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# **The dying patient: taboo, controversy and missing terms of reference for designers - an architectural perspective**

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**Abstract:**

Contemporary society has grown seemingly detached from the realities of growing old and subsequently, dying. A consequence, perhaps, of death becoming increasingly over-medicalised, 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 co-designing positive experiences of person-centred care *and* environments at the end of life.

## **Introduction**

The UK is facing a demographic shift; predictions suggest that by 2040 nearly one in seven people will be aged 75 or over[1]. The 'dying' population is also

facing a demonstrable change. Marked not only by 160,000 more people across the UK requiring palliative care by 2040[2] but in the very way in which people are dying. We are no longer dying from complications rooted in single diagnoses, but instead suffering from the complications of complex co-morbidities[3]. This shifting of 'ageing' and 'dying' populations has great implications on the way communities, social services and healthcare institutions are organised to support the well-being of these groups[4]. There is increasing reliance on third sector organisations - specifically care homes and hospice's - to provide care at end of life[5] with 27.5% of deaths in 2016 occurring in such locations. Still, it can be observed that deaths in hospices in the past decade have steadily reduced, suggesting they are increasingly being regarded as a place for respite and specialist care – rather than a place to die.

Biomedical advances are enabling us to live for longer and it appears to be doing so at the expense of what many describe as the overmedicalisation of death and dying[6]. Those dying, are stereotypically assumed to be at a similar stage in the life-course as those within the 'ageing'– or 'fourth-age' – population, i.e. having arrived at the 'final stage' of an ageing person. Here the authors have identified a potential controversy, inasmuch that the 'dying' may be falsely assumed to have characteristics associated with being 'elderly' and posit that there is no universal language on how to medically contextualise a person that is dying. This develops upon a key point emphasised by Dr.Nitin Ahuja in his article 'End Stages'; that "there are no universally advantageous circumstances for death"[7]. The lack, therefore, of a universal design language or context represents a significant problem, highlighted by arguments that successful person-centred care is composed of care-giving services and the associated built environment[8] that are irrespective of the persons age, diagnosis, or other protected characteristics such as race, covered by the Equalities Act 2010[9].

Furthermore, the impact of the COVID-19 pandemic on the charitable sector and healthcare environments indicates further inevitable change. Significant infrastructural adaptation will be required, including the built environment and architecture, which have a responsibility to respond to the contextual transformation of communities and collective aspirations "for a good life to the

very end”[10]. A recent publication by the Architect’s Journal, a popular platform in the UK for mainstream architectural journalism, gathered views from leading professionals stating that it is extremely implausible that healthcare environments will remain unchanged by the effects of the pandemic; advocating the vital role architects play in assisting healthcare providers to see the broader impact of design[11].

Professor Libby Burton, architect and founder of the Well-being In Sustainable Environments research group at Warwick University stated that:

*“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.”[12]*

Crucial to our experience of the world, besides social interactions with others, are our perceptions of, and connections to the built environment. This has been demonstrated by the lifetime work of Professor Roger Ulrich, author of the renowned 1984 study that found surgical patients offered a view of trees recovered more quickly and with less pain relief[13], but also his further work investigating the positive impact of our immediate environment on stress, well-being and overall healthcare quality[14]. As poet Wallace Stevens pens, “I am what is around me”[15] and the phenomenological way in which we respond to texture, material, and space, influences – for better or worse – our day to day lives. Whilst this paper does not have the scope to consider specific aesthetic details of palliative care environments, the authors recognise the urgency for this, and encourage further research into the area.

### **Current terms of reference and ‘outsider’ professions**

In current medical terminology, it can be observed that there are two terms of reference commonly used when discussing death and dying; end of life care (EoLC) and palliative care (PC). In this paper, EoLC is an identifying ‘catch-all’ 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[16]. It

includes any kind of care provided in hospitals, hospices and other institutional settings (such as care homes, prisons and hostels), care provided in the home and via outreach to people who may be homeless. Early recognition of those being in the last year of life ensures that “people receive better, coordinated end of life care”[17] and may help those at EoL and their care teams to better identify and prepare for appropriate and preferred place of death. What definitively constitutes a ‘good’ death may be subjective to the individual, however Meier et al. identified in 2016

*“11 (agreed) core themes of good death: preferences for a specific dying process, pain-free status, religiosity/spirituality, emotional well-being, life completion, treatment preferences, dignity, family, quality of life, relationship with HCP, amongst others”.[18]*

These are recognised as the requirements for 'good' palliative/end of life care practice as outlined in current WHO guidelines.

Palliative care advocates an approach to care which is person-centred and based on neither diagnosis nor prognosis, but on patient and carer needs[19]. In contemporary health care it is regarded as a holistic philosophy that supports care practices[20]. The term, ‘palliative’ was coined in 1973 by Canadian physician Balfour Mount following a visit to Dame Cicely Saunders newly built St. Christopher’s Hospice in London. Upon Mount’s return to Canada, the term ‘hospice’ was shunned by his contemporaries due to negative cultural connotations in the French language of low standards of dignity and care. In an interview about his work Mount describes ‘palliative’ as meaning ‘improving the quality of’[21]. Yet the very word ‘palliative’ originally derives from the Latin root, palliatus and later palliate, as meaning to ‘cloak’ or ‘hide’[22] instead supporting the contemporary view of the hiding of death and dying. Murray et al’s[23] earlier view that it is a place of care that supports a more peaceful death, provides appropriate medication and a holistic approach to care provided by experts - was the historical essence of palliative care. This vision, however, is no longer supported by the structural context of 21st century healthcare due to the influence of strategic, organisational and operational factors on the provision and delivery of EoLC and specialist palliative care. Strategic factors include both organisational and United Kingdom (UK) national level policy. In considering the

organisational level, local voluntary, statutory, professional and patient bodies influence and plan for service delivery as well as those operational factors which influence the day to day clinical care for the individual or groups of patients.

Despite these directives, there are still many groups that have minimal access to these services, whether associated with their medical diagnosis or lifestyle factors[24,25]. A recent unpublished NIHR evidence synthesis (personal communication, Hannigan, 2020) confirms inequality of access and provision of EoLC for people with severe mental illness, including people who are structurally disadvantaged, such as the homeless. In Wales, an estimated 24,000 of the 32,000 people dying would benefit from PC but over a quarter do not have access to it[26]. Furthermore, access to PC services for people who die from cancer is 46% compared to 5% from those dying from other conditions, including end-stage lung, heart, renal or liver failure[27] validating a National Audit Office survey that confirmed inequities in PC provision for both cancer and non-cancer patient populations.

Whilst the two terms above are established within healthcare, this paper suggests that these are liable to potential misinterpretation by ‘outsider’ professions. William M. Lamers posits that the multiple and overlapping terms used by healthcare professionals to describe care for the dying “is confusing and, in the absence of clear definitions, has contributed to needless controversy”[28]. Architects, as ‘outsiders’ to this specialised knowledge require the help of healthcare professionals in order to understand the specific building and environmental needs of those that are dying set apart from traditional typologies of care environments for the ‘ageing’, historically, the ‘elderly’ and ‘infirm’. Architect Professor Niall McLaughlin reflects on designing a multi award-winning respite centre for Alzheimer’s sufferers as being “a one-way journey and [that] no one can report on the passage”[29]. Commonplace buildings encountered in day to day life, such as houses or schools, afford architects and designers opportunities to gather lived experience and tacit knowledge of their requirements. Medical environments contrastingly, are problematic, as architects and designers may not have ‘access’ to first-hand lived experiences of these spaces in a similar way.

Here then is the greatest implication for our controversy; not only are the requirements of dying people misunderstood, but few convincing definitions exist within literature by which architects can absorb appropriate knowledge to serve their design practice. This paper poses that there is a relative paucity in architectural understanding of palliative care environments in comparison to other healthcare environments, that coupled with societal reluctance, therefore, negatively impact best practice for commissioning and designing environments of palliative care. David Clark's concern regarding the perspicuity of definitions[30] themselves is supported by Boyd et al. who assert that:

*“use of language matters, and getting it right or wrong can promote or prevent an ethos of shared endeavour across multidisciplinary teams.”[31]*

We must ask how a contextual architectural understanding of the identity of the 'ageing' and 'dying' populations can co-produce positive person-centred experiences of care services and spatio-material environments. The following is intended as an opening conversation in the broader dialogue of needing to understand, *who*, we are designing for.

### **Nearing end of life**

In many respects authors within the field of gerontology can be credited with demystifying the identity of its subject, with much emphasis placed on moving away from the stereotypical image of physical characteristics once associated with 'growing old'. American academic Bernice Neugarten first introduced the idea of 'Young-Old' (broadly those aged 55 to 75) and 'Old-Old' (those aged 75 and over) to acknowledge the breadth of circumstances presented by older persons in the 1980s, and to challenge the stereotypes of “older persons as sick, poor, enfeebled, isolated”[32]. Then in 1989 British social historian Peter Laslett sought to recognise what he regarded a societal shift from three traditional life phases – childhood, adulthood and old age – towards a four-phase schema in which old age covers two life phases with distinct attributes. His seminal work, *A Fresh Map for Life*, outlined a quadripartite division:



*“First comes an era of dependence, socialisation, immaturity and education; second an era of independence, maturity and responsibility, of earning and of saving; third an era of personal fulfilment; and fourth an era of final dependence, decrepitude and death.”[33]*

Laslett helped to import the University of the Third Age from America to Britain in the early 1980s and is credited with writing the objects and principles of the organisation[34]. Curiously ‘third age’ has not been adopted into common parlance, despite U3A’s relative success and continued expansion in the UK and overseas. Only in recent years has the concept been brought to an architectural audience through RIBA publication, ‘Silver Linings’, which presented an urban ‘Active Third Age’. Members of this ‘increased cohort’ were described as,

*“60-74 years old, and still very much engaged in leisure and cultural pursuits. They can expect a significant period – maybe a decade or more – between the end of their formal working lives and old age (the point at which they may require assistance or care.”[35]*

This report has become a significant touchstone for the UK architectural profession when thinking about, and designing, for ‘active agers’ – as yet no such document represents dying people. The ‘Silver Linings’ report forms part of a comprehensive literature base available for the design of residential care homes and similar such buildings; a contrast to the paucity for palliative care environments as identified by this paper.

Regarding the fourth age, Gilleard and Higgs have questioned its ‘rough formulation’ as a “social space marking the end or collapse of the ‘third-age project’ where power, status, and citizenship can no longer be enacted”, highlighting that its structural boundaries are cast “through a process of antagonistic reciprocity” with those that define the third age[36]. Furthermore, Gilleard and Higgs refer to the fourth age as a ‘social imaginary’ (a largely unstructured and inarticulate understanding of a social situation) and liken it to a metaphorical ‘black hole’. They suggest,

*“The fear of the fourth age is a fear of passing beyond any possibility of agency, human intimacy, or social exchange, of becoming impacted within the death of the social, a hyper-reality from which there is no reality to return.”[37]*

Gerontologists are calling time on stereotypical conceptions of the fourth age, suggesting that there is a lack of criticality around ‘stage-based’ thinking; the idea that the third age represents a ‘successful’ lifestyle, while the fourth age is a social position marked by decline. For instance, those studying dementia suggest we “develop new cultural narratives of deep old age,” which might “involve a willingness to normalise late life and frailties that occur over time, and recognition that communication and agency may look different in later life,”[38] Dementia, they argue, defies chronological ageing and blurs the boundaries of third and fourth ages. Death is similarly age-defying, affecting the young as well as the old.

Lastly, from gerontology, there is awareness that demographic ageing and the expanding cultures of the third age have “undermined the [historic] homogeneity of retirement”[39] and that corporality – the fitness of our bodies, rather than wealth – now constitutes a major social division in later life. Gilleard and Higgs suggest that,

*“...constrained by their lack of health or physical capital, are exposed to the limitations of their body that not only confine and constrain but also potentially render the person ‘alien’ to his- or herself.”[40]*

They posit that this division “prefigures a return to the nineteenth century categorisation” of those deemed ‘impotent through age’, suggesting that today’s care home has “replaced the workhouse as the institutional representation” of age associated fears and “health, rather than income, provides the main protection from its realisation”[41]. For them, the care home has become a new space, “a new void”[42] to be feared within society. This fear has been intensified as a result of the COVID-19 pandemic -with it being reported that residential care homes across North America and Europe “struggling to cope”[43] having borne the brunt of outbreaks, engendering negative connotations of care homes as ‘unsafe environments’. Unlike the workhouses and infirmaries of the past, these contemporary institutions represent a universal risk (determined by corporeal luck) and entering them marks the beginning of an irreversible process. Unless significant change occurs, this may predict a similar societal fate for the hospice, as they shift from places of death to costly environments of specialised care.

## **Dying**

Unlike ageing, our perception is that dying remains an aspect of life that is still very much taboo – one that is expected to be exacerbated by the impact of the COVID-19 pandemic[44]. Prior to COVID, EoLC was supported by effective communication, symptom control, comfort and the presence of those important to the dying person; supporting the established cultural rituals associated with loss and grief. In the UK, deaths have been impacted on during the pandemic by social distancing and PPE requirements negatively impacting on family experiences and grieving. As Yardley and Rolph note “hospitals have closed their doors to visitors, separating patients from family and friends”[45] with profound changes to the way we understand and cope with this event. Holistic and community care during the pandemic is also at risk, as discussed by Etkind et al. who state that this type of care “can be compromised by extreme pressure on [healthcare] services”[46] potentially adversely influencing lived experiences of dying at home.

The COVID-19 pandemic has brought about a reframing of contemporary society’s approach and attitude toward death and dying. Where this may have been considered pre-pandemic[47], the current events highlight exacerbations to the previously doubted experience of dying, providing an opportune moment to promote meaningful decision making at end of life[48]. Dying, is uncertain and unpredictable, but elements that are valuable are related as much to holistic and family care, compassion, communication and teamworking as to the formal management of pain and other physical symptoms. Though it is a process that can occur at any stage in the life course, including, during childhood, adolescence and young adulthood, social anthropologist Julia Lawton writes of the now “deodorised West”[49] that has very limited exposure or tolerance to the often dirty bodily realities of dying.

This lack of exposure is both, reflected and controlled, by the spatial approach to activities relating to the management of death in hospices and care homes. Mortuaries in hospices typically reflect hospital arrangements, ‘hiding’ these activities and associated spaces at a ‘back entrance’ (commonly alongside a service area) or perimeter of the building, separating it from more public or communal areas. Anecdotal reports from observation of hospices have

evidenced social rituals that have emerged to reinforce this 'hiding' in conjunction with the spatial layout. For instance, the prevalence of mortuaries in hospice's being given 'code-names' such as 'the Bluebell Room' to disguise mention of a death from patients and visitors. This quite powerfully demonstrates an attitude of the institutionalisation of death, that can be recognised as occurring in both medical and architectural contexts. This is not the case in countries such as Denmark - design guidance from the 'Programme for the Good Hospice in Denmark' actively promotes "one communal entrance"[50] reflecting a more visibly accepting culture toward death and dying. In order to "make public what had previously been hidden in or delegated to the private sphere"[51] the discussion of language related to the practice of care is a growing area of interest to anthropologists and sociologists, and thus, we argue must be extended to include practitioners.

The term 'dying' covers an extensive spectrum of people with complex physical, psychological, and emotional needs. When dealing with chronic illnesses Price and Cheek write of the "health professional and the health consumer as a convenient 'package' for a management strategy"[52]; the tension between patient and consumer being a key theme of 20<sup>th</sup> century history of medicine. The language here is reminiscent of a commercial product, the term 'consumer' offering the impression that 'care' is a commodity product that can be bought at varying degrees depending on wealth, or something that can be 'shopped around' for on an open market. Tomes describes the cultural transferral of habits developed for choosing products such as cars and appliances now being used to inform "our choice of doctors and medical treatments"[53]. Further to this Adams notes that architecturally, the hospitals of the 1980's evolved to reflect this with "multistory atria and retail establishments, looking more like shopping malls than homes"[54]. The term 'consumer' presents a misnomer for those at the end of their life as care "... is not *bought*, but actually *done* by the patient themselves"[55]. However, due to the often-serious effects of terminal illnesses this is not an act that is generally physically possible by the individual. For example, a lack of strength to swallow tablets, or the loss of appetite to follow specific diets. The term 'patient' therefore may still be relevant as an alternative to 'consumer'.

Yet, 'patient' is a term synonymous with modern medicine. In particular it has connotations of acute hospital care, of admission, treatment and then a return home; though a return to home is not potentially viable for a person at the end of life. Similarly, it insinuates a degree of corporeality and control over the physical body unlike Lawton's descriptions of the 'un-bounded body', a person suffering the effects of terminal illness that may be "falling apart at the seams"[56]. The above, supports what Harris described thirty years earlier as the "disadvantaged dying"[57] suggesting that the process of "death is being tamed so strongly by health services that it is now indistinguishable from emergency, acute and community care of the sick"[58]. The inability to provide appropriate care for people at the end of life raises questions about society's seemingly distant attitudes to growing older and mortality.

There is no universal language on how to medically contextualise a person that is dying; and subsequently no universal design language in which architects and designers can contextualise this person either. Mol, Moser and Pols write that "words without problematic histories just don't exist..."[59] and it is unlikely that *one* term will be found suitable for both the public and private realm without some negative connotations. This too, is evident in the architectural profession – 'user' is the most commonly used term to refer to the people expected to use a building or place. However, Professor Adrian Forty explains that the term has "...connotations of the disadvantaged or disenfranchised...and does not tolerate attempts to be given particularity"[60]. The term abstracts the people inhabiting a building to a generalised group with a set criterion of requirements that the architect may respond to. In its place architects may consider 'inhabitants' or 'occupiers' to refer to those using the building as it implies a diversity in activities and the potential requirements. Words and language, both medical and architectural in nature, must also become adaptable. Whilst these terms may not suggest direct architectural outputs, it is only with this critical prior understanding of the dying patient that architects may begin to design places of death that are supportive of patient-centred care.

## **Place of Death**

'Place' is synonymous with philosophies of geography and psycho-geography, often used in the exploration of dwelling or associated activities. However, 'place' as we define here for this paper, uses an architectural context, relating instead to the location, physical features and fundamental elements of the built environment. Dying, historically had occurred within the family home, with the living room traditionally becoming "a final domestic resting place"[61]. With the formation of the NHS and modern family structures relying less on inter-generational care, death is often no longer appropriate for the domestic setting. Much like the contemporary professional debate regarding the medicalisation of birth - which led to the development and normalisation of mid-wife led units and home births[62] – environments for palliative and EoLC evolved as a result of medicalisation of death. In 1962, Dame Cicely Saunders developed the 'hospice', as a unique building type providing solely care for the dying. Hospices aim to provide a physical environment that offer a person at the end of their life - "...an environment which maximise[s] the likelihood of a good end of life experience"[63] - yet they are still principally organised around the treatment of cancer as a singular diagnosis. Whilst many existing hospices are independently located, there is a growing desire for hospices to instead be within the grounds of larger hospitals to support the provision of more intensive medical procedures or treatments. This is similar to the relationship of palliative care environments within hospitals. As Adams highlights, palliative care wards are often immediately adjacent to, or subsumed within oncology departments with rooms that "often look identical to those for cancer patients"[64]. It could be seen that this architectural homogenization has contributed to further misunderstanding of the complexity of how we die, and how we may die 'well'. As highlighted previously, there is a disproportionate concentration of care on those suffering from cancer, due to its common association as a 'tragic' or 'untimely' death[65]. 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.

This focus on a popular singularity – 'the big C' – can also be perceived architecturally when considering Maggie's Centre's. The UK charity co-founded by architectural critic Charles Jencks, and subsequent author of "The Architecture

of Hope”[66], supports those that are terminally ill or affected by cancer, with over 25 buildings across the UK and Japan individually designed by architects of status or ‘starchitects’. Anecdotally, Maggie’s Centre’s within the architectural field have steadily become the ‘go-to’ reference for designers involved with places for death and dying. Maggie’s Centre’s do not however provide medical care but concentrate on social and community led care. This focus on cancer related illness has created what Harris suggests is an “underclass of dying people”[67]. Maggie’s Centre’s are celebrated as architecturally ‘exciting’ projects with often generous budgets, and an architectural brief encouraging playful exploration of spatial and material concepts of the ‘home’ as well as expressive building forms relating to the local built environment. This is in stark contrast to the historical role of architects and designers within healthcare settings that have been diminished in part due to institutional procurement schemes such as PFI (private finance initiatives) and design and build contracts where it has been observed that the “quality of the design has been lacking”[68]. Crucially however, Maggie’s Centre’s afford a generosity or ‘creative licence’ for architects that hospices are less able to provide, due to a greater multitude of medical and care parameters that make for a more intensive design process. The CEO of Maggie’s states that:

*“it is down to the architects to challenge the client, and from that ‘an uplifting and surprising building’ will unfailingly emerge” [69]*

Whilst it may be argued that Maggie’s Centre’s are not a functional or clinical comparison, the relationship between architecture, medicine and well-being fostered by their approach remains an inspiration for the potential outcomes of meaningful collaboration for palliative care environments. As earlier outlined, the hospice building no longer solely focuses on death and dying, meaning that these buildings may need to provide an environment for hope, well-being and support during the trajectory associated with end of life, with Maggie’s Centre’s offering a viable and aspirational framework for such an environment.

The ‘mis-match’ between the appropriate precedents for architects and designers may in part be due, as Verderber states, to the relatively small literature base on the best practice of the planning and design of hospice buildings[70] in comparison to broader or less specialist healthcare settings. There are three books that focus specifically on the hospice as a building typology for palliative

care: “Innovations in Hospice Architecture”[71] by Stephen Verderber and Ben Refuerzo, “Modern Hospice Design: the architecture of palliative care”[72] by Ken Warpole and more recently “The Production of Hospice Space: conceptualising the space of caring and dying”[73] by Dr Sarah McGann. This is not however, in spite of a lack of a thriving research community for palliative care 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 in the way that the Silver Linings report was able to do for the (active) third age and emphasising architectural responsibility for residential care homes. The design advice in the literature is typically presented as a set of ‘principles’; though Professor Ann Heylighen suggests that this mode of guidance “reduce[s] the human body to a source of an abstracted system of proportions”[74] often removed from the emotional human experience of places. It is vital that architectural responses to palliative care moves away from rigid literary proposals of ‘design principles’ and actively collaborates with the wider care team, constantly asking questions of how we may successfully implement person centred care.

## **Conclusion**

As we witness the older population grow, the dying population change, and conversations about how we choose to die unfold, architects have a responsibility to work alongside healthcare professionals, co-producing environments that can positively contribute to holistic experiences of dying. We have identified a paucity of terms of reference for dying persons who should not be considered a subset of ‘agers’ or assumed cancer patients. Mol, Moser & Pol write that “...perhaps care practices can be strengthened if we find the right terms for talking about them”[75]. We should remember that before buildings and drawings, come words. Those involved in the research of this topic need to listen together to develop a set of words and a robust language in which, design practitioners, care professionals, and the consumers of the services can inform and/or co-design



briefs used to commission the positive person-centred environments in which we hope to die. A multi-disciplinary approach of this kind would champion the current requirements of good health care to be co-produced in partnerships[76,77]. The value of the architect's role in care practices must be able to contribute and respond to the needs and well-being of the ageing and dying communities. As Niall McLaughlin Architects re-iterate, the 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...and how to contribute useful spatial understandings to the development of [these] medical fields.”[78]*

Architects, as ‘carers’ of the built environment, have a duty to remain sensitive to and informed about the changing needs and characteristics of the intended occupants of their buildings. Yet this can only happen alongside health professionals acknowledging the added value of good design and the impact of the built environment within broader designs of care giving. As we navigate the pandemic, the desire for change must not be neglected, resisting an impulse to deliver architectural environments from a historic template though it may be easier or quicker[79]. By bringing in architects as members of the wider care team, a dialogue can be instigated that challenges the opinion that “architecture is mute”[80] in the context of care.

We can observe that the approach championed by Maggie's Centre's is one such aspiration for what an architecture for the support of a ‘good death’ could look like; one that promotes a ‘home’ like environment. Yet ‘home’ or ‘home-like’ as an architectural concept and outcome are subjective to the individual and may be problematic, as Ahuja outlines:

*The rooms that soothe one person may alienate another. As such, I submit that hospice design and practice are necessarily and perpetually unstable.”[81]*

Whilst this paper did not set out to review the aesthetics or specific design of the palliative care environment, we consider that perhaps this instability may not necessarily be a negative outcome for the hospice building – but rather a catalyst for a participatory design process that is appropriate to each setting, context and community. Architects and designers sensitive to local context and needs could

work to involve and learn from the experiences and knowledge of staff, volunteers, community members and patients, in conjunction with health boards to manage and positively shape future developments and aspirations for care in the area, defined by the very people who will inhabit it. The hospice building will likely remain a clinically led environment, but that does not mean it cannot incorporate aspects of architectural empathy needed to counteract negative connotations of a typical healthcare institution. Further research into the themes of architectural empathy is required, but we call for collaboration and opportunities for co-production to facilitate and promote this; for action from a multi-disciplinary care team that recognises the strengths of each profession in support of the progress of positive experiences for the dying patient away from home.

## **Bibliography**

- Adams, Annmarie. "Home and/or Hospital: The Architectures of End-of-Life Care." *Change Over Time* 6 (01/01 2016): 248-63.  
<https://doi.org/10.1353/cot.2016.0015>.
- . *Medicine by Design: The Architect and the Modern Hospital, 1893–1943*. University of Minnesota Press, 2008.  
<http://www.istor.org/stable/10.5749/j.ctttv5mt>.
- Ahuja, Nitin. "End Stages." *Places Journal* (05/15 2018).  
<https://doi.org/10.22269/180515>.
- Architects, Niall McLaughlin. "Alzheimer's Respite Centre." *Bartlett Design Research Folios* (2016). <http://bartlettdesignresearchfolios.com/alzheimers-respite-centre/read/>.
- Architects, SIGNAL. *Programme for the Good Hospice in Denmark*. (Realdania, 2006).  
<http://www.hospiceforum.dk/media/TheGoodHospiceInDenmark.pdf>.
- Barac, Matthew, Will Hunter, and James Parkinson. *Silver Linings: The Active Third Age and the City*. (London: RIBA/ Building Futures, 2013).  
<https://www.architecture.com/-/media/gathercontent/silver-linings/additional-documents/silverliningstheactivethirdageandthecitypdf.pdf>.
- Batalden, Maren, Paul Batalden, Peter Margolis, Michael Seid, Gail Armstrong, Lisa Opiari-Arrigan, and Hans Hartung. "Coproduct of Healthcare Service." *BMJ Quality & Safety* 25, no. 7 (2016): 509. <https://doi.org/10.1136/bmjqs-2015-004315>. <http://qualitysafety.bmj.com/content/25/7/509.abstract>.
- "U3a." n.d, 2019, <http://u3a.org.uk/the-u3a-story.html> (U3A).
- Boyd, K., and S. A. Murray. "Recognising and Managing Key Transitions in End of Life Care." [In eng]. *Bmj* 341 (Sep 16 2010): c4863.  
<https://doi.org/10.1136/bmj.c4863>.
- Boyd, Kirsty, Sebastien Moine, Scott A. Murray, Deborah Bowman, and Nicole Brun. "Should Palliative Care Be Rebranded?". *BMJ* 364 (2019): l881.  
<https://doi.org/10.1136/bmj.l881>.  
<http://www.bmj.com/content/364/bmj.l881.abstract>.
- Cheyne, Helen, Clare Leon-Villapalos, and Mary Wells, "Covid-19: Why Are People Dying Alone? ," *Blog / BMJ Global Health*, 18th May 2020, 2020,  
<https://blogs.bmj.com/bmigh/2020/05/18/covid-19-why-are-people-dying-alone/>.
- Clark, David. "Between Hope and Acceptance: The Medicalisation of Dying." [In eng]. *BMJ (Clinical research ed.)* 324, no. 7342 (2002): 905-07.  
<https://doi.org/10.1136/bmj.324.7342.905>.  
<https://www.ncbi.nlm.nih.gov/pubmed/11950744>  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1122840/>.

- , "Controversies in Palliative: A Matter of Definition," *End of life studies*. University of Glasgow, 18th January 2019 2019, <http://endoflifestudies.academicblogs.co.uk/controversies-in-palliative-care-a-matter-of-definition/#comments>.
- . "From Margins to Centre: A Review of the History of Palliative Care in Cancer." *The Lancet Oncology* 8, no. 5 (2019/08/19 2007): 430-38. [https://doi.org/10.1016/S1470-2045\(07\)70138-9](https://doi.org/10.1016/S1470-2045(07)70138-9). [https://doi.org/10.1016/S1470-2045\(07\)70138-9](https://doi.org/10.1016/S1470-2045(07)70138-9).
- Connolly, Kate. "Care Homes across Globe in Spotlight over Covid-19 Death Rates " *The Guardian* (London), 9th April 2020. <https://www.theguardian.com/world/2020/apr/09/care-homes-across-globe-in-spotlight-over-covid-19-death-rates>.
- Council, General Medical. *Treatment and Care Towards the End of Life: Good Practice in Decision Making*. General Medical Council (2010). <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life>.
- Curie, Marie. *Triggers for Palliative Care: Summary for Wales*. (2015). <https://www.mariecurie.org.uk/policy/publications>.
- Curie, Marie, and The Bevan Foundation. *Death and Dying in Wales*. (2014). <https://www.mariecurie.org.uk/policy/publications/archive>.
- Darley, Gillian. "Maggie's Manchester by Foster + Partners: 'What Matters Is Not to Lose That Joy of Living in the Fear of Dying.'." *The Architectural Review*. (25th October 2016). <https://www.architectural-review.com/10014035.article>.
- "Palliative | Definition of Palliative in English by Lexico Dictionaries." n.d, <https://www.lexico.com/en/definition/palliative>.
- "End of Life Care Profiles: February 2018 Update." Gov.uk 2018, accessed 27th May 2020, <https://www.gov.uk/government/publications/end-of-life-care-profiles-february-2018-update/statistical-commentary-end-of-life-care-profiles-february-2018-update#summary>.
- Etkind, S. N., 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, no. 1 (2017): 102. <https://doi.org/10.1186/s12916-017-0860-2>. <https://doi.org/10.1186/s12916-017-0860-2>.
- Etkind, Simon N., Anna E. Bone, Natasha Lovell, Rachel L. Cripps, Richard Harding, Irene J. Higginson, and Katherine E. Sleeman. "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, no. 1 (2020): e31-e40.  
<https://doi.org/10.1016/j.jpainsymman.2020.03.029>.
- Exley, Catherine. "Review Article: The Sociology of Dying, Death and Bereavement." [In eng]. *Sociol Health Illn* 26, no. 1 (Jan 2004): 110-22.  
<https://doi.org/10.1111/j.1467-9566.2004.00382.x>.
- Forty, Adrian. *Words and Buildings : A Vocabulary of Modern Architecture*. London: Thames & Hudson, 2000.
- Gawande, Atul. *Being Mortal : Medicine and What Matters in the End*. First edition. New York : Metropolitan Books, Henry Holt and Company, 2014., 2014.
- Gilleard, Chris, and P. Higgs. "Aging without Agency: Theorizing the Fourth Age." *Aging & Mental Health* 14, no. 2 (2010): 121-28.  
<https://doi.org/10.1080/13607860903228762>.  
<https://doi.org/10.1080/13607860903228762>.
- Gilleard, Chris, and Paul Higgs. "Ageing, Corporeality and Social Divisions in Later Life." *Ageing and Society* 37, no. 8 (2017): 1681-702. <https://doi.org/DOI:10.1017/S0144686X16000532>. <https://www.cambridge.org/core/article/ageing-corporeality-and-social-divisions-in-later-life/FA8BEF01E67E646B32E26697AB8D8569>.
- Government, HM. *Equality Act*, 2010.
- Grenier, Amanda, Liz Lloyd, and Chris Phillipson. "Precarity in Late Life: Rethinking Dementia as a 'Fraild' Old Age." *Sociology of Health & Illness* 39, no. 2 (2019/08/19 2017): 318-30. <https://doi.org/10.1111/1467-9566.12476>.  
<https://doi.org/10.1111/1467-9566.12476>.
- Hall, Lauren K. *The Medicalization of Birth and Death*. Baltimore, MD: John Hopkins University Press, 2019.
- Hanratty, B., L. Holmes, E. Lowson, G. Grande, J. Addington-Hall, S. Payne, and J. Seymour. "Older Adults' Experiences of Transitions between Care Settings at the End of Life in England: A Qualitative Interview Study." [In eng]. *J Pain Symptom Manage* 44, no. 1 (Jul 2012): 74-83.  
<https://doi.org/10.1016/j.jpainsymman.2011.08.006>.
- Harris, L. "Continuing Care. The Disadvantaged Dying." *Nursing times* 86 (1990): 26-9.
- Heathcote, Edwin. *The Meaning of Home*. London: Frances Lincoln, 2012.
- Heylighen, Ann, Caroline Van Doren, and Peter-Willem Vermeersch. "Enriching Our Understanding of Architecture through Disability Experience." *Open House International* 38, no. 1 (2013): 7-19.

- Hockey, Jenny. *Experiences of Death: An Anthropological Account*. Edinburgh: Edinburgh University Press, 1990.
- Jencks, Charles. *The Architecture of Hope : Maggie's Cancer Caring Centres*. Maggie's Cancer Caring Centres. New edition. ed.: Frances Lincoln, 2015.
- Kellehear, Allan. *A Social History of Dying*. Cambridge: Cambridge University Press, 2007.
- Lamers, William M. "Defining Hospice and Palliative Care." *Journal of Pain & Palliative Care Pharmacotherapy* 16, no. 3 (2002/01/01 2002): 65-71.  
[https://doi.org/10.1080/J354v16n03\\_07](https://doi.org/10.1080/J354v16n03_07).  
[https://doi.org/10.1080/J354v16n03\\_07](https://doi.org/10.1080/J354v16n03_07).
- Laslett, Peter. *A Fresh Map of Life: The Emergence of the Third Age*. London: Weidenfeld and Nicolson, 1989.
- Lawton, Julia. "Contemporary Hospice Care: The Sequestration of the Unbounded Body and 'Dirty Dying'." *Sociology of Health & Illness* 20, no. 2 (1998/03/01 1998): 121-43. <https://doi.org/10.1111/1467-9566.00094>.  
<https://doi.org/10.1111/1467-9566.00094>.
- Mayland, Catriona R., Andrew J. E. Harding, Nancy Preston, and Sheila Payne. "Supporting Adults Bereaved through Covid-19: A Rapid Review of the Impact of Previous Pandemics on Grief and Bereavement." [In eng]. *Journal of pain and symptom management* 60, no. 2 (2020): e33-e39.  
<https://doi.org/10.1016/j.jpainsymman.2020.05.012>.  
<https://pubmed.ncbi.nlm.nih.gov/32416233>  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7228694/>.
- McCormack, Brendan, Tanya McCance, and Hester Klopper. "Person-Centred Practice in Nursing and Health Care : Theory and Practice." [In English]. (2017).  
<http://search.ebscohost.com/login.aspx?direct=true&scope=site&db=nlebk&db=nlabk&AN=1289475>.
- McGann, Sarah. *The Production of Hospice Space : Conceptualising the Space of Caring and Dying*. Ashgate, 2013.
- Meier, Emily A., Jarred V. Gallegos, Lori P. Montross Thomas, Colin A. Depp, Scott A. Irwin, and Dilip V. Jeste. "Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue." *The American Journal of Geriatric Psychiatry* 24, no. 4 (2016/04/01/ 2016): 261-71.  
<https://doi.org/https://doi.org/10.1016/j.jagp.2016.01.135>.  
<http://www.sciencedirect.com/science/article/pii/S106474811600138X>.

- Mol, Annemarie, Ingunn Moser, and Jeannette Pols. *Care in Practice: On Tinkering in Clinics, Homes and Farms*. Care in Practice. Vol. 8, 2010.  
doi:10.14361/transcript.9783839414477.
- Murray, Scott A., Marilyn Kendall, Kirsty Boyd, and Aziz Sheikh. "Illness Trajectories and Palliative Care." [In eng]. *BMJ (Clinical research ed.)* 330, no. 7498 (2005): 1007-11. <https://doi.org/10.1136/bmj.330.7498.1007>.  
<https://pubmed.ncbi.nlm.nih.gov/15860828>  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC557152/>.
- Neugarten, Bernice L., and Dail Ann Neugarten. "The Young-Old and the Age-Irrelevant Society." In *The Meanings of Age: Selected Papers of Bernice L. Neugarten*, 37-8. Chicago: University of Chicago Press, 1996.
- Payne, Sheila. "From Here to There: Reaching out for Palliative Care." *European Journal of Palliative Care* 18, 6 (November/December 2011 2011): 264-65.
- Physicians, Royal College of. *Talking About Dying*. (2018).  
<https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead>.
- Price, Kay, and Julianne Cheek. "Avoiding Death: The Ultimate Challenge in the Provision of Contemporary Healthcare?". *Health Sociology Review* 16, no. 5 (2007): 397-404. <https://doi.org/10.5172/hesr.2007.16.5.397>.
- Råheim, Målfrid, Liv Heide Magnussen, Ragnhild Johanne Tveit Sekse, Åshild Lunde, Torild Jacobsen, and Astrid Blystad. "Researcher-Researched Relationship in Qualitative Research: Shifts in Positions and Researcher Vulnerability." [In eng]. *International journal of qualitative studies on health and well-being* 11 (2016): 30996-96. <https://doi.org/10.3402/qhw.v11.30996>.  
<https://pubmed.ncbi.nlm.nih.gov/27307132>  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4910304/>.
- Science, Government Office for. *Future of an Ageing Population*. HM Government (2016).  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/816458/future-of-an-ageing-population.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/816458/future-of-an-ageing-population.pdf).
- Seow, Hsien, and Daryl Bainbridge. "A Review of the Essential Components of Quality Palliative Care in the Home." [In eng]. *Journal of palliative medicine* 21, no. S1 (2018): S37-S44. <https://doi.org/10.1089/jpm.2017.0392>.  
<https://pubmed.ncbi.nlm.nih.gov/29283868>  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5733665/>.
- Stevens, Wallace. *Harmonium*. Faber and Faber, 2001.



- Team, The United Kingdom Palliative Care Funding Review. "Funding the Right Care and Support for Everyone: Creating a Fair and Transparent Funding System." *Journal of Pain & Palliative Care Pharmacotherapy* 25, no. 4 (2011/11/11 2011): 362-64. <https://doi.org/10.3109/15360288.2011.621020>.  
<https://doi.org/10.3109/15360288.2011.621020>.
- Tomes, Nancy. "Introduction  
This Isn't Your Father's Patient." In *Remaking the American Patient*. How Madison Avenue and Modern Medicine Turned Patients into Consumers, 1-16: University of North Carolina Press, 2016.
- Turakhia, Puja , and Brandon Combs. "Using Principles of Co-Production to Improve Patient Care and Enhance Value." *AMA Journal of Ethics* 19, no. 11. (2017): 1125-31. <https://journalofethics.ama-assn.org/article/using-principles-co-production-improve-patient-care-and-enhance-value/2017-11>.
- Ulrich, R., C. Zimring, Xiaobo Quan, Anjali Joseph, and R. Choudhary. "The Role of the Physical Environment in the Hospital of the 21st Century." *The Center for Health Design* (01/01 2004).
- Ulrich, Roger. "View through a Window May Influence Recovery from Surgery." *Science (New York, N.Y.)* 224 (05/01 1984): 420-1.  
<https://doi.org/10.1126/science.6143402>.
- "Balfour Mount." Portraits, McGill University, n.d, accessed 16th July, 2020, <https://www.mcgill.ca/palliativecare/portraits-0/balfour-mount>.
- Verderber, Stephen. *Innovations in Hospice Architecture*. Edited by Ben J. Refuerzo. London: Routledge, 2005.
- . "Residential Hospice Environments: Evidence-Based Architectural and Landscape Design Considerations." *Journal of Palliative Care* 30, no. 2 (2014/06/01 2014): 69-82. <https://doi.org/10.1177/082585971403000202>.  
<https://doi.org/10.1177/082585971403000202>.
- Waite, Richard, and Greg Pitcher. "How Will Covid-19 Change the Design of Health Facilities?" *Architect's Journal* (28th May 2020 2020). Accessed 1st June 2020. <https://www.architectsjournal.co.uk/news/how-will-covid-19-change-the-design-of-health-facilities/10047080.article?blocktitle=coronavirus&contentID=25133>.
- Warwick University, Institute of Health. *Health @ Warwick: An Update*. Institute of Health, Warwick University (2010).  
[https://warwick.ac.uk/fac/cross\\_fac/healthatwarwick/publications/update/update\\_15.pdf](https://warwick.ac.uk/fac/cross_fac/healthatwarwick/publications/update/update_15.pdf).
- Weaver, Matt. "Good Design 'Must Be a Pfi Priority'." (17th October 2002).  
<https://www.theguardian.com/society/2002/oct/17/urbandesign.privatefinance>.



Worpole, Ken. *Modern Hospice Design : The Architecture of Palliative Care*. London, New York: Routledge, 2009.

Yardley, Sarah, and Martin Rolph. "Death and Dying During the Pandemic." *BMJ* 369 (2020): m1472. <https://doi.org/10.1136/bmj.m1472>.  
<http://www.bmj.com/content/369/bmj.m1472.abstract>.

---

[1] Government Office for Science, Future of an Ageing Population, HM Government (2016),  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/816458/future-of-an-ageing-population.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/816458/future-of-an-ageing-population.pdf).

[2] S. N. Etkind et al., "How many people will need palliative care in 2040? Past trends, future projections and implications for services," *BMC Medicine* 15, no. 1 (2017),  
<https://doi.org/10.1186/s12916-017-0860-2>, <https://doi.org/10.1186/s12916-017-0860-2>.

[3] Marie Curie, Triggers for palliative care: summary for Wales (2015),  
<https://www.mariecurie.org.uk/policy/publications>.

[4] Government Office for Science, 2019, 6

[5] "End of Life Care Profiles: February 2018 update," Gov.uk 2018, accessed 27th May 2020, <https://www.gov.uk/government/publications/end-of-life-care-profiles-february-2018-update/statistical-commentary-end-of-life-care-profiles-february-2018-update#summary>.

---

[6] David Clark, "Between hope and acceptance: the medicalisation of dying," *BMJ* (Clinical research ed.) 324, no. 7342 (2002), <https://doi.org/10.1136/bmj.324.7342.905>, <https://www.ncbi.nlm.nih.gov/pubmed/11950744> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1122840/>.

[7] Nitin Ahuja, "End Stages," *Places Journal* (05/15 2018), <https://doi.org/10.22269/180515>.

[8] Brendan McCormack, Tanya McCance, and Hester Klopper, "Person-centred practice in nursing and health care : theory and practice," (2017), <http://search.ebscohost.com/login.aspx?direct=true&scope=site&db=nlebk&db=nlabk&AN=1289475>.

[9] HM Government, Equality Act, (2010).

[10] Atul Gawande, *Being Mortal : medicine and what matters in the end* (First edition. New York : Metropolitan Books, Henry Holt and Company, 2014., 2014). 245

[11] Richard Waite and Greg Pitcher, "How will COVID-19 change the design of health facilities?," *Architect's Journal* (28th May 2020 2020). <https://www.architectsjournal.co.uk/news/how-will-covid-19-change-the-design-of-health-facilities/10047080.article?blocktitle=coronavirus&contentID=25133>.

[12] Institute of Health Warwick University, *Health @ Warwick: An Update*, Institute of Health, Warwick University (2010), [https://warwick.ac.uk/fac/cross\\_fac/healthatwarwick/publications/update/update\\_15.pdf](https://warwick.ac.uk/fac/cross_fac/healthatwarwick/publications/update/update_15.pdf).

[13] Roger Ulrich, "View Through a Window May Influence Recovery from Surgery," *Science* (New York, N.Y.) 224 (05/01 1984), <https://doi.org/10.1126/science.6143402>.

[14] R. Ulrich et al., "The role of the physical environment in the hospital of the 21st century," *The Center for Health Design* (01/01 2004).

[15] Wallace Stevens, *Harmonium* (Faber and Faber, 2001). 107

[16] General Medical Council, *Treatment and care towards the end of life: good practice in decision making*, General Medical Council (2010), <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life>. 8

[17] Royal College of Physicians, *Talking About Dying* (2018), <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead>. 3

[18] Emily A. Meier et al., "Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue," *The American Journal of Geriatric Psychiatry* 24, no. 4 (2016/04/01/ 2016), <https://doi.org/https://doi.org/10.1016/j.jagp.2016.01.135>, <http://www.sciencedirect.com/science/article/pii/S106474811600138X>. 261

[19] K. Boyd and S. A. Murray, "Recognising and managing key transitions in end of life care," *Bmj* 341 (Sep 16 2010), <https://doi.org/10.1136/bmj.c4863>.

[20] B. Hanratty et al., "Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study," *J Pain Symptom Manage* 44, no. 1 (Jul 2012), <https://doi.org/10.1016/j.jpainsymman.2011.08.006>.

- 
- [21] "Balfour Mount," Portraits, McGill University, n.d, accessed 16th July, 2020, <https://www.mcgill.ca/palliativecare/portraits-0/balfour-mount>.
- [22] "Palliative | Definition Of Palliative In English By Lexico Dictionaries," n.d, <https://www.lexico.com/en/definition/palliative>.
- [23] Scott A. Murray et al., "Illness trajectories and palliative care," *BMJ (Clinical research ed.)* 330, no. 7498 (2005), <https://doi.org/10.1136/bmj.330.7498.1007>, <https://pubmed.ncbi.nlm.nih.gov/15860828>, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC557152/>.
- [24] Catherine Exley, "Review article: the sociology of dying, death and bereavement," *Sociol Health Illn* 26, no. 1 (Jan 2004), <https://doi.org/10.1111/j.1467-9566.2004.00382.x>.
- [25] Sheila Payne, "From here to there: reaching out for palliative care," *European Journal of Palliative Care* 18, 6 (November/December 2011 2011).
- [26] Marie Curie and The Bevan Foundation, *Death and Dying in Wales* (2014), <https://www.mariecurie.org.uk/policy/publications/archive>.
- [27] The United Kingdom Palliative Care Funding Review Team, "Funding the Right Care and Support for Everyone: Creating a Fair and Transparent Funding System," *Journal of Pain & Palliative Care Pharmacotherapy* 25, no. 4 (2011/11/11 2011), <https://doi.org/10.3109/15360288.2011.621020>, <https://doi.org/10.3109/15360288.2011.621020>.
- [28] William M. Lamers, "Defining Hospice and Palliative Care," *Journal of Pain & Palliative Care Pharmacotherapy* 16, no. 3 (2002/01/01 2002), [https://doi.org/10.1080/J354v16n03\\_07](https://doi.org/10.1080/J354v16n03_07), [https://doi.org/10.1080/J354v16n03\\_07](https://doi.org/10.1080/J354v16n03_07).
- [29] Niall McLaughlin Architects, "Alzheimer's Respite Centre," *Bartlett Design Research Folios* (2016), <http://bartlettdesignresearchfolios.com/alzheimers-respite-centre/read/>. 15
- [30] David Clark, "Controversies in palliative: a matter of definition," *End of life studies*, University of Glasgow, 18th January 2019 2019, <http://endoflifestudies.academicblogs.co.uk/controversies-in-palliative-care-a-matter-of-definition/#comments>.
- [31] Kirsty Boyd et al., "Should palliative care be rebranded?," *BMJ* 364 (2019), <https://doi.org/10.1136/bmj.l881>, <http://www.bmj.com/content/364/bmj.l881.abstract>.
- [32] Bernice L. Neugarten and Dail Ann Neugarten, "The Young-Old and the Age-Irrelevant Society," in *The Meanings of Age: Selected Papers of Bernice L. Neugarten* (Chicago: University of Chicago Press, 1996).
- [33] Peter Laslett, *A Fresh Map of Life: The Emergence of the Third Age* (London: Weidenfeld and Nicolson, 1989).
- [34] "U3A," n.d, 2019, <http://u3a.org.uk/the-u3a-story.html> (U3A).

---

[35] Matthew Barac, Will Hunter, and James Parkinson, *Silver Linings: The Active Third Age and the City* (London: RIBA/ Building Futures, 2013), <https://www.architecture.com/-/media/gathercontent/silver-linings/additional-documents/silverliningstheactivethirdageandthecitypdf.pdf>. 8

[36] Chris Gilleard and P. Higgs, "Aging without agency: Theorizing the fourth age," *Aging & Mental Health* 14, no. 2 (2010), <https://doi.org/10.1080/13607860903228762>, <https://doi.org/10.1080/13607860903228762>.

[37] Gilleard and Higgs, 2010, 125

[38] Amanda Grenier, Liz Lloyd, and Chris Phillipson, "Precarity in late life: rethinking dementia as a 'fraild' old age," *Sociology of Health & Illness* 39, no. 2 (2019/08/19 2017), <https://doi.org/10.1111/1467-9566.12476>, <https://doi.org/10.1111/1467-9566.12476>. 327

[39] Chris Gilleard and Paul Higgs, "Ageing, corporeality and social divisions in later life," *Ageing and Society* 37, no. 8 (2017), <https://doi.org/DOI:10.1017/S0144686X16000532>, <https://www.cambridge.org/core/article/ageing-corporeality-and-social-divisions-in-later-life/FA8BEF01E67E646B32E26697AB8D8569>.

[40] Gilleard and Higgs, 2017, 1696

[41] Gilleard and Higgs, 2017, 1696

[42] Gilleard and Higgs, 2010, 126

[43] Kate Connolly, "Care homes across globe in spotlight over Covid-19 death rates " *The Guardian* (London), 9th April 2020, <https://www.theguardian.com/world/2020/apr/09/care-homes-across-globe-in-spotlight-over-covid-19-death-rates>.

[44] Catriona R. Mayland et al., "Supporting Adults Bereaved Through COVID-19: A Rapid Review of the Impact of Previous Pandemics on Grief and Bereavement," *Journal of pain and symptom management* 60, no. 2 (2020), <https://doi.org/10.1016/j.jpainsymman.2020.05.012>, <https://pubmed.ncbi.nlm.nih.gov/32416233> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7228694/>. 33

[45] Sarah Yardley and Martin Rolph, "Death and dying during the pandemic," *BMJ* 369 (2020), <https://doi.org/10.1136/bmj.m1472>, <http://www.bmj.com/content/369/bmj.m1472.abstract>.

[46] Simon N. Etkind et al., "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, no. 1 (2020), <https://doi.org/10.1016/j.jpainsymman.2020.03.029>. 37

[47] Hsien Seow and Daryl Bainbridge, "A Review of the Essential Components of Quality Palliative Care in the Home," *Journal of palliative medicine* 21, no. S1 (2018), <https://doi.org/10.1089/jpm.2017.0392>, <https://pubmed.ncbi.nlm.nih.gov/29283868> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5733665/>.

- 
- [48] Helen Cheyne, Clare Leon-Villapalos, and Mary Wells, "COVID-19: Why are people dying alone? ," Blog | BMJ Global Health, 18th May 2020, 2020, <https://blogs.bmj.com/bmjgh/2020/05/18/covid-19-why-are-people-dying-alone/>.
- [49] Julia Lawton, "Contemporary Hospice Care: the Sequestration of the Unbounded Body and 'Dirty Dying'," *Sociology of Health & Illness* 20, no. 2 (1998/03/01 1998), <https://doi.org/10.1111/1467-9566.00094>, <https://doi.org/10.1111/1467-9566.00094>. 134
- [50] SIGNAL Architects, *Programme for the Good Hospice in Denmark* (Realdania, 2006), <http://www.hospiceforum.dk/media/TheGoodHospiceInDenmark.pdf>. 84
- [51] Annemarie Mol, Ingunn Moser, and Jeannette Pols, *Care in Practice: On Tinkering in Clinics, Homes and Farms*, vol. 8, *Care in Practice*, (2010). 8
- [52] Kay Price and Julianne Cheek, "Avoiding death: The ultimate challenge in the provision of contemporary healthcare?," *Health Sociology Review* 16, no. 5 (2007), <https://doi.org/10.5172/hesr.2007.16.5.397>.
- [53] Nancy Tomes, "INTRODUCTION  
This Isn't Your Father's Patient," in *Remaking the American Patient, How Madison Avenue and Modern Medicine Turned Patients into Consumers* (University of North Carolina Press, 2016). 1
- [54] Annmarie Adams, "Home and/or Hospital: The Architectures of End-of-Life Care," *Change Over Time* 6 (01/01 2016), <https://doi.org/10.1353/cot.2016.0015>. 257
- [55] Mol, Moser and Pols, 2010, 9
- [56] Lawton, 1998, 128
- [57] L. Harris, "Continuing care. The disadvantaged dying," *Nursing times* 86 (1990).
- [58] Allan Kellehear, *A Social History of Dying* (Cambridge: Cambridge University Press, 2007). 249-50
- [59] Mol, Moser and Pols, 2010, 10
- [60] Adrian Forty, *Words and buildings : a vocabulary of modern architecture* (London: Thames & Hudson, 2000). 312-15
- [61] Edwin Heathcote, *The Meaning of Home* (London: Frances Lincoln, 2012). 34
- [62] Lauren K Hall, *The Medicalization of Birth and Death* (Baltimore, MD: John Hopkins University Press, 2019).
- [63] David Clark, "From margins to centre: a review of the history of palliative care in cancer," *The Lancet Oncology* 8, no. 5 (2019/08/19 2007), [https://doi.org/10.1016/S1470-2045\(07\)70138-9](https://doi.org/10.1016/S1470-2045(07)70138-9), [https://doi.org/10.1016/S1470-2045\(07\)70138-9](https://doi.org/10.1016/S1470-2045(07)70138-9). 430-438
- [64] Adams, "Home and/or Hospital: The Architectures of End-of-Life Care." 259

---

[65] Jenny Hockey, *Experiences Of Death: An Anthropological Account* (Edinburgh: Edinburgh University Press, 1990). 78

[66] Charles Jencks, *The Architecture of Hope : Maggie's cancer caring centres*, New edition. ed., Maggie's cancer caring centres, (Frances Lincoln, 2015).

[67] Harris, 1990, 2

[68] Matt Weaver, "Good design 'must be a PFI priority'," (17th October 2002). <https://www.theguardian.com/society/2002/oct/17/urbandesign.privatefinance>.

[69] Gillian Darley, "Maggie's Manchester by Foster + Partners: 'What matters is not to lose that joy of living in the fear of dying.'," *The Architectural Review* (25th October 2016). <https://www.architectural-review.com/10014035.article>.

[70] Stephen Verderber, "Residential Hospice Environments: Evidence-Based Architectural and Landscape Design Considerations," *Journal of Palliative Care* 30, no. 2 (2014/06/01 2014), <https://doi.org/10.1177/082585971403000202>, <https://doi.org/10.1177/082585971403000202>. 69

[71] Stephen Verderber, *Innovations in Hospice Architecture*, ed. Ben J. Refuerzo (London: Routledge, 2005).

[72] Ken Worpole, *Modern Hospice Design : the architecture of palliative care* (London, New York: Routledge, 2009).

[73] Sarah McGann, *The production of hospice space : conceptualising the space of caring and dying* (Ashgate, 2013).

[74] Ann Heylighen, Caroline Van Doren, and Peter-Willem Vermeersch, "Enriching our understanding of architecture through disability experience," *Open House International* 38, no. 1 (2013). 7-19, 17

[75] Mol, Moser and Pols, 2010, 11

[76] Maren Batalden et al., "Coproduction of healthcare service," *BMJ Quality & Safety* 25, no. 7 (2016), <https://doi.org/10.1136/bmjqs-2015-004315>, <http://qualitysafety.bmj.com/content/25/7/509.abstract>.

[77] Puja Turakhia and Brandon Combs, "Using Principles of Co-Production to Improve Patient Care and Enhance Value," *AMA Journal of Ethics* 19, no. 11 (2017). <https://journalofethics.ama-assn.org/article/using-principles-co-production-improve-patient-care-and-enhance-value/2017-11>.

[78] Niall McLaughlin Architects, 2016, 15

[79] Waite and Pitcher, "How will COVID-19 change the design of health facilities?."

[80] Annmarie Adams, *Medicine by Design: The Architect and the Modern Hospital, 1893–1943* (University of Minnesota Press, 2008). <http://www.jstor.org/stable/10.5749/j.ctttv5mt>.

---

[81] Ahuja, "End Stages."