurred a few years after their mother's death during which the researcher was much 'closer' to their grief, recording significant amounts of auto-ethnographic writing in a personal diary that was skimmed for relevant academic and architectural content. The research for this thesis takes place seven years after Jen's death, time which has given the researcher time to heal. Nevertheless, the second phase of research, Building Observation, marked the first time the researcher had spent sustained periods of time back in the clinical settings of a hospice ward since her mother had died. Despite the time passed and the researcher's best intentions to remain as subjective as possible, insider status had inevitable negative potential for harm. Undertaking this study with the benefit of further distance from the experience with Jen, the researcher from a professional perspective was able to develop resilience in knowing when and where to seek help in support of their personal well-being.

Critical to being able to undertake and continue the fieldwork was the support of the researcher's academic supervisors who recognised, more so, the potential for harm. Therefore, they ensured that structural support was put in place. Firstly, one of the supervisors, who as an overall gatekeeper and key member of staff at the case study setting oversaw the observation sessions in the hospice. Describing themselves as a 'mother hen', the supervisor's indirect presence during the fieldwork in a nearby workspace within the setting meant that, not only did the researcher have the confidence that someone known to them was directly available if needed during the sessions, but there was an empty and neutral space to retreat once the session was finished to decompress. Acting, in another capacity as a gatekeeper, the supervisor confirmed ahead of the observation sessions

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498 Gair, 'Feeling Their Stories: Contemplating Empathy, Insider/Outsider Positionings, and Enriching Qualitative Research', *Qualitative Health Research*, 22.1 (2011), 134-43, p.138

499 Anderson, 'Analytic Autoethnography', *Journal of Contemporary Ethnography*, 35.4 (2006), 373-95, p.389

if the proposed locations for that day were viable – thus offering a dual safeguarding role, as this protected both the researcher and the inhabitants of the spaces. The second way in which the supervisory team managed the researcher was in championing well-being via open discussions in supervisory meetings and suggesting the organisation of a de-briefing meeting with the spiritual care co-ordinator at the case study setting once the fieldwork had been completed. Though in contrast to the findings of Bloor and others, that doctoral researchers are most at risk of physical and emotional harm when undertaking qualitative research owing to 'supervisors who are failing to manage researcher risks effectively'<sup>500</sup> – the researcher here feels that the support of their supervisors was effective in reducing harm due to their insider status. Furthermore, this enabled the researcher to feel confident in 'deliberate self-exposure'<sup>501</sup> to research within the field of death and dying given their insider status and thus 'speak their own truth in ways that contribute to knowledge and understanding'<sup>502</sup> of an architectural building type under-researched.

Exploring the insider status of the researcher it is evident that this had both negative and positive influences on the research process. However, the language of insider-outsider positionality implies a distinct boundary, of an identity that is turned on or off. Reducing positionality to a 'simplistic dualism...as either an empathic insider or an ill-informed outsider can deny the powerful, political complexities inherent in the concepts, and deny other research possibilities and potential'.<sup>503</sup> Indeed, there were occasions where concern was raised by academic colleagues about the closeness of the researcher to the field as an insider and having undue emotional influence on the rigour of the thesis. Yet, despite the researcher willingly entering the field within which they have personal experience – it was not felt that this solely defined the research process. Though it is evident that the closeness offered by prior knowledge of the in-patient hospice was beneficial to certain aspects of the research - this did not occur in a vacuum. Previous experience was not enough to dispel the anxieties of allowing an outsider into a highly sensitive setting. Here, the researcher concurs with Breen that insider and outsider positionality is rather one of being 'in the middle'<sup>504</sup>

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500 Bloor and others, 'Unprepared for the Worst: Risks of Harm for Qualitative Researchers', *Methodological Innovations Online*, 5.1 (2010), 45-55, p.45

501 Jenny Hockey, 'Closing in on Death? Reflections on Research and Researchers in the Field of Death and Dying', *Health Sociology Review*, 16.5 (2007), 436-46

502 Emerald and Carpenter, 'Vulnerability and Emotions in Research: Risks, Dilemmas, and Doubts', *Qualitative Inquiry*, 21.8 (2015), 741-50, p.748

503 Gair, 'Feeling Their Stories: Contemplating Empathy, Insider/Outsider Positionings, and Enriching Qualitative Research', *Qualitative Health Research*, 22.1 (2011), 134-43, p.138

504 Breen, 'The Researcher 'in the Middle?: Negotiating the Insider/Outsider Dichotomy', *ECU Publications*, 19 (2007) p.163



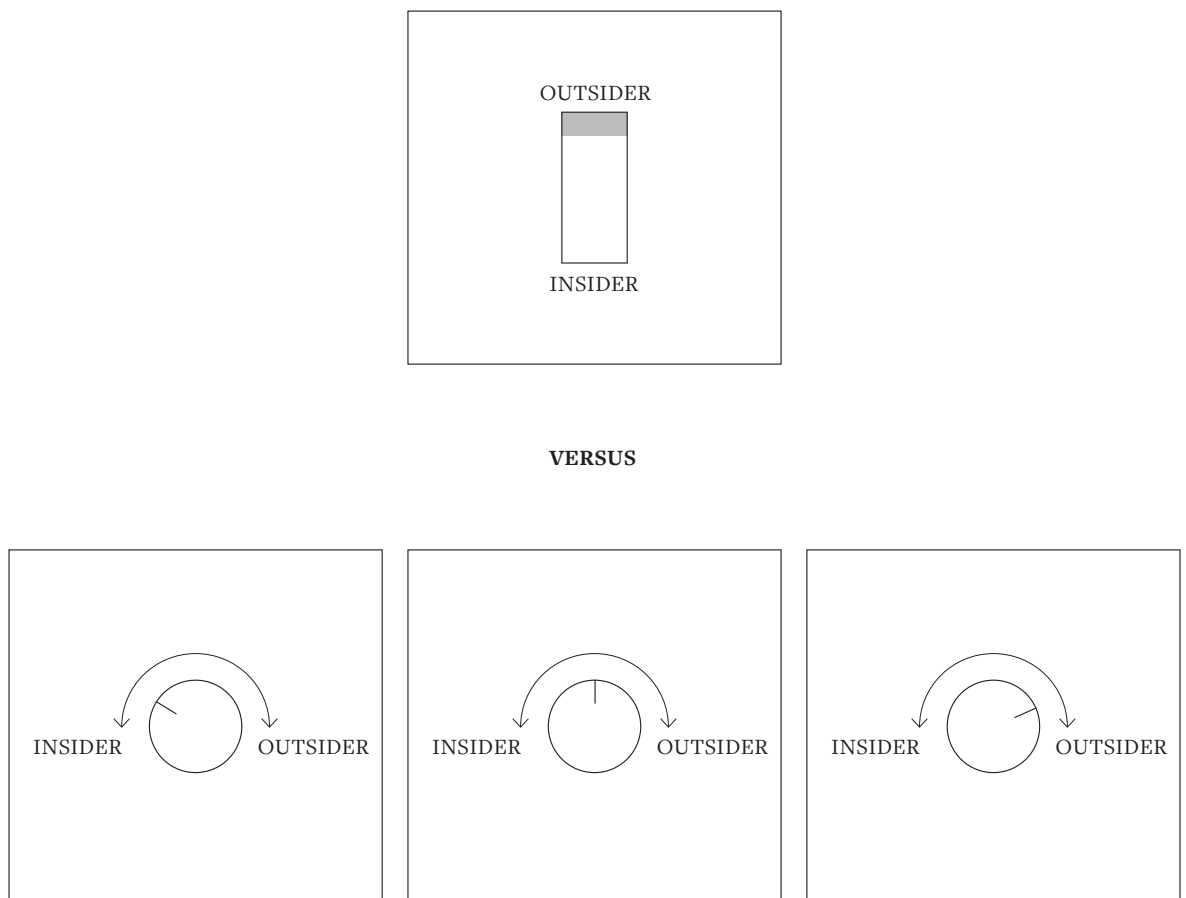


Fig. 7-6. Insider vs. outsider

Using the analogy of lightswitches, the top image describes the rigid model of insider versus outsider, of which only one position can be dominant. The image below, depicts this dualistic positionality as a sliding scale which moves in and between the two identities.

and is more akin to a position of a sliding scale that is 'better conceptualised on a continuum'.<sup>505</sup> The researcher recognises that there were situations during the fieldwork where they felt less or more inside or outside and that this shifted in alignment with the environment, people, and surroundings at the time.

Those undertaking qualitative studies, by its very nature are situated within the research process and 'cannot retreat to a distant "researcher" role'<sup>506</sup>, as described in Fig.7-6. In further support of Breen's position, the researcher poses that one can never explicitly disentangle or leave behind a specific aspect of their being in the fluidity of qualitative research:

we may be closer to the insider position or closer to the outsider position, but because our perspective is shaped by our position as a researcher (which includes having read much literature on the research topic), we cannot fully occupy one or the other of those positions.<sup>507</sup>

As such, this in-between state, it is felt enriched the research despite the ethical concerns for the researcher's well-being. The informal tacit knowledge did not fully shape the design of the research and subsequent fieldwork by generalising the individual experience of the researcher – but rather allowed recollections of what architectural theorist Juhani Pallasmaa describes as 'the minute situations of daily life'<sup>508</sup> to offer clarity and enlightenment.

### Impact for research in practice

Documented in the preceding section are 'ethically important moments' encountered by the researcher during building observation undertaken in the in-patient hospice setting. In a similar vein to this - informal research is undertaken by architects and designers in daily practice. This research - with a little 'r' unveils potential for ethical concerns regarding their responsibilities and positionality. As consultants, contracted to perform pre-agreed services on professional contracts, they are invited into the environments of which they are working. This does not afford insider status

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<sup>505</sup> Ibid, p.163

<sup>506</sup> Dwyer and Buckle, 'The Space Between: On Being an Insider-Outsider in Qualitative Research', *Int J Qual Meth*, 8 (2009) p.61

<sup>507</sup> Ibid, p.61

<sup>508</sup> Pallasmaa, *The Eyes of the Skin: Architecture and the Senses* (Chichester; Hoboken, NJ: Wiley-Academy ; John Wiley & Sons, 2005), p.65

but lessens the extent to which they may be considered outsiders. As such, to discuss project briefs or hold design meetings with members of staff may not require ethical approval in the same manner, if at all, as was required by the researcher for this thesis. It may be argued that subjecting architects and designers to the same level of ethical review as academics may not be proportionate to their involvement in the field. The reality of RIBA work stages<sup>509</sup>, and financial constraints, does not allow time for research and brief development before RIBA Stage 0, Strategic Definition. This combination of restrictions 'often result in a minimal user engagement, designers are unable to obtain this direct input from users and become dependent upon indirect sources of human information'.<sup>510</sup> Additionally, the duration of site visits could be constrained by potential journey times between the architect's office and the client's location thus reducing the time available to be immersed in the context of their proposed end user. Furthermore, as Hignett and Lu write 'for large organisations in particular, the architect may be buffered from the actual building users by client committees, estates departments, in-house project managers'.<sup>511</sup>

Writing in 'The Problem with Ethics' Hodge described colleagues involved in qualitative studies that did not value time invested in the field; concluding that research practice in the manner of "drop in, get the data, get out"...is unlikely to provide anything other than superficial data that ignores nuance and change'.<sup>512</sup> Here then lies a critical issue for the ethical practice of architects whom may not recognise that the work they do day-to-day carries ethical implications. As Breen summarises 'architectural practitioners are primarily concerned with the conception and realisation of built environments, inclined to move on swiftly to the next project, generally spending little time evaluating precise effects of their creations after they have been built'.<sup>513</sup> Many architects who have designed in-patient hospices recognise the need to engage with the members of staff and if possible, patients or visitors, to gain clarity and understanding regarding the aspirations for their spatial requirements in everyday life. Short visits may not afford reliable analysis of the multitude of user narratives and the way in which they inhabit the hospice building at various times. Furthermore, a pre-arranged structured phone interview with an architect working for a practice that specialises in hospice design revealed that there was no involvement of ethical review

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509 RIBA, 'Riba Plan of Work 2020', (London, Royal Institute of British Architects, 2020)

510 Annemans and others, 'Informing Hospital Design through Research on Patient Experience', *The Design Journal*, 20.sup1 (2017), S2389-S96, p.S2390

511 Hignett and Lu, 'An Investigation of the Use of Health Building Notes by Uk Healthcare Building Designers', *Applied Ergonomics*, 40.4 (2009), 608-16, p.613

512 G. Derrick Hodge, 'The Problem with Ethics', *PoLAR: Political and Legal Anthropology Review*, 36.2 (2013), 286-97, p.292

513 Breen, '11 Designerly Enquiry', in *Ways to Study: Design Research and Typology* (OpenCourseWare: TU Delft, 2020) pg.99

when working with stakeholders of projects as part of their design process. It was noted that speaking with members of staff regarding their job roles was not thought to pose any ethical implications.<sup>514</sup> To an academic researcher this may raise concerns of bias. It would certainly be ethically dubious with regards to participant recruitment and the potential for coercion, miscommunication, and misrepresentation, and how the data collected is presented back to hospice organisations as the participants employers.

Further reflecting on the notion of 'dropping in', we must also consider the ethical role of architects beyond their direct involvement during the RIBA Workstage's 0, Strategic Definition, to 6, Handover. Though not required by law, post-occupancy evaluations (POE) offer architects (and their clients) a method in which to learn about the way the building they have designed performs. A joint report into the use of POE by the University of Reading and RIBA states that:

POE is widely recognised as being central to addressing the gap between designed intentions and the actual outcomes in use, and pivotal in understanding the wider socio-economic, environmental and cultural impacts of investment in good design. POE is not just about energy and user satisfaction but can also include more intangible issues such as productivity, identity, atmosphere and community.<sup>515</sup>

Engaging with the client's post-completion provides the opportunity to reflect and to offer ongoing support for the building in use and its future needs, particularly for clients with long term interests in a building. However, POE is not yet an industry norm or regulatory requirement – highlighted by the findings of 2020 the annual survey of the Architects Journal's top 100 architectural practices in the UK:

post-occupancy evaluation is 'always' done by just 4 per cent of AJ100 practices and 'frequently' done by 22 per cent, while a quarter of firms never do so and around half (48 per cent) only seek to evaluate the performance of their projects 'occasionally'<sup>516</sup>

Literature around POE poses several reasons as to why this is not yet a standard part of the architect's practice that relate to the inherent organisation of the construction industry. There are the additional costs and commitment of time associated with the commissioning and completion

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514 Annie Bellamy, Phone Interview to In-patient hospice specialist - Architect received 27th January

515 RIBA and others, 'Pathways to Poe, Value of Architects', University of Reading, RIBA, 2016), p.1

516 Philip Watson, The Uncomfortable Truth About Post-Occupancy Evaluation (Architect's Journal: 2020) <<https://www.architectsjournal.co.uk/news/opinion/the-uncomfortable-truth-about-post-occupancy-evaluation>> [accessed 15th July]

of the study; the lack of a clear definition of what a POE encompasses, and a hesitation toward the process for its potential to bring attention to aspects of poor performance.<sup>517</sup> Hay et al point to this perception of POE's potential to emphasise negative aspects of a project as 'a particular problem from an insurance point of view'<sup>518</sup> – expressing that this might not only hinder architect's desire to carry out POE related work but that there is inadequate protocol within the insurance industry itself to cover this, risking rises in professional indemnity insurance (PII) premiums.

POE also raises the question of who the information serves. Does it remain with solely the architect and the client, creating a silo of knowledge for specialist architecture practices to hold insider knowledge unavailable to others? Or is there a responsibility and mechanism by which POE could publish and disseminate their findings for others to learn from? These two approaches highlight the contrasting interests between architectural researchers and practitioners; the former retains potential fee earning opportunities by maintaining exclusivity and specialism, the latter achieves intellectual capital from sharing, much like the way in which hospice providers have developed an informal support network to exchange knowledge regarding building projects as discussed in Chapter Four. It is worth acknowledging that in the aforementioned report, one of the case studies discussing POE in practice was in fact JDDK, an architectural practice that specialises in the design of in-patient hospices who have partnered with Northumbria University to map their post-occupancy analysis. However, despite this information being collated as an on-going initiative since 2016 that highlights their own findings of best practice it is not clear how this information is shared or made accessible to others beyond a poster that was presented at a UK palliative care conference, see Fig.7-7.

## Chapter reflections

Reflecting on the role of ethics in this research, foremost it must be acknowledged that as the researcher has direct personal experience of the in-patient hospice, there was an acute awareness of the necessity to ensure ethical practice for any type of research that may take place in that environment; whether quantitative or qualitative. The ethical encounters of the researcher align with Pollock's conclusion that 'the need for ethical review and regulation is not at issue. However,

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<sup>517</sup> RIBA and others, 'Pathways to Poe, Value of Architects', University of Reading, RIBA, 2016) p.1

<sup>518</sup> Hay and others, 'Post-Occupancy Evaluation in Architecture: Experiences and Perspectives from Uk Practice', *Building Research & Information*, 46.6 (2018), 698-710, p.702

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copyright reasons

Fig. 7-7. Hospice POE study

A summary of the findings of JDDK's POE project in collaboration with Northumbria University and an external research company.

[they] must be appropriate and proportionate to the risks involved'<sup>519</sup> to ensure that innovative research is not prevented, especially that which involves multiple disciplines and serves vulnerable and in need population groups.<sup>520</sup> Critical to this position is the acknowledgement that the formal process of ethical review is but one element that encompasses a holistic approach to 'ethics. Finding common ground between the existing literature on the role of REC's, the experience of the gaining ethical approvals in the case of this thesis was that of bias toward non-clinical research and disciplines. As Pollock states the 'regulatory mechanisms intended to protect participants now threaten to under-mine and even stifle the research enterprise, especially as this relates to sensitive issues and hard to reach groups'.<sup>521</sup>

Overall, the process to gaining full ethical approval required seven applications to three separate institutions and took just over a year to complete, see Fig.7-1 on pg.265. This represented just over a third of the official length of registration<sup>522</sup> of the researcher as a self-funded doctoral candidate and was a period of anxiety, as the uncertainty of access put the intended project and thesis at risk. Consequently, this experience became a distinct area of interest for the researcher; mirroring the sentiments expressed by Tutenal and others on their experience with gaining access that 'its time-consuming nature led to fixation (and frustration), and the relief of finally being granted approval helped to turn this fixation into attention for what we had learned.'<sup>523</sup> The combination of both personal experience of the field in question and the prolonged ethical review process exposed and emphasised the researcher's understanding of the importance of ethics in research, beyond perhaps what is considered normal. This intertwined status, of personal experience and academic practice overlapping created a space for reflection and the opportunity to embrace personal experience to make sense of, and analyse, wider cultural experiences. Despite using their insider status to vouch for the validity of the research this was not enough to advocate for the undertaking of practice-led design research in a healthcare setting with no prior exposure to architectural academia. Access and learning how to 'fit in', was therefore entirely dependent on the collaboration with critical academic 'friends' and gatekeepers with existing relationships within the case study setting.

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519 Pollock, 'Procedure Versus Process: Ethical Paradigms and the Conduct of Qualitative Research', *BMC Medical Ethics*, 13.1 (2012), 25, p.9

520 Ibid.

521 Ibid., p.1

522 At Cardiff University, the academic institution of the researcher, PhD's consist of three years of registered study and a fourth year of writing up.

523 Tutenal and others, 'Conversations between Procedural and Situated Ethics: Learning from Video Research with Children in a Cancer Care Ward', *The Design Journal*, 22.sup1 (2019), 641-54, p.643



The original proposal to include patients was considered but discounted due to ethical concerns and even with 'access' the researcher still did not have access to the subsequent desired research participants. This was only able to be arranged with the support of the gatekeepers. These instances of 'fitting in' highlights the extra demand on researchers from 'outsider' and/or niche professions to be agile and flexible and the additional labour this creates. When considering collaborative or multi-disciplinary research, 'fitting in' may be a prerequisite to being accepted by the other disciplines and/or identifying the values in approaches that differ to the norm. However, in the case of this research, this was not shared, but rather tipped in favour of clinical bias as an authoritative benchmark that itself directed the research despite the healthcare profession seeking to be more inclusive. Cohen and Fenster state that 'the intersection between architecture and care ethics [shows] that projects that involve both care and architecture partially express each domain, but jointly reflect both of them'.<sup>524</sup> A key takeaway then from reflecting ethically on the research suggests a 'meeting in the middle' as that joint reflection, see Fig.7-8 – that architectural researcher's (and practitioner's) must engage with the reality of the ethical implications of their research and that healthcare professionals may need to be more open to inter-disciplinary research in order that innovative and moments of reflection on best practice can occur.

It was noted that the researcher's dual positionality and emotional involvement was observed throughout the process as giving rise to unexpected benefits to the research process. The suggestion that 'dying and being bereaved are apparently the prerogative of some kind of minority'<sup>525</sup> offers an explanation towards perhaps why the 'insider' position of the researcher here in fact provided common ground between themselves and the research participants of the hospice case study. It was observed on several occasions that by offering the story of their own experience of a hospice in introducing the research to potential participants broke down several social barriers towards the presence and acceptance of an academic researcher. The closeness that the researcher had experienced of the everyday hospice appeared to expose a familiarity that contributed to what Lewis and Russell define as being ethnographically 'embedded'. They describe a situation where their research necessitated collaboration with participants and that by the end of the process the research participants associated them closely with the topic but recognised them as being separate.<sup>526</sup>

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524 Cohen and Fenster, 'Architecture of Care: Social Architecture and Feminist Ethics', *The Journal of Architecture*, 26.3 (2021), 257-85 p.260

525 Hockey, Jenny. (2007). Closing in on death? Reflections on research and researchers in the field of death and dying. *Health Sociology Review*. 16. 436-446. 10.5172/hesr.2007.16.5.436, pg. 438

526 Lewis, S., & Russell, A. (2011). Being embedded: A way forward for ethnographic research. *Ethnography*, 12(3), 398-416. Retrieved from <http://www.jstor.org/stable/24048145>

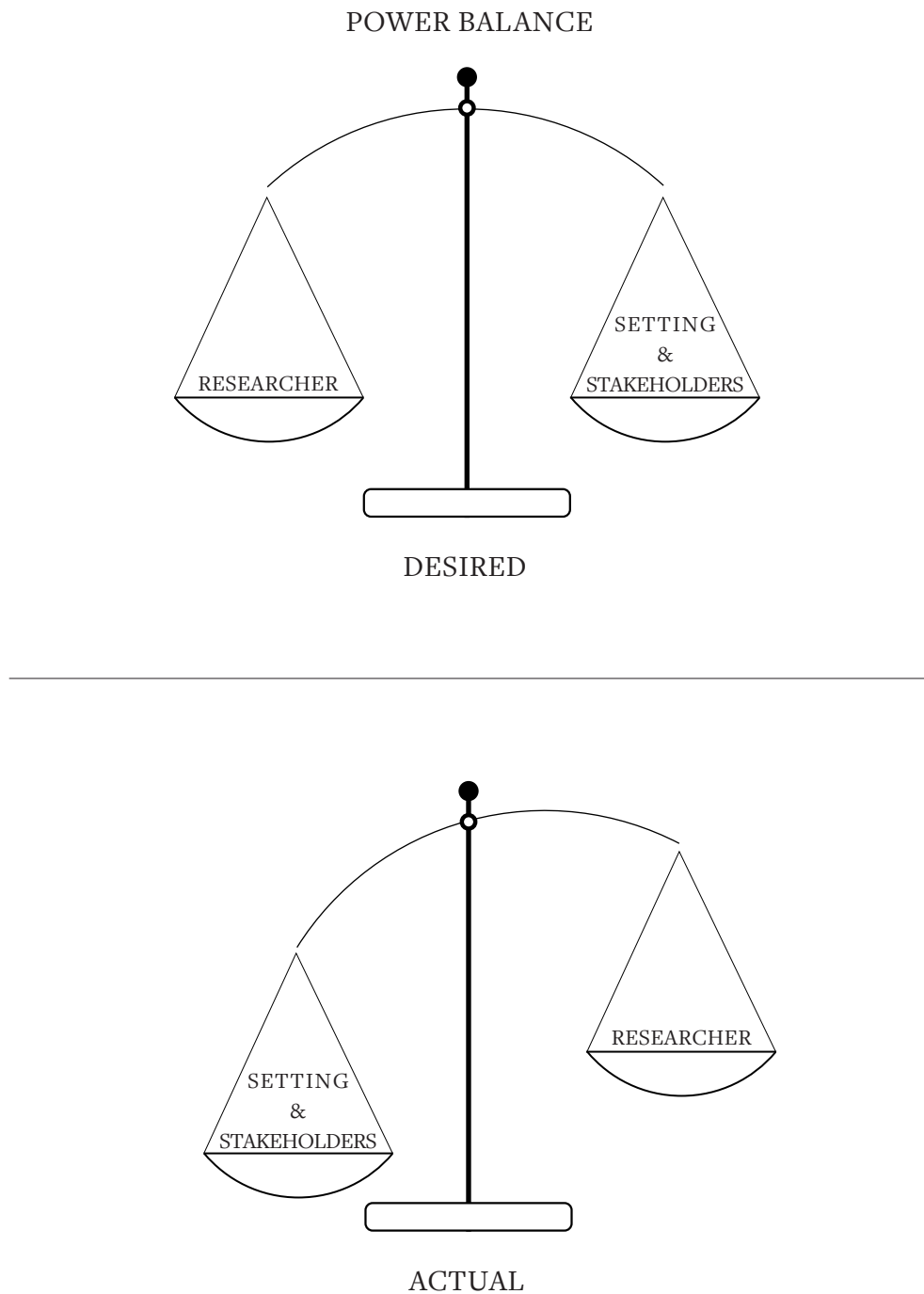


Fig. 7-8. Imbalance in the field

These scales represent the imbalance of power during the research process - where the top image shows the 'meeting in the middle' of collaborative practice - the below shows how during the fieldwork it was experienced that the setting exerted more influence over the process.

Beyond REC's and other formal procedures, ethics in practice emphasises the importance for architects and designers to possess the ability to recognise, judge and respond to ethical issues in live contexts and settings.<sup>527</sup> Whilst empathy is a vital skill within an architect's 'toolbox' – this thesis argues that empathy can be interpreted as what Haji and others regard as 'responsible agency'.<sup>528</sup> Rather than being a one-time exercise that superficially engages people during the early design phases, the ethical architect's agency in influencing the design of positive environments it is considered would find benefit in integration from conception to inhabitation. Though in reference to academic ethics it is argued here that 'the lack of consensus about ethical and methodological rigor might produce conference presentations, monographs, and ethnographic essays of questionable quality'.<sup>529</sup> This lack of clarity is also apparent in architectural practice itself when entering particularly sensitive environments.

Flora Samuel states in 'Why Architects Matter' that 'the [architectural] profession has been attending to issues of aesthetics and style when it should have been developing its ability to improve the relationship between people and the built environment.'<sup>530</sup> This quote emphasises the recent prevalence of large scale developments by 'starchitects' that place priority and value on morphology rather than the particular needs of the buildings users or vernacular context of the site and location. Ethical practice, that we might consider an approach to cultivating this relationship is a burgeoning area of interest in the architectural profession. Though it is not yet formally recognised as a skill required by graduates of Part I and II by ARB and RIBA, the introduction of RIBA's draft Knowledge Schedule is a step towards this.<sup>531</sup> This is not to say that it is not recognised by various architectural academics as a key graduate attribute for those studying architecture, and that there are attempts to embed this skill into the delivery of architectural education through design studio and research modules. Currently under review, RIBA's 'The Way Ahead' and the draft competency regarding ethical practice goes some way to addressing this knowledge gap but confirms the need for architects and designers to be critically aware of the broader implications of ethics and the wider professional context within which they operate.

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527 Guillemin and Gillam, 'Ethics, Reflexivity, and "Ethically Important Moments" in Research', *Qualitative Inquiry*, 10.2 (2004), 261-80, p.269

528 Ishtiyaque Haji and others, 'Architecture, Ethical Perception, and Educating for Moral Responsibility', *The Journal of Aesthetic Education*, 47.3 (2013), 1-23, p.20

529 Hodge, 'The Problem with Ethics', *PoLAR: Political and Legal Anthropology Review*, 36.2 (2013), 286-97, p.287

530 Samuel, 'Why Architects Matter : Evidencing and Communicating the Value of Architects', (2018) p.238

531 RIBA, 'Knowledge Schedule: Ethical Practice', RIBA, 2021)

# Practice Note 4

## Beyond co-production

The fourth and final practice note returns to a first person narrative to discuss the researcher's experience of engaging with those outside the architectural profession as a means of further exploring co-production. This included working with hospice industry professionals as part of a emerging community of practice at national conference on hospice care and publishing an article in a peer-reviewed journal as a critical lens on the use of language used in death and dying by both architects and healthcare professionals.

From the outset of my doctoral studies I was adamant that the outcome of the work would not be a bound document that gathers dust sitting on a shelf. I hoped and aimed to find tangible or real world impact on architectural practice and perhaps more importantly the inter-disciplinary relationship of healthcare and the built environment in end of life care. I hoped to achieve this partly by undertaking the research using a practice-led approach, but perhaps more crucially by wholeheartedly engaging with and developing a multi-disciplinary community of practice. The architectural community can be fairly insular, and one that struggles to find its place and voice academically amongst other more scientific disciplines. I could well have found myself at the end of my doctoral studies having only occupied and been in conversation with those concerned with design that completely bypasses the expertise of those that use the hospice building.

Valuable and meaningful change could only come from a collaborative process that involved a coming together of professions working towards similar goals. Throughout my studies I have tried to immerse myself within the worlds of both architecture and healthcare, attending conferences focused on palliative care research framed around the contributions of architecture and design to health and well-being and vice versa, architectural research conferences highlighting the importance of understanding typologies such as the hospice as independent from the reference of hospitals. Attending conferences spanning the boundaries has been invaluable; it has enabled me to build a network of others from amongst architecture and healthcare who are interested or actively working in the peripheries of health and well-being and the built environment.

In addition to attending a mixture of research events I have developed a community of practice for the thesis by fostering an informal and ongoing relationship with a number of charities, most notably Tenovus Cancer Care and HospiceUK who wrote letters of support. I first made contact with HospiceUK in September 2017 as I was in the process of applying for a PhD studentship. I was keen to gain their feedback and perspective and exchanged numerous phone calls and emails with the then Head of Research, to see how my research might align with its core values and principles or fill knowledge gaps. As a self-funded student I approached both HospiceUK and Tenovus Cancer Care (a national Welsh cancer charity) to see if they offered grants or bursaries to early career researchers. Unsurprisingly both were unable to offer me financial support - but what transpired was perhaps more meaningful.

My contact at HospiceUK left her position a short time after I officially began my studies, though we still keep in contact via social media. The position was never filled, but various other members of the senior management team picked up support of my work. The team at HospiceUK assisted me with my requests for information and data regarding hospice providers, and future planning for how they might help with recruitment for my fieldwork. Sporadically HospiceUK would get in touch to see how my work was progressing, and if there was anything they could assist with. A pivotal moment in working with the healthcare industry was being invited by HospiceUK's Chief Clinical Officer to attend and contribute to an event she was organising called "Revolutionary Clinicians" an invite only event that aimed to provide 'protected space' for the 'what if' questions about developing prototypes for new models of care and collaborative approaches to end of life care.

It was such a pleasure to make contact with Annie and I was delighted when she was able to join us for the Revolutionary Clinicians event. The session she led gave the senior health care participant much to consider and ponder. The day focussed on new models of end of life care.

Annie facilitated the attendees to work in small groups to consider beyond what care is needed but where that care is actually given. The following discussion was rich and impactful. The groups fed back that using the architect out line Annie provided they had considered the building design and infrastructure, the “feel” of the setting and reducing any unnecessary prominence of health care details or symbols. Discussion also included the materials of the build, the colour used for the decor, the use of light and the need for privacy without feeling isolated. It was a highly valued session in the day and I look forward to seeing it within the context of the finished thesis.

Thank you Annie for the preparation and thought that went into your time with us

Carole Walford RN, MSc, BSc (Hons), PGDE (A).

Chief Clinical Officer - Hospice UK

Testimonial from Carole Walford to Annie Bellamy, following the Revolutionary Clinicians event

November 2020



The lead for the event had invited me to develop a breakout activity that would focus on what a hospice provider might do if they were offered a high-street shop on peppercorn rent. This tied into contemporary architectural discussions on adaptive and creative re-use of disused spaces. In order to fully utilise the time we had, acknowledging that the audience for this task may have never engaged with architectural or design based terms or processes, I drew on my teaching experience and scenario-based design.

Here, I set up a narrative of an imaginary town setting the parameters and constraints of the local context in terms of care provision. In addition to bring the exercise to 'life' I provided a scaled drawing of a shop space to encourage critical thinking about the care needs and their implications for the built environment.

A note on process & method:

My involvement in the Revolutionary Clinicians was not as just a delegate, as usual at conferences, but as a member of the team of professionals that brought together to help plan the day's events. In the process of writing the brief and activity for my session I attended a number of planning meetings, seeking feedback on my proposal and ensuring it fit within the key principles of the event. The most junior person there and the only person outside of the healthcare profession, I expected the experience to be one that I could use as practice for future attendance at healthcare dominant events. However, my positionality was viewed more postively - and my 'outsider' position was able to take on more of a role of a 'critical friend'. Though I was not able to comment on the technical aspects of the event that focused on care - I was able to bring an alternative perspective to the planning and the event.

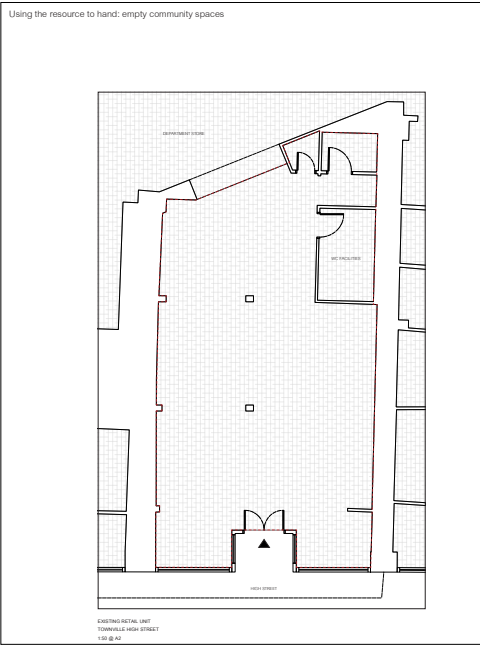


### Using the resource to hand: empty community spaces.... Creative use ... and then what?

Annie Bellamy, PhD Candidate, Welsh School of Architecture, Cardiff University

[www.hospiceuk.org](http://www.hospiceuk.org)

FOLD HERE



**Using the resource to hand: empty community spaces**  
130 sq.m on the ground floor of Glebe's Department Store, Townville High Street

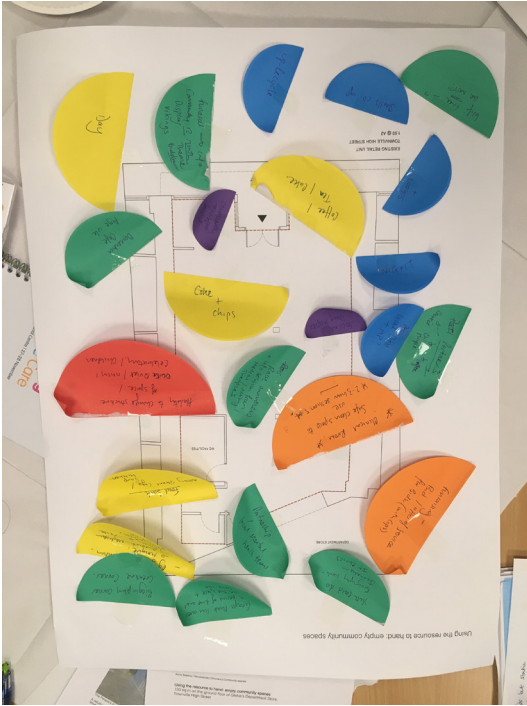
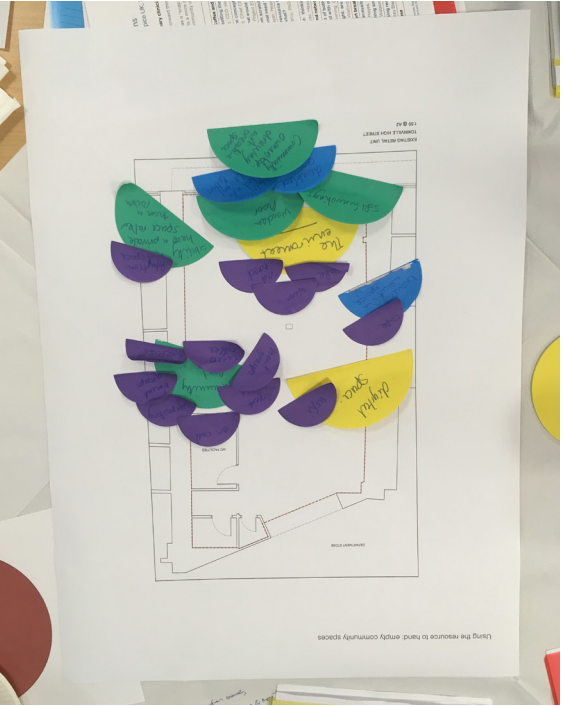
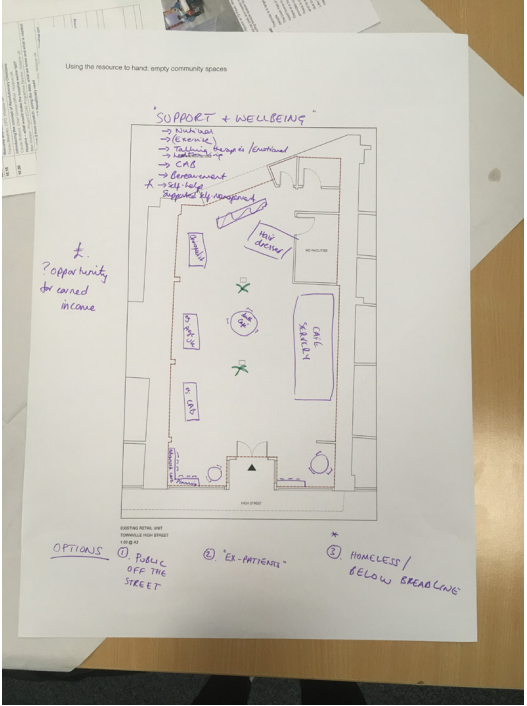
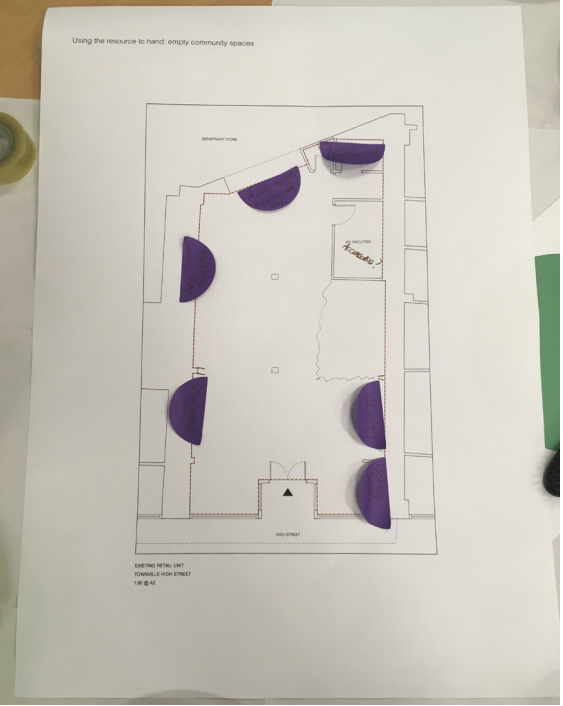
**Context:**

- Townville is a large sized town in the midlands, with a population of around 85,000 people.
- The town has a significant community of settled EU citizens, higher than similar sized towns in the surrounding locality.
- There is a bus stop within a 10-minute walking distance to the department store that provides connections to the suburban areas and local villages.
- There is one local in-patient hospice and day hospice centre that serves the town and its wider settlement areas, however it is difficult to reach via public transport due to its semi-rural location.
- Like many high streets, Townville's High Street is facing decline, but it has seen a rise in local 'pop-up' and local charity retail shops.

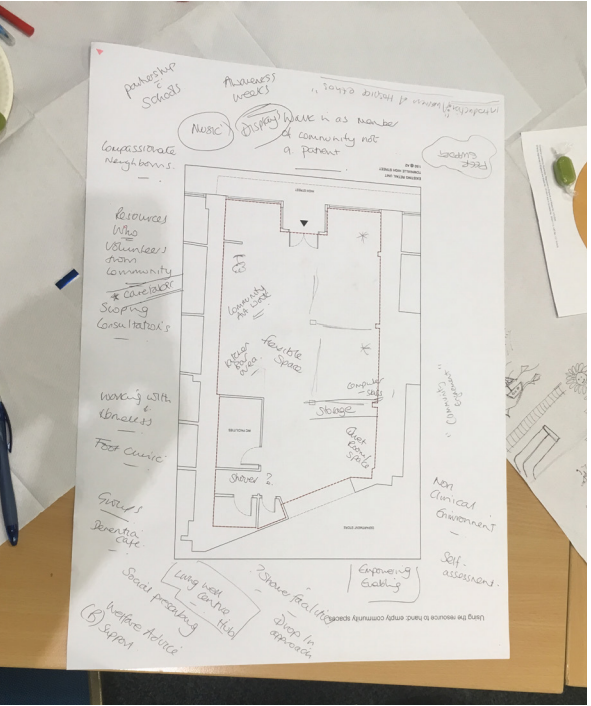
**Brief:**  
The local hospice would like to know what a space in the heart of the community might also be able to offer those living with long term conditions. The hospice champions that 'care in the community' is care by the community and would like to expand its outreach programme - what other services might be useful to provide in an urban location? Are there other programmes that the hospice could partner with to provide? The hospice doesn't necessarily want another charity shop, but there could be commercial elements to the space to provide some form of income, e.g. coffee shop/pay what you can cafe etc.

**Space:**  
The local department store has recently been refurbished and as part of its community engagement plans to re-invigorate the local high street has offered the local hospice a 130 sq.m space on its ground floor at a peppercorn rent for 18-months. The space previously used to house a coffee-shop chain concession and has existing WC facilities (shown on the plan) and a number of other separate spaces. The frontage of the shop space is floor to ceiling glass windows, with an entrance off the street, the shop space is also connected to the rest of the department store at the back of the shop. The shop has been left with new floors and decorated plainly. There are a number of steel columns, but the rest of the space is open. There is a small budget for renovation or adding simple partition walls etc.

**Collaborators:**  
This programme will only be possible in collaboration with other teams; think about the different organisations that might be suitable to work with to make the space feasible. This might include: architects to design or conduct community engagement; local builders to help with construction; local youth groups or schools; other local community groups. Perhaps the local council could be approached to help or work in partnership with to help deliver various social or medical services?



The activity was quick-fire, with only a short time for my presentation to introduce the activity starting. During the task I did my best to move around the room dropping in and out of conversations. I found that ideas being put forth were innovative in their approaches to care and had potential significance for the way that hospices can brief and commission places and spaces. The images below document the different outcomes of the tables; though only one table used the plan as a footprint drawing furniture and plants - the sheets represent an hour of incredibly lively and innovative thinking that re-framed how the delegates understood that design and architecture can be deployed to strengthen the principles of care.





The relationship I have forged with HospiceUK and my subsequent involvement in the Revolutionary Clinicians event emphasised the validity and importance of my desire to ensure that the thesis can find a way of instigating or influencing inter-disciplinary collaboration moving forward for the commissioning and design of hospice buildings by engaging meaningfully in co-production. But the event, exposed me to a new perspective on the potential value of embracing other professions. As the very nature and climate of hospice care undergoes a shift, due to the ageing population, the rise of co-morbidities and the impact of the COVID-19 pandemic healthcare professionals are recognising the need to adapt and innovate in order to develop new best practices of care. The beginning of this thesis highlighted the need for the architectural community to be willing to collaborate within this context in order to design proactively not reactively.

Having the opportunity to surround myself with healthcare professionals exposed a significant appetite for collaboration and change that embraces the link between architecture and design and health and well-being. I met a large number of delegates who were interested in the activity I ran, those who just wanted a chat about the fact they are undertaking design projects, or some who just wanted to exchange details as a network of those saw the potential value in the exercise, emphasising that the desire to co-produce environments of care is palpable and desired. The event demonstrated just how important it is to create accessible platforms for knowledge exchange so that conversations can be had more fluidly. More importantly is how these platforms could be used as a form of outreach. I refer here to the ways in which architectural practices are approached and chosen to be involved in healthcare projects that can be typically the domain of medical architecture specialists. It requires clients who are able to see the value of engaging architects in delivering their vision for the built environment and have the finances and time to explore this. The event additionally highlighted the difference in language used by each profession - something I was previously aware of as the architectural profession is commonly mocked by those outside the field for its often pretentious and overworked language. Working more and more with those in healthcare has helped me develop a vocabulary that remains professional and expert but nevertheless accessible so that work between professions can be clear but meaningful.

## The dying patient: taboo, controversy and missing terms of reference for designers—an architectural perspective

### Abstract

Contemporary society has grown seemingly detached from the realities of growing old and subsequently, dying. A consequence, perhaps, of death becoming increasingly overmedicalised, nearly one in two UK nationals die institutional deaths. In this article we, two architectural scholars engaged in teaching, research and practice and a nurse and healthcare scholar with a focus on end-of-life care and peoples' experiences, wish to draw attention to a controversy resulting from a paucity in current literature on the terms of reference of the dying 'patient' as we navigate the future implications of the COVID-19 pandemic. This contributes to a relative lack of touchstones for architects to refer to when designing person-centred palliative care environments. Unlike common building types, architects are extremely unlikely to have lived experience of palliative care environments as patients; and therefore, require the help of healthcare professionals to imagine and empathise with the requirements of a person dying away from home. This paper includes a review of ageing and dying literature to understand, and distil from an architectural perspective, who, design professionals, are designing for and to remember the nuanced characteristics of those we hold a duty of care toward. We ask readers to heed the importance of accurate terms of reference, especially when commissioning and/or designing environments of palliative care. Furthermore, we put forward an appeal for interdisciplinary collaboration to develop a framework for codesigning positive experiences of person-centred care and environments at the end of life.

Bellamy A, Clark S, Anstey S, The dying patient: taboo, controversy and missing terms of reference for designers—an architectural perspective, *Medical Humanities* 2022; 48:e2-e9.

Article published in *BMJ Medical Humanities*

# 8

## Conclusion

This chapter presents a summary of the thesis, highlighting key research findings and claiming the originality of the research. Implications for architectural practice and further studies are discussed and recommended. It precedes a personal epilogue that closes the thesis.

## Research findings

The primary research findings of the thesis are addressed below, following the chronological order of the chapters.

Chapter 2 addresses the broader concept of hospice, its origins and history culminating in a discussion on the landscape of death and dying in the UK. Hospice was the original term of reference that encompassed a holistic approach to care for the dying. There are now however multiple and evolving definitions with many associated terms of reference. Though its ideology could be said to remain, contemporary society, the increasing medicalisation of death and unclear language has begun to erode this. New terms of reference, particularly palliative care - which finds its etymological root in 'hiding'<sup>532</sup> and the current nomenclature end of life care - have contributed to a confusion within both the public and healthcare professionals themselves as to the definition and role of hospice care. These factors have been compounded by the growing prevalence of patients with complex co-morbidities and the resultant shift of services that hospices aim to provide. Furthermore, the emergence of the COVID-19 pandemic has disrupted perspectives and experiences of death and dying.

Chapter 3 evaluated the hospice building as a typology separate from other related healthcare environments. Beginning with an outline of hospice buildings' historical evolution, from ancient histories to contemporary iterations that align with modern definitions of hospice care; it was identified that holistic landscapes of care have seemingly been lost from contemporary models of healthcare environments. Moving forward, critically, an examination of St Christopher's Hospice - often cited as the first contemporary hospice - revealed that the concept of co-production was fundamental to its architectural development, with the client/architect partnership of Dame Cicely Saunders and Peter Smith working hard to unify the requirements and aspirations of both. The context within which the modern hospice movement developed was influenced by several factors, such as negative societal attitudes to death and dying and the overt specialisation of healthcare architecture industry. Moreover, the apparent lack of available literature regarding the hospice environs design that aligns with this shift serves to highlight that the current architectural language of the hospice typology appears to remain in line with outdated expectations and standards. Exploring built precedent and specialist building typologies associated with hospice, it found a

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<sup>532</sup> Bellamy and others, 'The Dying Patient: Taboo, Controversy and Missing Terms of Reference for Designers—an Architectural Perspective', *Medical Humanities* (2020), medhum-2020-011969, p.2

diversity of architectural references as well as some points of contention and confusion. Maggie's Centres are informally referenced as key precedents for hospice requirements; however, these are critically different to palliative care environments as more client than clinically focused. Thus, strategies and approaches to the design of their centres are not directly translatable to hospices. However, the reciprocal relationships as fostered by Maggie's Centres does offer benchmarks and principles for co-production.

The scoping studies of Chapter 4 explored the perspective of three third-sector Welsh hospice organisations and their relationships with architects in relation to building and renovation projects. These demonstrated diverse impressions of the role of architects and subsequent value - or not - they could bring to both design processes and outcomes in terms of the quality of built environments for hospice care. Each setting represented different contexts of hospice facility: i) an old purpose-built facility that had undergone numerous renovation projects, ii) a facility housed in a previously residential building that had been extended to meet hospice requirements, and iii) a recent new-build facility. Walking interviews with key stakeholders, from the settings - managers some of whom had a clinical background - revealed that each had established individual strategies that either involved architectural professionals or not. Nightingale House and St. David's appeared more open and flexible in accommodating meaningful collaborative approaches in comparison to the transactional relationship described by Skanda Vale. The extent to which co-production was encouraged and utilised by Nightingale House and St. David's hospice differed, however it was evident that where genuine co-production manifested, standard design practice was challenged for the better. Norms for the design of healthcare environments as guided by conventional procurement processes or regulation from interested parties, such as infection control are obstacles that hamper innovation and even, simply different approaches. Where healthcare and architecture professionals acted as a coherent team justification for innovation or change were interwoven. The walking tours, however, were not value free and thus created motivation for the incorporation of a broader variety of voices from the case study setting.

Chapter 5, the case study at the centre of the thesis, is typical of 'everyday' palliative care environments rather than that of an architectural exemplar or new-build setting. Research encounters recorded via in-depth interviews highlighted implications of perceived and actual design agency. The study highlighted a dichotomy between those who provide care, and those whose work supports both carers and the physical environment of care, such as building

maintenance staff. Conversations with rarely consulted members of non-clinical staff emphasised their hidden expertise and sense of duty that contributed to small yet pivotal changes to building fabric, for example the installation of a canopy to the mortuary door. Internal co-production between staff groups that drew on the specialist knowledge and awareness of the sensitivities of the environment was evident, such as amending the window design during renovation. A significant issue uncovered was the tension between short-term reactive and long-term proactive change, and hospice organisations' preparedness to meet changes in requirements set out by national guidance regarding EoLC. A critical reflection on the initiation of change, was its hierarchy. For example, National/Governmental strategies feed from the top-down, but with relatively short timelines to enact meaningful architectural adjustments within the built environment has led to reactive change, based on availability of funds that encourages piecemeal change rather than holistic transformation.

In the final part of the thesis, Chapter Six explored a designerly perspective and analysis of the case study setting. Considering the historical evolution of the built environment of the hospice setting the involvement of architects was absented, and aligned to the relative scale of the intervention, limited to larger scale projects that necessitated liaison with the local planning authority. The analysis contained within this chapter observed instances where meaningful change to the in-patient hospice case study was enabled by small interventions. These were not proposed by architects or design professionals, but those who experience the hospice day-to-day, thereby absenting architects from the generation of knowledge regarding the finer scale of needs of the in-patient hospice. Larger interventions, such as the enclosure of the balconies and the addition of a first floor to the northern wing were proposed in response to changing needs of patients, but also the growing requirement of space for staff. However, as only one could be actioned due to financial constraints, this demonstrates the wider pressures faced by third-sector hospice providers in being able to commission and deliver projects within reasonable periods after the need is identified. Highlighting this further, it was also found that donations made to the hospice may come with specific conditions on what it can be used for. This furthermore highlights the potential value of a vision plan or similar prepared by architects that could be used as a strategy to scope out and procure alternative services or approaches in readiness for financially viable periods.

The closing chapter of the thesis documented the ethical issues and constraints faced during this study. Practically, gaining access and fitting into clinically dominant environments presented

substantial challenges that included numerous ethical applications and the modification of the design researcher's 'architectural' language and tone. The nature of undertaking research in these locations requires consideration of patient confidentiality, safety, and well-being first and foremost. However, the process of procedural ethics encountered by the researcher meant that although access was eventually formally granted, this did not equal access to the reality of the setting. A gatekeeper was required to provide further access and could advocate for the research and conduct of the researcher. The experience of ethics within this study highlighted that empathy, flexibility and resilience are critical tools for both architectural researchers and practitioners. Noting that an architectural practice working closely with hospice providers gave little consideration toward ethical implications of the design process emphasises the responsibility of architectural educators to prepare future designers with the skills to navigate ethically sensitive contexts as currently championed by RIBA's Ethical Practice Knowledge Schedule.

## Co-production

Reflecting on both the key findings of the study as described above and the research question of this thesis – it is indisputable that principles of co-production are critical to the ongoing contemporary development of the in-patient hospice as an environment of palliative care. The in-patient hospice, as a reflection of the state of palliative/EoLC care in the UK, is at a critical juncture, with the impact of the COVID-19 pandemic impacting on the use and attitudes to healthcare environments. With a relatively small literature base and lack of clear references as to the range of inhabitants using the hospice in conjunction with the ever-changing complexities of diagnoses and their spatial requirements – the relationship between architects and hospice providers is more important as ever. The necessity of an informed brief and collaborative approach highlights the importance of co-production in generating open platforms for knowledge transfer that can work toward reducing the perpetuation of architectural tropes or a focus on interior design without consideration of deeper issues. This thesis posits that the sharing of specialist knowledge regarding hospice care and its associated environments must adapt to place equal value on those whose roles are not specifically clinical and whose role supports the infrastructure of the hospice building. The findings of this study, demonstrate that meaningful interactions with hospice settings contribute to a more holistic awareness of in-patient hospices beyond stereotypical assumptions of care at the end of life. Insights from not only healthcare professionals but building maintenance and housekeeping teams contributed a more democratic perspective of the environment. The fieldwork undertaken



for this study, using architectural design tools such as large-scale drawings, maps and physical models enabled health practitioners and staff at the case study setting to comprehend practicalities of design. Furthermore this 'reaching out' from an architectural perspective gave a new vision and consideration towards the hospice environment for those working there. Therefore, we might consider that co-production might not only result in a tangible physical outcome but can additionally act as a mediator or advocate to generate deeper shared understanding.

RealDania's *Programme for the Good Hospice in Denmark*<sup>533</sup> report proposed an 'organisational model for the ideal implementation process'<sup>534</sup> into the architectural delivery of palliative care environments. As one of few intensive studies into the in-patient typology, on the surface this appears to be an appropriate benchmark. However, the diagram, shown in Fig.8-1, shows architects as part of the internal team and with the voice of patients missing. Based on the evidence gathered in this study, it is theorised that missing from the report's framework is co-production between all the groups identified as a vital tool to ensure that knowledge and expertise is meaningfully shared. In times of economic downturn, the services of architects may be seen as superfluous; evidenced by the absence of architects from the fieldwork settings. Therefore, this model is reliant on the assumption that in-patient hospices continue to exist. Currently in-patient hospices exist in a state of vulnerability - relying on charitable donation and the generosity of volunteers. Furthermore, this model makes the proposition for the delivery of a single hospice, not as part of a wider organisational context in the wider world. Furthermore, the proposed model might be considered ideal if hospices were considered as part of mainstream healthcare, however it instead explores the proposition for the delivery of a single hospice without any context with wider policy and influence.

## Key messages

Reflecting on the above, in considering the design of in-patient hospices, it is vital to note that difficulties in access and constraints of the RIBA Plan of Work means that it is unlikely that architects will be involved in meaningful and extended conversations with stakeholders directly to better understand the requirements of the building. As Annemans and others note 'in the case of vulnerable groups like hospital patients, practical and ethical restrictions make it hard for designers

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<sup>533</sup> Architects, 'Programme for the Good Hospice in Denmark', 2006)

<sup>534</sup> Ibid. p.106

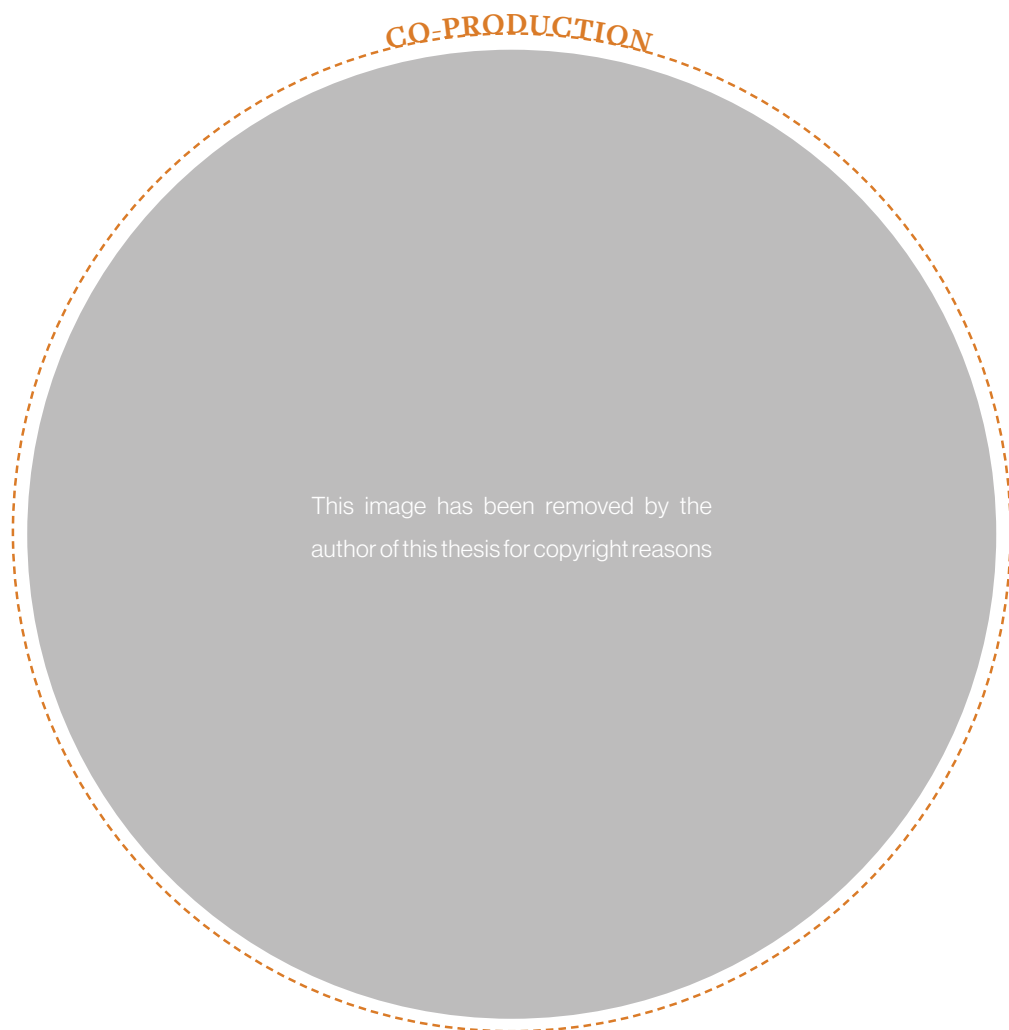


Fig. 8-1. Locating co-production

A diagram taken from RealDania's report "The Good Hospice Programme" regarding hospice design in Denmark - this diagram suggests the potential relationships between key stakeholders in a hospice project. However, as the alteration above suggests, missing from this is the concept of co-production, which this thesis posits could encompass all these relationships.

to actually engage with them.<sup>535</sup> Access to members of staff may be perceived as easier and less ethically demanding – however this does not mean that this group should be treated with any less consideration with regards to ethically sensitive conversations or design/research activities. Despite the obstacles that architects may encounter when trying to undertake early-stage research, in search of intersubjectivity and shared understanding of the material and spatial requirements of a palliative care environment, a key takeaway from this study is an appeal for architects to talk to all users of in-patient hospices and other palliative care environments. It is crucial that all users of the hospice and their voices are given opportunities to share their knowledge, expertise, and everyday experiences in support of co-production and democratic decision making. The growing medicalisation of death and dying can be said to have created a clinical bias of the perceptions of those that work in hospices. The reality of hospice care is that non-clinical roles, such as maintenance and housekeeping were perceived as invisible within the landscape of hospice care. However, as evidenced by the research encounters discussed in Chapter 5, they are as much engrained in the environment as clinical roles, as such should therefore be valued as equal.

Moreover, considering the issue of access in engaging with in-patient hospices, or any other palliative care environment, it is hugely important that architects meaningfully reflect on the ethical implications of visiting and working within these locations. As the researcher experienced first-hand during a building observation session, when they became aware of an acutely sensitive situation, they were not told to leave but rather left at their own accord to protect the members of public. The insider positionality of the researcher meant that they were able to make that instinctive judgement, but it may have been that another researcher without this knowledge may have stayed in the location. The act of engaging with the setting in this way gave life and soul to the study, rather than being a purely mechanical analysis of space and place, and as such developed an exemplar for the ethical behaviour of architects in sensitive locations. This example of conduct in sensitive locations is of particular importance for architects who may have no previous training or awareness of ethics when undertaking common activities such as site visits or client meetings. In recognising the significance of this, the researcher would propose to further co-produce ethical protocols or guidance notes, taking cues from the *Will I cause harm?: Practising Ethics Guides for built environment research*<sup>536</sup> research project, that can be used in to navigate sensitive situations

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535 Annemans and others, 'Informing Hospital Design through Research on Patient Experience', *The Design Journal*, 20.sup1 (2017), S2389-S96, p.S2390

536 Dr David Roberts, Rendell, Professor Jane, Padan, Dr Yael, Markowitz, Ariana, Osuteye, Dr Emmanuel, *Practising Ethics* (2022) <<https://www.practisingethics.org/practices>> [accessed 10th May]

and contexts in support of conduct that exemplifies ethical practice and principles.

In contemplating the potential difficulty of access and involvement for architects working with in-patient hospices, there is furthermore the complication of the intentional absencing of the architect. This was evidenced in the field, with Skanda Vale, St David's and the primary case study setting, the Cardiff and Vale Hospice each mentioning how different aspects – fees, professional interest and interference – led to the roles of architects being purposively diminished in favour of internally hospice led design projects and interventions. The most pertinent of these reasons perhaps being that of the financial commitment required by a hospice to involve and pay the professional fees of an architect - a reason even more valid now given the financial vulnerability faced by many hospices due to the impact of COVID-19. However, the above does not necessarily need to signal architects' involvement in palliative care environments as only being when required for large scale projects, and this study evidences the value of architects' expertise even for small interventions. This thesis proposes that whilst architects may not be affordable for small to medium level changes, a strategic approach to longer term vision/master planning could offer hospices a chance to benefit from the expertise and skillset of architects, in and through this process offer opportunities to discuss both smaller details as well as more speculative futures. A five-year plan for example, like the quinquennial reports conducted by conservation architects for church buildings – might undertake a holistic review of the hospice environment, spotting areas for opportunity, conducting staff forums, reviewing regional and national level policies as well as commenting on likely or necessary running repairs. Most importantly this type of review would offer an opportunity to address the reactive nature of design changes as discussed in Chapter 5. A strategic review of changes and proposals could be sub-divided into scales of financial obligation that would allow hospices to budget for these to be met over time or as one-off funding or bequests become available.

## Originality

The thesis makes a significant contribution to the development of architectural knowledge into hospice care. This is particularly timely given the current momentum for change within the hospice sector, with publications and policies such as the Lancet report<sup>4</sup> and the Health and Care act<sup>537</sup> outlining a roadmap to 're-evaluate our relationship with death, and [act as] a catalyst

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<sup>537</sup> Parliament, 'Health and Care Act', 2022)

for radical change.<sup>538</sup> The study demonstrates a synthesis between, and generation of, shared understanding of architectural and healthcare perspectives of the in-patient hospice. It achieves equipoise between architecture and healthcare by bringing these two worlds together throughout the research process that addresses the tension between design aspirations for home-like environments and the growing over-medicalisation of hospice care. The study is original in its approach to co-production – as being not only a focus of the analysis – but in its entire approach being co-produced between an architectural scholar and healthcare professionals. Drawing on its interdisciplinary nature, the research project took influence from and aligned to principles of co-production throughout, from the application of mixed methods of architectural, health and social sciences to the study design. Echoing the interdisciplinary mode of study, the insights presented by this thesis will be of value to not only architectural academics and practitioners but healthcare professionals and other associated persons with interest in commissioning and running palliative care environments, and potentially other related environments such as residential care homes. This study furthermore finds originality simply in its existence. It was noted at the outset of this study, four years ago, that there was a relative lack of literature regarding the in-patient hospice. In this time there has not been, that the researcher is aware of, any other study that has sought to address or achieve this balance, despite growing appetite and motivation for positive contributions to the experience of death and dying. In utilising a practice-led and interdisciplinary approach, this study not only challenges architectural practice of hospice care but moreover provides a provocation for the current state of architectural education, and how architectural designers are trained.

The study is further made original by the weight given to 'other' non-clinically based members of staff voices and experiences. As palliative care has evolved over the years to become more medicalised, so has a bias developed that places clinical expertise as a primary narrative alongside or even above patients and/or visitors. This is one of the first studies that considers the organisational experience of those who work in support of the building – such as maintenance and housekeeping staff – as being equal to those who work in support of clinical care practices. This equity and synergy of experience provides this thesis with a uniquely holistic understanding of the hospice building environment. Not only does it offer insights into the obstacles faced around co-production but promotes an in-depth awareness of the broad variety of voices and perspectives beyond the obvious clinical experience of a healthcare environment. This might of be value as background knowledge for architectural practitioners who are unable to invest large amounts of

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538 Sallnow and others, 'Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life', *Lancet*, 399:10327 (2022), 837-84,

time pre-RIBA Stage 1 (predicated on project preparation and brief development) to consider the breadth of palliative/end of life care environments. The creation and inclusion of 'practice notes' that are interspersed between the respective parts of the thesis offers creative insight into the use of elements more common to architectural practice. These sections provide 'snapshots' of the supportive work undertaken on the fringes of the study and offer potential interest for those working in design research as ways of enabling clear communication with non-architectural professionals.

The justification and choice of the case study and walking tours have additionally contributed to the originality of this study. It was decided to focus on research settings that were characteristic in their condition and context of many hospices across the UK rather than a hospice designated as exemplar or critically acclaimed by the architectural community.<sup>539</sup> By focusing on settings that met this norm the study resisted a bias toward foregrounding design and chasing locations that are not representative of the typical situation of hospice care. Further originality is claimed by the sites being explicitly from the third sector; gaining access to third-sector locations present unique difficulties, specifically the potential for organisational gatekeeping to hamper research methods and decrease in researcher freedom by controlling the research process. An added complication to approval of access for this study was the architectural nature of the research, which was unfamiliar – alien even – to the organisation in comparison to more commonplace healthcare studies. Owing to the impact of the COVID-19 pandemic the future viability/sustainability of the case study location is uncertain. As such, if the facility were to close this thesis provides documentation of the context, constraints, and opportunities that the building offered as a historic record of life in this hospice building at a pivotal point in the development and evolution of hospice care.

The decision to draw upon the researcher's insider positionality had significant influence on the originality of this study. It was unique in applying the personal experience of the researcher as a method by which to challenge practice; and is original inasmuch that the researcher is unaware of any academic study of this topic that acknowledges or reflects on this positionality. Not only was this a valuable reflexive and reflective tool, but it also offered positive advantages for the research process, such as developing kinship with the research participants. As Breen, summarising Bonner and Tolhorst, states, this insider knowledge can provide a 'superior understanding of the group's culture; the ability to interact naturally with its group and its members; and a previously established

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<sup>539</sup> It should be noted however, that one setting from the walking tour, St. David's was awarded a number of architectural prizes, however this was not a driver of its inclusion in the study.

and, therefore greater, relational intimacy with the group'.<sup>540</sup> The study draws upon this point of reference, albeit not as a formal research encounter but one that enriches the fieldwork process. This engagement with the researcher's own perspectives grounded the study and brought prior knowledge of the subtleties of the hospice environment that were beneficial during fieldwork to minimise potential situations of ethical concern. By recognising the value of the prior experience with regards to this study, the space between the insider and outsider position of the researcher is broken down, despite traditional academia's discouragement of this. In doing so this study achieves the intersubjectivity as described by Niall McLaughlin earlier in the thesis, whereby architects must endeavour to imagine what it is to be others experiencing a place.

### Practical limitations

Besides the ethical constraints discussed in Chapter 7, the primary limitation to the study was the impact of the COVID-19 pandemic. Fieldwork activities, such as interviews and building observation within the case study location were finalised as the pandemic began to emerge in early December 2019, reaching Wales in March 2020. As part of the research design and ethical approval conditions from the case study organisation it was proposed that following completion of the fieldwork initial data analysis would be collated and presented back to the research participants for the purposes of member-checking and to present design ideas. Employing member-checking is a recognised tool to reduce the influence of researcher bias and improve the credibility of results<sup>541</sup> and as Birt et al comment is being increasingly used by qualitative researchers as means to provide rigour in an 'evidence-driven world'.<sup>542</sup> As the impact of the pandemic became clear in early 2020, with restrictions on social contact, the hospice was closed to visitors and essential staff. Subsequently research participants were lost due to attrition, amplified by the effects of pandemic working. As a result of the aforementioned reasons member-checking was unviable. Without the benefit of this exercise, the researcher has made concerted efforts to avoid supposition and over-generalisation.

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<sup>540</sup> Breen, 'The Researcher `in the Middle?: Negotiating the Insider/Outsider Dichotomy', ECU Publications, 19 (2007) p.163

<sup>541</sup> Linda Birt and others, 'Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation?', *Qualitative Health Research*, 26 (2016) p.1810

<sup>542</sup> Ibid. p.1802



## Further studies

The study was subject to limitations owing to ethical concerns and collaboration with the third-sector case study requiring a gatekeeper to facilitate access. One such future study could take the work of this thesis and develop it through the broadening of access. This might be achieved through:

- talking with larger groups of research participants, for example undertaking focus groups as was initially proposed in this study
- employing different methods for fieldwork, such as participant observation<sup>543</sup>, and potentially longer engagement as per traditional ethnographic studies
- and perhaps most critically, engaging with different groups of research participants, such as patients, carers and families and other supportive roles within the hospice organisation, those that work alongside the in-patient hospice care team.

Reflecting on the original research aims outlined in the researcher's application to the programme, the thesis evolved considerably from a plan to '[develop an] understanding of the psychological voices'<sup>544</sup> of those at the end of life. It was first proposed that the thesis would find focus as a phenomenological study documenting the architectural atmospheres and experience of patients and visitors within the hospice environment. The sensitive ethical concerns of recruiting patients and visitors as research participants meant that interacting with and analysing this aspect of the hospice environment was unachievable during the limits of this study. As highlighted previously, there is a relative lack of architectural research that directly engages in a phenomenological manner with those experiencing palliative care environments first-hand. An area of value for further study, following on from the work of this thesis would be a project to revisit this phenomenological focus to explore the human condition as influenced by the built environment. Studies already undertaken regarding phenomenology of place within in-patient hospices by nurses and social anthropologists have suggested that contemporary hospices generate feelings of 'homelessness' where people disconnect from their lifeworld and relationships.<sup>545</sup> Furthermore they highlight hospice environments as encompassing feelings of 'no-place['s]' that seek to cloak and protect

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543 Owing to the ethical limitations the fieldwork undertook observation of the case study building only.

544 Annie Bellamy, 'Phd Proposal', (N.A., 2017) p.3

545 Rasmussen, B. H., Jansson, L. and Norberg, A. (2000) 'Striving for becoming at-home in the midst of dying', *American Journal of Hospice and Palliative Medicine*®, 17(1), pp. 31–43. doi: 10.1177/104990910001700109.

people from the realities of dying.<sup>546</sup> Further studies into the architectural mitigation of identified keywords, such as 'homelessness', could be of value. Yet 'home' or 'home-like' as architectural concepts and outcomes are subjective to the individual and may be problematic, as Ahuja outlines 'the rooms that soothe one person may alienate another...[as such] hospice design and practice are necessarily and perpetually unstable.'<sup>547</sup> Therefore, there is a requisite for architectural design to submit to a deep research ethic in order to continually move forward practice – not just engage in situated one-off projects. Much like the hospices from the walking tours described developing a community of practice, communicating, and visiting other hospice settings when embarking on a project, this could be of benefit to architects also, perhaps through post-occupancy evaluation (POE).

Projects such as in-patient hospices with vast social value, not only for individuals but whole communities need dedication and motivation to go beyond standard practice. These would for example seek to deliver outputs that speak to architectural practitioners and the industry regarding finer details of design strategies and aesthetics but that crucially, as Wong and others attest, go beyond merely highlighting aspects of interior design and decoration.<sup>548</sup> This would explore fundamental elements of architectural design such as lighting, materiality, tectonics, and sensory qualities. A study with a design led direction might be conducted with a practice-based approach - in contrast to this study's practice-led approach - using design itself as the research method that has a focus on the outcomes of design practice. This kind of approach might look to previous publications of other building typologies, such as the RIBA's Building Futures *Silver Linings: The Active Third Age and the City*<sup>549</sup> which inspired a sister design competition with an industry sponsor. Not only did the research from the Silver Linings report contribute to a change in architectural practitioners' attitude toward housing for older people, the competition running in parallel offered an experimental space for practitioners to explore innovative and forward-thinking ideas. Similarly, RealDania's *Programme for the Good Hospice in Denmark*<sup>550</sup> co-produced report that outlined frameworks for the delivery of hospice buildings in Denmark alongside the delivery of live projects trialling this could be re-imagined with a UK focus.

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546 Lawton, J. (1998), 'Contemporary Hospice Care: the Sequestration of the Unbounded Body and 'Dirty Dying''. *Sociology of Health & Illness*, 20: 121-143. doi:10.1111/1467-9566.00094

547 Ahuja, 'End Stages', *Places Journal* (2018)

548 Kevin Wong and others, 'Designing the Physical Environment for Inpatient Palliative Care: A Narrative Review', *BMJ Supportive & Palliative Care* (2021), bmjspcare-2021-003087, p.6

549 Matthew Barac and others, 'Silver Linings: The Active Third Age and the City', (London, 2013)

550 Architects, 'Programme for the Good Hospice in Denmark', (2006)

Similarly, the limitations imposed by the impact of COVID-19 offer another branch for further research inasmuch that there are recognised repercussions of the pandemic on healthcare environments. As mentioned in the thesis, the effect of the pandemic on funding for third-sector hospices has led to many - despite emergency government funding measures - facing a precarious financial position. As such some are threatened with cuts to services or even closure. A study that seeks to explore the impact on hospice buildings with regards to physical space (for example, infection control and social distancing) and additionally the perception toward entering hospice environments would be of benefit for palliative care environments and providers. The findings of such a study could contribute finer grain knowledge of the future evolution of the hospice environment directly influenced by the post-pandemic context, clinically, architecturally and from wider societal perspectives.

## Impact

### Research skills, dissemination & networking

The researcher had prior experience in academic research having undertaken and written a Master's level project and dissertation; however the four year process of engaging with this doctoral study allowed the development of more rigorous and professional research skills. It supported the researcher's growth in not only, research design, but implementation of mixed research methods - especially in the case of this study with participants from background likely to be unfamiliar with architecture as a focus. Belonging to a School of Architecture, but co-supervised by an academic from the School of Healthcare Sciences emphasised the need to develop a robust language to communicate concepts and analysis with clarity. Critically, it also contributed greatly to the researcher's awareness of and ability to collaborate and co-produce.

The researcher has presented associated work at international and national research conferences in both the architectural and healthcare professions, receiving commendations for the work and contributing to their exposure of other modes of academic communication. The researcher was confident in presenting work owing to the nature of architectural education engaging with project reviews, in which students are asked to verbally and visual present their academic design projects. The manner of these reviews however invites a style of presentation often seen as a defence of their work, rather than a critical evaluation of process and outcome. The act of presenting to

other professional audiences highlighted to the researcher the importance of language in interdisciplinary settings, and the presentation of arguments based on clear methods and evidence. Furthermore, presenting to mixed audiences, often with many inquisitive questioners, highlights the appetite to engage with this topic highlighting growing academic and professional engagement. Further to this the researcher has also been invited to act as a peer-reviewer for an article published in the *BMJ Supportive and Palliative Care Journal*.

Engaging with others through conferences gave the researcher a platform to disseminate related work and findings, as well as the opportunity to develop a community of practice. Conversations and discussions held during such research events enabled the researcher to broaden their scope and knowledge of the hospice sector. Further to this networking, the researcher has established working relationships with senior figures from within the hospice sector, such as HospiceUK and Tenovus Cancer Care. A particularly measurable example of growing impact was the invitation to run a workshop at HospiceUK's 'Revolutionary Clinicians' event held at their headquarters at Hospice House, London. The event was attended by around thirty staff members from hospices nationwide across a variety of roles, from clinicians to management. Intending to confront current thinking regarding the context of hospice care in the UK, the researcher's workshop challenged the delegates with thinking about 'other' spaces in communities that hospices might inhabit in addition to permanent environments of care and the potential requirements of these spaces to encourage use by wider community groups, see Practice Note 4. It is intended that the researcher will consolidate the findings of the study into a summary and distribute this to the research partners and members of the broader network mentioned above to disseminate the findings further afield.

Building upon involvement at the Revolutionary Clinicians event, the researcher has most recently been invited as an expert voice to contribute academic research on exemplary architecture for care and well-being to the preparation of design information for the replacement of a major cancer hospital in Cardiff, Wales. This role offers an opportunity to translate the background knowledge and workings of the thesis into a digestible format for architectural practitioners, signposting to exemplary practice and highlighting the crucial themes and areas of importance to be considered when designing a cancer care centre. The researcher has also since been appointed a member of the 'Senses in Healthcare Architecture and Design: Developing Guidance for Hospitals' Working Group, that aims to produce a guidance note for engagement with sensory environments in healthcare design and sensory research toolkit for use in hospitals. The project is led by Victoria

Bates of University of Bristol and has been developed alongside Architects for Health as part of a UKRI-funded 'Future Leaders Fellowship' on the sensory environment of the NHS hospital. Involvement in the above projects demonstrates a practicable platform for associated academic activities, contributing to research projects that will have tangible impact on the state of healthcare and design.

## Pedagogy

A key takeaway from the study was that of the responsibility of architectural education to both nurture and challenge students in being critical about how the buildings they design are going to be used and their sensitivity to different contexts of environments. This study not only cultivated an interest in the processes and application of research ethics but also the topical theme of ethical practice; a soon to be a mandatory competency for architects. Now a Lecturer in Architecture, the researcher is determined in encouraging their students in conversations around architecture on what Jeremy Till describes as 'the values and consequences of the spaces'<sup>551</sup> that challenges their decision making and future practice. Moreover, a crucial principle of students future practice that the researcher believes is vital to cultivate is intersubjectivity (described previously in Chapter 7) and the ability to question stereotypes of both groups of inhabitants and building types, engaging as far as possible with the users to meaningfully understand their needs and spatial requirements.

Through the researcher's teaching practice, as a design studio tutor during their doctoral studies at their host institution and their recent appointment as a Lecturer at another institution, they have had direct impact working with approximately three hundred students. It is also crucial to note that through collaboration with their two supervisors and contributing to their own shared understanding of the topic in architecture and healthcare sciences, this thesis has demonstrated indirect impact of many more students through their respective teaching practices. The researcher, alongside their doctoral supervisor, co-ran a second-year thematic studio of twenty students for the undergraduate architecture programme at a leading UK institution. The studio brief challenged students to design a respite centre, challenging students to question their potentially stereotypical assumptions about specific communities/end-users and their spatial and contextual requirements. Building on the importance of unpacking empathetic attributes, the researcher has since written a brief for a thematic studio for fourth year Master of Architecture students in an English context. With a more

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<sup>551</sup> Jeremy Till, *How Will Architects Be Educated in 20 Years Time?* (201) <<http://www.jeremytill.net/read/97/how-will-architects-be-educated-in-20-years-time>> [accessed 8th January]

in-depth theoretical underpinning this brief asked students to situate themselves within a specific issue that affects 12–17-year-olds and develop an ethically led design response. Feedback from a student in the second-year unit commented that they felt proud of the work they undertook for the project and considered it a breakthrough moment as they developed as a designer and future architect.<sup>552</sup> Further impact can also be demonstrated via lectures; the first concerning the method of auto-ethnography and the second regarding research ethics in design research. Through the academic appointment of the researcher as a Lecturer at another leading UK institution, the impact of the researcher's practice has been further extended to cohorts at another institution, with a lecture given to two-hundred second-year students of various architectural programmes regarding ethnography, using the thesis study as an example.

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<sup>552</sup> Anonymous Student, Untitled Message to Annie Bellamy received 1st November

## Epilogue

Since I introduced my personal experience and motivations for undertaking this doctoral study at the beginning of the thesis, it felt fitting that it closes with a reflection on where I am now - at the end of this journey. Four years later from setting out on my doctoral studies, and six years on from the Master's dissertation that started it all. Looking back over this time, I can see how much I have grown across all aspects of my life. The Master's dissertation was raw, less academic, and with distance what I can now recognise as being a cathartic emotional response to my grief at the time. My doctoral studies, with the benefit of time and distance moved this intensely personal experience into a more rigorous public and professional facing space that has been strengthened by additional studies to develop my knowledge of hospice. In a way, I can see that the process of this study has given me strength to empower myself to generate something positive from. My grief is not gone by any means and the loss of my mother, and the circumstances of which, I will carry with me forever. However, I have become that bit more resilient in the face of reminders in everyday life. Embracing a topic so close to my own experiences has been one of my greatest challenges; and this study amongst so much else, has given me the confidence in recognising my own limitations, especially in entering hospice environs. My Master's dissertation was characterised by youthful naivety at the expense of my



own well-being, where now I am instead mindful of the impact on myself and the importance of protecting those researching as well as those being researched. An inadvertent outcome of the study is now my ongoing interest in the role of ethics in architectural practice and research. Further to which I am undertaking a research study at the institution I am employed as a Lecturer on the role of ethics in undergraduate architectural education investigating knowledge transfer between practitioners and students.

Though this study had a personal motivation, it has also given me an invaluable opportunity to grow both academically and professionally. I have been presented with the world of academic research and have learnt tremendously about research practice, research methods, research ethics, to name but a few areas. I have found the confidence to co-write an article that was published in a well-respected non-architectural peer-reviewed journal, design and conduct in-depth interviews with research participants with little background knowledge of architecture. A primary desire at the time of writing the proposal for my application to the programme, was that whatever the outcome, the work would navigate a relationship with architectural practice and wider industry. The real-life motivation of taking on this topic was one that was passionate about making a change and having impact on other experiences and lives. My original proposal outlined my intentions to not just undertake the research but be someone actively involved in designing 'better' spaces for palliative care. To this end, I saw that the trajectory of my life

post-PhD would be to enter back into professional practice and become a registered Architect going on to work at a studio that focused on healthcare.

Reflecting on the four years of this study and my growing involvement and enjoyment in and of architectural education, qualifying as an Architect is no longer where I see myself heading. Working with students has given me an opportunity to learn from them and mature in my design thinking, helping to support students in their own discovery of the design process. I set out to study architecture at 18 fulfilling a childhood dream and whilst my passion for actively designing has not gone, this is no longer my *modus operandi*. In my original research proposal and application, I described my aims of producing a ‘first response guide that offers key principles of the approach to design’<sup>553</sup> for palliative care environments. I can recognise that, however admirable my original aspirations, this thesis provides awareness as a building block for the work of others to take forward. I have left behind the naïve expectations of single-handedly changing the way architects design hospices, with the influence of teaching helping me to see more clearly the change I am able to make. Disseminating thinking, sharing an approach to design, an agitator who can encourage conversations with students that challenges their thinking and future practice. As one person, I cannot change design to be better - as an educator, supporting those going onto work in the profession I can be behind pushing for awareness and responsibility, planting seeds for change.

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<sup>553</sup> Bellamy, 'Phd Proposal', (N.A., 2017) p.4

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## Appendices

Appendix 1  
*ethics approvals & risk assessment*

**WELSH SCHOOL OF ARCHITECTURE**  
**ETHICS APPROVAL FORM FOR STAFF AND PHD/MPHIL PROJECTS**

Tick one box:	<input type="checkbox"/> STAFF	<input checked="" type="checkbox"/> PHD/MPHIL
Title of project:	Designing Dying Well: Toward a new approach to the design of in-patient palliative care environments for the terminally ill	
Name of researcher(s):	Annie Bellamy	
Name of principal investigator	Annie Bellamy	
Contact e-mail address:		
Date:	10.05.19	

Participants		YES	NO	N/A
Does the research involve participants from any of the following groups?	• Children (under 16 years of age)		•	
	• People with learning difficulties		•	
	• Patients (NHS approval is required)		•	
	• People in custody		•	
	• People engaged in illegal activities		•	
	• Vulnerable elderly people		•	
	• Any other vulnerable group not listed here		•	
• When working with children: I have read the Interim Guidance for Researchers Working with Children and Young People ( <a href="http://www.cardiff.ac.uk/archi/ethics_committee.php">http://www.cardiff.ac.uk/archi/ethics_committee.php</a> )				•

Consent Procedure		YES	NO	N/A
• Will you describe the research process to participants in advance, so that they are informed about what to expect?		•		
• Will you tell participants that their participation is voluntary?		•		
• Will you tell participants that they may withdraw from the research at any time and for any reason?		•		
• Will you obtain valid consent from participants? (specify how consent will be obtained in Box A) <sup>1</sup>		•		
• Will you give participants the option of omitting questions they do not want to answer?		•		
• If the research is observational, will you ask participants for their consent to being observed?		•		
• If the research involves photography or other audio-visual recording, will you ask participants for their consent to being photographed / recorded and for its use/publication?		•		

Possible Harm to Participants		YES	NO	N/A
• Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort?			•	
• Is there any realistic risk of any participants experience a detriment to their interests as a result of participation?			•	

Data Protection		YES	NO	N/A
• Will any non-anonymous and/or personalised data be generated or stored?		•		
• If the research involves non-anonymous and/or personalised data, will you:	• gain written consent from the participants	•		
	• allow the participants the option of anonymity for all or part of the information they provide	•		

Health and Safety		YES	
Does the research meet the requirements of the University's Health & Safety policies? ( <a href="http://www.cf.ac.uk/osheu/index.html">http://www.cf.ac.uk/osheu/index.html</a> )		•	

Research Governance		YES	NO	N/A
Does your study include the use of a drug? You need to contact Research Governance before submission ( <a href="mailto:resgov@cf.ac.uk">resgov@cf.ac.uk</a> )			•	
Does the study involve the collection or use of human tissue? You need to contact the Human Tissue Act team before submission ( <a href="mailto:hta@cf.ac.uk">hta@cf.ac.uk</a> )			•	

<sup>1</sup> If any non-anonymous and/or personalised data be generated or stored, *written consent* is required.



Prevent Duty	YES
<p>Has due regard be given to the 'Prevent duty', in particular to prevent anyone being drawn into terrorism?</p> <p><a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/445916/Prevent_Duty_Guidance_For_Higher_Education_England_Wales_.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/445916/Prevent_Duty_Guidance_For_Higher_Education_England_Wales_.pdf</a></p> <p><a href="http://www.cardiff.ac.uk/publicinformation/policies-and-procedures/freedom-of-speech">http://www.cardiff.ac.uk/publicinformation/policies-and-procedures/freedom-of-speech</a></p>	•

If any of the shaded boxes have been ticked, you must explain in Box A how the ethical issues are addressed. If none of the boxes have been ticked, you must still provide the following information. The list of ethical issues on this form is not exhaustive; if you are aware of any other ethical issues you need to make the SREC aware of them.

Box A The Project (provide all the information listed below in a separate attachment)
<ol style="list-style-type: none"> <li>1. Title of Project</li> <li>2. Purpose of the project and its academic rationale</li> <li>3. Brief description of methods and measurements</li> <li>4. Participants: recruitment methods, number, age, gender, exclusion/inclusion criteria</li> <li>5. Consent and participation information arrangements - please attached consent forms if they are to be used</li> <li>6. A clear and concise statement of the ethical considerations raised by the project and how is dealt with them</li> <li>7. Estimated start date and duration of project</li> </ol> <p>All information must be submitted along with this form to the School Research Ethics Committee for consideration</p>

Researcher's declaration (tick as appropriate)	
• I consider this project to have <b>negligible ethical implications</b> (can only be used if none of the grey areas of the checklist have been ticked).	•
• I consider this project research to have <b>some ethical implications</b> .	
• I consider this project to have <b>significant ethical implications</b>	

Advice from the School Research Ethics Committee

STATEMENT OF ETHICAL APPROVAL

31 July 2019



Annie Bellamy  
Welsh School of Architecture, Bute Building  
King Edward VII Avenue, Cardiff

Dear Annie

**The building in practice:  
architectural reflections on the life of the in-patient hospice building**

At its meeting of 30 July 2019, the School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

**Pass –and that you proceed with your Research in collaboration with your supervisor**

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months' time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely



28 June 2019

Dear Ms Bellamy

**Project Title: The Architecture of Palliative care: toward a new approach to the architecture and design of in-patient hospices**

**Project Reg number:**

**Ethics reference: EC1903.418b (welsh school of architecture)**

The following documents were received:

Document	Version	Date
Study Protocol	2.0	21 May 2019
Patient Information Sheet	1.0	21 May 2019
Consent Form	1.0	21 May 2019
Confirmation of Sponsor		18 May 2019
Evidence of Ethical Approval		10 May 2019

I can confirm that the above study documentation has been reviewed, as part of the clinical audit and effectiveness meeting on the 6<sup>th</sup> June 2019, and a favourable opinion has been agreed and the Organisation will take part in the study.

I understand that there may also be further parts to your study including an observational study of the environment at the hospice. These are likely to require further approval and I


May I take this opportunity to remind you that it will be your responsibility to:



- ☐ Any safety issues that the organisation should be aware of.

Yours Sincerely




Dear Ms Bellamy,

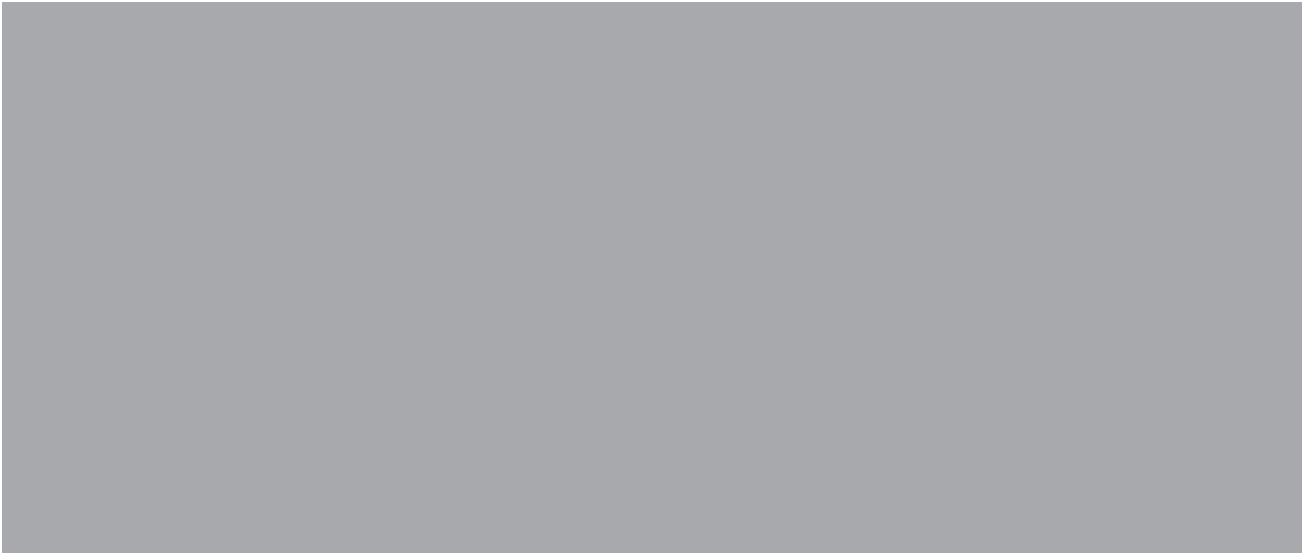
**Project Title: The Architecture of Palliative care: toward a new approach to the architecture and design of in-patient hospices.**

**Ethics reference: EC1903.418b (welsh school of architecture)**



The following documents  
were received:

Document	Version	Date
Study Protocol	2.0	21 <sup>st</sup> May 2019
Patient Information Sheet	1.0	21 <sup>st</sup> May 2019
Consent Form	1.0	21 <sup>st</sup> May 2019
Confirmation of sponsor		18 <sup>th</sup> March 2019
Evidence of ethical approval		10 <sup>th</sup> May 2019



- ☐ Inform the organisation of any amendments relating to the protocol, or study documentation including personnel changes and amendments to the actual or anticipated start / end dates
- ☐ Any safety issues that the organisation should be aware of



## Welsh School of Architecture Risk Assessment

<b>Risk Assessment (RA) Title</b> Remember to complete Footer details	Designing Dying Well: Fieldwork	Date of Risk Assessment 28.06.19	Review Date (if applicable)	Version Number 2
--	---------------------------------	-------------------------------------	-----------------------------	---------------------

### Summary of Activity RA Covers

Location: Marie Curie Hospice, Cardiff and the Vale, Bridgeman Road, Penarth, CF64 3YR

This risk assessment covers fieldwork activities to be undertaken by Annie Bellamy, a WSA PGR student in support of her doctoral thesis "Designing Dying Well". This fieldwork involves the travel to and from the Marie Curie Cardiff and the Vale Hospice in Penarth via public transport (train), and the specific research activities of focus groups and observational studies. The total number of focus groups estimated are two sessions of 1-2 hours. The observation will take place over a designated period of time, expected to be over a month (the length and timetable of this is subject to confirmation of all required ethical approvals.)

The focus group will be organised in liaison with the hospice management team. Upon arrival the Lead Investigator Annie Bellamy (potentially accompanied by one or both of her supervisors, Dr Sam Clark or Dr Sally Anstey) will sign in as a guest at the hospice and proceed to a meeting room pre-booked for the focus group. The focus group activity will take place with a pre-selected group of various staff members of the hospice. Sat around a table, the focus of the group will be on a series of large-scale printed drawings that the Lead Investigator will encourage participants to draw and write on.

The observation, as the focus group above will be organised in liaison with identified members of the hospice management and clinical teams - "mediators". This fieldwork activity will be undertaken solely by the Lead Investigator, Annie Bellamy. Over a period of time (duration tbc by the hospice governance committee) she will travel by public transport to the hospice and sign in at the reception. She will arrange access to a locker or secure location to leave personal belongings such as coats/bags etc, so they do not pose a trip hazard to herself or any member of staff or the public. She will make contact with the 'mediator' who will assess whether the location for the day is appropriate to be observed. When given approval, the Lead Investigator will proceed to the research location and find a suitable area within to stand/sit to take notes on the study focus. The Lead Investigator will not engage directly with any member of staff or the public and will be guided by the 'mediator' if it necessary for her to stop the study and vacate the area. The Lead Investigator will take all appropriate steps to ensure she does not hinder the working processes of the hospice, by avoiding standing in awkward locations or having loose items on the floor.

RA Title	Designing Dying Well: Fieldwork	Version Number	2
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RA Assessor(s)		Person(s) RA Covers	Annie Bellamy
Contact Details		Location(s) RA Covers	Marie Curie Cardiff and the Vale Hospice, Penarth, Wales

NOTE: Arrangements must be in place to communicate new and / or revised Risk Assessments to relevant persons.  
Older versions must be removed from use and filed for future reference/archive.



No	What are the Hazards?	Who/What is at Risk?	Existing Controls	Risk Factor			Further Controls	Risk Factor			Action By	Action Complete
				S	L	R		S	L	R		
1.	Travel – public transport (Slip / trips / falls, collision injuries)	AB	Train tickets will be booked via carriage provider, and AB to follow safety information provided by the train company.	2	1	2	N/A					
2.	Travel – hire car (Collision injuries, risk of breakdown)	AB	Hire car to be booked as and when needed by AB for visits that public transport is not appropriate i.e. rural locations and those that require overnight stays. The University Driving Policy will be adhered to. <a href="https://intranet.cardiff.ac.uk/intranet/staff/documents/health-safety-and-wellbeing/core/Driving-at-Work-Policy-and-Guidance.doc">https://intranet.cardiff.ac.uk/intranet/staff/documents/health-safety-and-wellbeing/core/Driving-at-Work-Policy-and-Guidance.doc</a> As advised, AB will purchase zero excess damage waiver policies on collection of the cars. Responsibility of local highway laws and the car will remain the responsibility of AB. AB will not drink and drive.	3	1	3	N/A					

No	What are the Hazards?	Who/What is at Risk?	Existing Controls	Risk Factor			Further Controls	Risk Factor			Action By	Action Complete
				S	L	R		S	L	R		
			AB, if driving alone will be vigilant to avoid driving whilst tired. If she feels ill or tired, she will take a break.									
3.	Lack of available communication methods in reporting a hazard/potential hazard	AB	AB will carry a fully charged mobile phone at all times. Emergency services will be contacted in case of a serious emergency.  AB will make sure to provide notice to the school manager and her supervisor when she leaves for visits and the expected return time; and provide them with contact details and a next of kin contact in case of emergencies.	1	1	1						
4.	Incliment weather (slips / trips / falls on journey to research location)	AB	The weather forecast will be checked, and appropriate precautions will be taken. If an accident occurs, AB will seek relevant help or call for help.	2	1	2	N/A					
5.	Slip / trips / falls within the hospice environment	AB	AB will make sure that any personal belongings (coats, bags etc) are kept in a secure place during observation periods, so no loose items are in the working areas	2	1	2	N/A					



No	What are the Hazards?	Who/What is at Risk?	Existing Controls	Risk Factor			Further Controls	Risk Factor			Action By	Action Complete
				S	L	R		S	L	R		
			of the hospice so as not to interfere in the working space of the staff or the public.  Any accidents that take place within the hospice environment will be reported to the hospice manager or staff member in charge of first aid.									
6.	Collision injuries within the hospice environment	AB / member of staff or public	AB will be alert to others in the location she is observing and will make sure to find areas to observe that are out of the way of the day to day practice of members of staff or members of the public. If she is involved in a collision, the incident will be reported immediately to members of the hospice staff who will assist. Any hospice specific health and safety procedures will be followed.	2	1	2						
7.	Fire	AB	AB will undergo an induction session with a member of the hospice management team so she is familiarised with the fire and emergency evacuation plans of the hospice and will follow procedures for evacuation in the event of fire.	3	1	3	N/A					

RA Title	Designing Dying Well: Fieldwork	Version Number	2
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No	What are the Hazards?	Who/What is at Risk?	Existing Controls	Risk Factor			Further Controls	Risk Factor			Action By	Action Complete
				S	L	R		S	L	R		
8.	Stress / emotional distress to members of the public or the researcher herself	AB + members of the public or staff	<p>The research activity is purely observational and will not engage directly with any individual in the research setting. The observation will only take place in pre-approved communal locations, and not in private bedrooms.</p> <p>AB will work with a number of identified members of the clinical team (mediators) who will be a point of contact between AB and individual. This will include advising if a location is not appropriate to be in, or to leave if a situation changes. The 'mediator' will be a contact for a member of the public to talk to should they feel uncomfortable with the research activity.</p> <p>Dr Sally Anstey, a supervisor of the study, is the Link Lecturer between the University and the hospice, and she will be available for guidance and a point of contact should AB witness behaviour that causes concern.</p> <p>AB witnessed her Mother's passing in a hospice a number of years, and should this cause distress to herself as the researcher -her supervisors will monitor her through the process and if deemed</p>	1	3	3						

RA Title	Designing Dying Well: Fieldwork	Version Number	2
----------	---------------------------------	----------------	---



No	What are the Hazards?	Who/What is at Risk?	Existing Controls	Risk Factor			Further Controls	Risk Factor			Action By	Action Complete
				S	L	R		S	L	R		
			necessary AB will seek the necessary support from either the University counselling service, or the School of Healthcare Sciences counselling services for those specifically witnessing clinical									



RISK FACTOR = SEVERITY X LIKELIHOOD

REMEMBER: Arrangements must be in place to communicate new and / or revised Risk Assessments requirements to relevant persons.

## Appendix 2

### *research resources*

## The building in practice: architectural reflections of the life of the in-patient hospice building

Example timetable of activities (dates are indicative and for the purpose of timetabling)

### Phase One:

w/c 02.09.19– 13.09.19

- Posters will be put up and displayed in all areas of the hospice site advertising that in two weeks' time observation will be taking place
- A similar poster will be emailed electronically to all members of staff during this period

### Phase Two:

w/c 16.09.19

- Poster's will be put up and displayed in all areas of the hospice site advertising that observation is taking place.
- Active observation will take place in morning or afternoon slots.
- Time will be given in a following session for notes to be organised by the Lead Investigator.
- Example schedule's are shown below, covering weekday observation, partial weekday and weekend and observation overnight

	Mon	Tues	Weds	Thurs	Fri	Sat	Sun
(8:00 – 12:00) AM	ENTRANCE		CORRIDOR		DAY HOSPICE	No observation over the weekend	
(1:00 – 6:00) PM	CORRIDOR	DAY HOSPICE	ENTRANCE	STAFF ROOM	ENTRANCE		

	Mon	Tues	Weds	Thurs	Fri	Sat	Sun
(8:00 – 12:00) AM					DAY HOSPICE	ENTRANCE	STAFF ROOM
(1:00 – 6:00) PM			ENTRANCE	STAFF ROOM		CORRIDOR	ENTRANCE

	Mon	Tues	Weds	Thurs	Fri	Sat	Sun
(8:00 – 12:00) AM						No observation over the weekend	
(1:00 – 6:00) PM							
OVERNIGHT	CORRIDOR			ENTRANCE			

# Would you like to take part in research?

**“The building in practice: architectural reflections on the life of the in-patient hospice building”**

Annie Bellamy, an Architecture PhD student from Cardiff University is looking for members of staff to take part in a focus group for 1-2 hours max to talk and draw about your experience of this hospice building!

If you would like to take part please send an email by August 6th to [REDACTED]

OR

[REDACTED]



## Any Questions? Contact Us

Principal Researcher

Annie Bellamy, PhD candidate, Welsh School of Architecture,

[REDACTED]

Academic Supervisors

[REDACTED]

# Observational research notice

Annie Bellamy, is an Architecture PhD candidate from Cardiff University studying the hospice building. (Not people or their care.)

In two weeks she will be here to observe this part of the building, and this means you may see her sitting or walking around.

She will be wearing a large name badge so you can easily identify her.



## Any Questions? Contact Us

Principal Researcher

Annie Bellamy, PhD candidate, Welsh School of Architecture,

[Redacted contact information]

Academic Supervisors

[Redacted contact information]



# Observational research is taking place today

Annie Bellamy, an Architecture PhD candidate from Cardiff University is studying the hospice building. (Not people or their care.)

She is here today to observe this part of the building, and this means you may see her sitting or walking around.

She will be wearing a large name badge so you can easily identify her.



## Any Questions? Contact Us

Principal Researcher

Annie Bellamy, PhD candidate, Welsh School of Architecture,

[Redacted contact information]

Academic Supervisors

[Redacted contact information]

**'The Architecture of Palliative Care' - Staff Consent Form - Confidential data**

*'The Architecture of Palliative Care' is a doctoral research project that is exploring the physical and mental experience of the in-patient hospice across key user groups to develop new approaches and recommendations for future best practise for architects and designers that encourages a more open and dignified attitude to end of life care.*

I understand that my participation in this project will involve taking part in a group led workshop focusing on understanding the staff experience of working in the existing building at Holme Tower, Penarth. The workshop will run activities such as group discussions and a drawing exercise that explores the past layouts of the hospice.

☐

I understand that my participation within the workshop will be recorded by an audio device. Any data transcribed and used within the final thesis will be completely anonymised.

☐

I understand that any drawings or visual media I produce as part of the group workshop may be reproduced as images within the final thesis document.

☐

I understand that my participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason.

☐

I understand that I can ask for the information I provide to be deleted/destroyed at any time and, in accordance with the Data Protection Act, I can have access to the information at any time.

☐

I understand that I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with supervisors Dr Sam Clark or Dr Sally Anstey (please see attached information sheet for contact details)

☐

I understand that the information provided by me will be held confidentially, such that only the Principal Investigator, Annie Bellamy, can trace this information back to me individually. The information will be retained until the thesis is due to be completed (circa. 2022) when it will be deleted/destroyed.

☐

Signed:

Date:

### The Architecture of Palliative Care – Information Sheet for staff members

#### The thesis:

The 2015 VOICES survey found that 82% of people expressed the desire to die at home, yet half the population will die in a hospital setting. (ONS, 2016) The in-patient hospice however is neither 'hospital' nor 'home' and are often described as 'homes away home'.

Architecturally, they have a unique identity that has so far remained fundamentally undocumented. This research is seeking to engage with the different types of people using the hospice to understand and suggest future best practice for architects and designers of in-patient hospices.

This study undertaken by Annie Bellamy as a post-graduate researcher at the Welsh School of Architecture, part of Cardiff University is looking to gather information and stories from in-patient hospice teams to learn more about how the built environment can provide support to those working in the hospice environment.

#### Your participation:

The qualitative data collected from the workshops and interviews will be anonymised and transcribed and used to reveal experiences and support the research development of best practise. The findings from this focus group will provide key themes and areas for the Principal Researcher to focus on in the next phase of observational research.

Should you wish to speak to the principal researcher or the academic supervisor from the university to ask any questions or ask to be withdrawn from the study, contact details and information are listed below:



#### Principal Researcher

Annie Bellamy, PhD candidate, Welsh School of Architecture, Cardiff University

Annie is a Part II qualified architectural designer who graduated from the Welsh School of Architecture and Central Saint Martin's College of Art and Design with First Class Honours at undergraduate and graduate level. She has worked for a number of award-winning practices but has maintained a dedication to people-centred design returning to the Welsh School of Architecture to undertake this research.

### The Building in Practice - Observational Research - Consent Form

*'The Architecture of Palliative Care' is a doctoral research project that is exploring the physical and mental experience of the in-patient hospice across key user groups to develop new approaches and recommendations for future best practise for architects and designers that encourages a more open and dignified attitude to end of life care.*

I understand that on behalf of the hospice, the built setting of the Marie Curie Cardiff and the Vale hospice will be observed without interference at a number of different locations within the hospice building and at a variety of times and days within the week.

☐

I understand that the Principal Researcher, Annie Bellamy, will be taking notes and drawings of data relevant to the aims and objectives of the study activity.

☐

I understand that on behalf of the hospice, the participation in this study is entirely voluntary and that you can withdraw the hospice from the study at any time without giving a reason.

☐

I understand that I can ask for the information I provide to be deleted/destroyed at any time and, in accordance with the Data Protection Act, I can have access to the information at any time.

☐

I understand on behalf of the hospice, I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with supervisors Dr Sam Clark or Dr Sally Anstey (please see attached information sheet for contact details)

☐

I understand that on behalf of the hospice, the information collected will be held confidentially. The information will be retained until the thesis is due to be completed (circa. 2022) when it will be destroyed.

☐

Signed:

Date:

## Appendix 3

### *research training*

## Certificate of Attendance

This is to certify that  
**Annie Bellamy**

attended the training entitled

**Communicating with Research Participants:  
Be Competent & Confident**

on

11<sup>th</sup> April 2019

at

Support & Delivery Centre, Cardiff



**CPD Hours = 7**



---

**Lynette Lane**  
Senior Training & Development Manager  
Health and Care Research Wales  
Support Centre

## Certificate of Attendance

**Annie Bellamy**

attended

**Introduction to Good Clinical Practice (GCP):**  
A practical guide to ethical and scientific quality standards in  
clinical research

on 24<sup>th</sup> May 2019

Sessions include:

1. The Value of Clinical Research and the role of NIHR CRN & Health and Care Research Wales
2. Introduction to research and the GCP standards
3. Preparing to deliver your study
4. Identifying and recruiting participants: Eligibility & Informed Consent
5. Data collection and ongoing study delivery
6. Safety reporting and Study closure

Including EU Directives, Medicines for Human Use (Clinical Trials) Regulations and the UK Policy Framework for Health and Social Care Research, as applied to the conduct of Clinical Trials and other studies conducted in the NHS

**This course is accredited by the CPD Certification Service (6.5 Hours) and the Royal College of Physicians (6 CPD points) CPD Code: 125254**



**Lynette Lane**  
Senior Training & Development Manager  
Health and Care Research Wales Support  
Centre



**Emma Lowe**  
NIHR CRN Learning & Development Lead



Appendix 4  
*letters of support*

4<sup>th</sup> March 2018

Dear Annie,

**Re: Designing dying well: *towards a new approach to the design of palliative care environments for the terminally ill***

I am writing to confirm Hospice UK's support of the above study. There is a paucity of evidenced based tools and resources in this area and we welcome robust, relevant research to improve the lives and experiences of dying people and their caregivers.

Hospice UK is the national charity for hospice and palliative care and committed to ensuring excellence in end of life through research, practice, policy and education. Our four strategic objectives are:

1. Extend our reach and enable hospice quality care to be delivered in any setting;
2. Tackle inequality and widen access to hospice care;
3. Work with communities to build capacity and resilience to care for those at the end of life;
4. Empower a strong, dynamic and responsive hospice sector

One of the ways that we reach our objectives is to support the design and dissemination of high quality research that adds value to the body of evidence as well as contribute to the mobilisation of knowledge into practice through our networks, publications and events.

We look forward to the conduct, analysis and dissemination of this study's findings.

Yours sincerely,

Hospice UK, Hospice House, 34 – 44 Britannia Street, London WC1X 9JG

**Tel:** 020 7520 8200 **Fax:** 020 7278 1021 **Email:** [info@hospiceuk.org](mailto:info@hospiceuk.org) [www.hospiceuk.org](http://www.hospiceuk.org)

Company Limited by Guarantee, Registered in England and Wales No. 2751519,  
Charity registered in England and Wales No. 1014851 and in Scotland No. SC041112. VAT No. 731 304476, registered office as above.

17.05.18

To whom it may concern,

At Tenovus Cancer Care, we are involved in research at all aspect of the Cancer journey, from prevention through to end of life care. I recently met with Anne Bellamy who described to me her fantastic research proposal. I was particularly taken with her interesting and novel approach of using the role of architecture in an area such a palliative care.

We are very happy and willing to support Anne with her research in any way deemed suitable and useful. Examples of this may include assisting with participant recruitment or testing ideas with our Research Network, a database of individuals affected by cancer who have indicated a willingness to be involved in research. This is not an exhaustive list by any means.

If you require any further information, please do not hesitate to contact me on



**Call us free, 365 days a year**

**0808 808 1010**

**Ffoniwch ni, 365 diwrnod y flwyddyn**

Gleider House, Tŷ Glas Road, Cardiff CF14 5BD. Tŷ Gleider, Heol Tŷ Glas, Caerdydd CF14 5BD.  
Patron: HRH The Princess Royal Noddwraig: Ei Huchelder Brenhinol Y Dywysoges Frenhinol



Cofrestrwyd gyda'r



FUNDRAISING  
REGULATOR  
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