

**Informal Carers and Care-Embedded Social Work:  
Improving Residential and Nursing Home Admission**

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Dad, you aren't with us as I reach the end of this journey. Just knowing how proud you would have been, has kept me going at the most challenging of times. I promised you that I'd see this through – and I have. This is for you.

## **Dedication**

In loving memory of Mel Jones (1949 -2018)

## Abstract

This study explores social work practice with informal carers during long-stay residential and nursing home entry. Specifically, it uses ethnographic methods to examine the importance of social workers undertaking their roles and responsibilities with *care*, when working with informal carers at such times. The study considers the extent to which social workers undertake their roles and responsibilities in “caring ways” (Engster 2005, p. 54) during care home admission processes and highlights the potential barriers to caring in the context of contemporary social work practice.

The findings of the study show that informal carers are often deeply impacted by their experiences of care home admission and that many grapple with the enormous practical and emotional challenges faced. It is also seen, however, that when social workers undertake their roles and responsibilities *with care*, there is significant potential for alleviating the stresses and anxieties of informal carers. The study develops the concept of *care-embedded social work* to draw together and to test out the importance of various dimensions of care within admission-related social work practice. It examines the effects of caring on the lives of older people with dementia, their informal carers and on social workers themselves, as they undertake their day-to-day roles and responsibilities.

Despite the potential of caring social work, the findings of the study show that levels of caring within social work practice are variable. The research explores the impacts of neoliberalisation on the caring practises of social workers, with a specific focus on the pressures of time. It also considers the actions needed to enable social work to become a more consistently *care-embedded* profession.

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# Chapter One: Introduction

## Aims and Objectives

This study explores social workers' engagement with caring practises when working with informal carers at times of long-stay, residential and nursing home admission. Many social work theorists have expressed concerns that levels of caring within social work practice have diminished since the implementation of the National Health Service and Community Care Act 1990 (see Dustin 2007; Ray et al. 2009; Munro 2011). It is argued that the Community Care legislation changed the roles and tasks of social workers in unprecedented ways (for example La Valle and Lyons 1996; Postle 2002; Harris 2003) with the result that practitioners were seen as less able to undertake their roles and responsibilities *with care* (Meagher and Parton 2004).

In reality, however, it is often difficult to determine the extent and impacts of caring within social work. Banks (2008) argues that much of the writing on care within social work practice is in fact “speculative” (p. 1243). Likewise, Engen et al. (2021) claim that the concept of care remains under theorised within the social work literature and Hay (2019) asserts that few studies have produced findings that promote “concrete understandings” (p. 365) of the ways in which care is enacted within the everyday roles and responsibilities of social workers. This study aims to address this important gap in the research literature. Observational methods are used to directly examine performances of care, within the day-to-day social work interactions of a small group of practitioners within one Welsh Local Authority. The study also considers the potential barriers to social workers undertaking their work *with care*.

To my knowledge, the care home admission experiences of informal carers have not previously been used as a lens through which to explore the importance of care in social work practice. Nevertheless, existing research implies the critical importance of care at this time and during this process. This study draws extensively upon the ethic of care literature and according to that literature, care has a fundamental purpose: the alleviation of suffering and distress (Gilligan 2003; Noddings 2003). As will be seen in Chapter Two, care home admission is an experience characterised by high levels of suffering and stress. Many informal carers provide care to older people with dementia

for significant lengths of time before considering a move into a care home setting (Willoughby and Keating 1991; Nolan et al. 1996a). The experience of then facilitating care home entry is often extremely distressing (Dellagesa and Mastrian 1995; Ryan and Scullion 2000). Critically, what professionals *do* at such times has the potential to make a significant difference to the overall outcomes of the care home admission process.

## **Terminology Used Within This Study**

### **‘Informal Carer’**

When using the term ‘informal carer’ within this study, I refer to those who provide care to older people with dementia in an informal (non-contracted or unpaid) capacity. Informal care is generally provided by family members within the home (domestic) setting (Phillips 2007) but may also be provided by non-family members, such as close friends and neighbours (Bulmer 2015). Within the care literature the term ‘informal carer’ is sometimes used interchangeably with other terms, like “family carer” (Nolan et al. 1996a). However, I chose not to use the term “family carer” within this study, as I did not wish to exclude ‘non-family’ members from participating in the research (such as a close friend caring for an older person with dementia). I recognise that the term ‘informal carer’ is not unproblematic (see Greenwood et al. 2018). Phillips (2007) suggests that some carers might object to the use of the term “informal” on account of the levels of planning and organisation needed to incorporate “care routines” (p. 23) into their daily lives. Larkin et al. (2018) also argue that some people might not “self-identify” (p. 62) as carers at all, simply seeing their caring roles as “a normative extension” (p. 62) of their responsibilities as family members (see also Gladstone et al. 2006). In undertaking this study, I therefore recognised the need to use the term ‘informal carer’ cautiously and with careful explanation when in discussion with research participants (see Chapter Four).

### **‘Residential’ and ‘Nursing Homes’**

Rowles and Teaster (2016) state that the phrase ‘long-term care’, encapsulates all of those services provided in meeting the long-term needs of older people with chronic and sustained health issues. Residential and nursing homes are part of a “continuum”

(Rowles and Teaster 2016, p. 10) of long-term care services. Generally, older people access residential or nursing homes when their needs can no longer be met within the home environment through for example, ‘domiciliary care’ services (see Chapter Two). At such a point, many older people move out of their own homes and into separate living accommodation, with the availability of staff for “round the clock” (Falk et al. 2012, p. 999) supervision and assistance. Consistent with the wider academic literature, I use the terms residential and nursing home synonymously with other terms, such as “institutional care” (Falk et al. 2012), “care home” (Gardiner et al. 2020) and long-term care setting or long-term care environment.

### **‘Care’**

It is challenging to think and to write about care. Care and caring are vague and imprecise concepts (Phillips 2007) and are conceptualised in the vast literature on care in a multiplicity of ways (see Morse et al. 1990; Souriel 1997). As such, I want to be specific as to how I use the term *care*, within the context of this thesis.

Consistent with much of the care literature, I use the term care to refer to services of care or to the practical tasks or activities undertaken by care-givers when meeting the needs of another person (Tronto 1994). As stated within the preceding section, those who provide care (‘care-givers’) can be both ‘informal’ (the family and friends of an older person) and ‘formal’. Formal care-givers (such as care workers within care home settings or domiciliary care workers) are typically employed by care agencies.

In her research exploring the roles of social workers in achieving care for people with dementia, Brannelly (2006) appears to adopt a service or ‘task-based’ conceptualisation of care. Here, caregiving is very much seen in terms of the provision of “hands on care” (p. 200) and as such, is provided by the “home care workers” (p. 200) who visit those with dementia in their own homes. I adopt a broader conceptualisation of care in this thesis, however, focusing on the qualitative character of care and the ways in which authentic caring qualities and characteristics achieve the stated purposes of care (that is, the alleviation of suffering and distress). As such, I explore the importance of care as a qualitative approach, to the undertaking of practitioner roles and responsibilities. It is to this approach that I refer, when discussing the importance of *care-embedded social work* in the context of this thesis.

The ‘ethic of care’ literature highlights the “obligatory character” (Vanlaere and Gastmans 2011, p. 161) of care; here care is seen as identifiable by the presence of certain qualities and characteristics and it is these characteristics that enable care to achieve its core purposes. Tronto (1994; 2010) argues that much of what is called care in caring institutions is in fact, gravely lacking in care. Holstein et al. (2011), use the term “authentic caring” (p. 128) to distinguish between care that incorporates caring qualities and characteristics, and care that does not. When social workers perform care in accordance with caring qualities and characteristics, they act in what Engster (2005) calls “caring ways” (p. 54).

## **Biography of the Topic**

As is the case with much social work research (D’Cruz and Jones 2014), my interest in this field of study arose as a result of my own experience as a social worker, having been qualified for twenty-three years. The majority of my time in practice was spent within the field of adult social care. I worked primarily with older people and their families and there were many occasions where the outcomes of assessment indicated a need for long-term residential or nursing home admission.

I often worked closely with informal carers at such times, particularly when an older person had dementia and therefore potentially lacked the capacity for independent decision-making<sup>1</sup>. I was often struck by the seeming emotional impacts of care home admission and the challenges informal carers experienced when undertaking their admission-related roles and responsibilities. Many of the informal carers with whom I worked appeared deeply distressed at the prospect of an older person entering a long-stay residential or nursing home setting.

I frequently reflected upon the potential value of my role as a social worker when working in such contexts. I had qualified as a social worker in 1996 shortly after the implementation of the National Health Service and Community Care Act 1990. As

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<sup>1</sup> The provision for informal carers to enact these decision-making responsibilities is found within the Mental Capacity Act 2005, through a Lasting Power of Attorney.

noted earlier in this chapter, the legislation was seen to alter the roles and tasks of social workers in unparalleled ways, with critics drawing attention to the ways in which social work became an increasingly administrative task within the context of ‘managerialism’<sup>2</sup> (Munro 2011). I often wondered whether and to what extent, my work was effective in meeting the needs of informal carers in situations of admission, having a particular concern as to the extent to which the emotional needs of older people and informal carers were met at such times.

In a sense (and given the timing of my qualification), I had little else with which to compare statutory social work. I had not worked within the statutory sector prior to the changes brought about by the then relatively new legislation. Nevertheless, I distinctly recall conversations with more longstanding colleagues who complained about the impacts of ‘managerialism’ upon their practise. Such social workers spoke of the ways within which the preoccupation with processes and paperwork was seen to detract from their ability *to care* for individuals and families.

The comments of these social workers stuck with me. From the perspectives of these practitioners, the profession of social work had suffered serious losses as a result of the changes implemented through the 1990 legislation. When the time came for me to embark upon my PhD study, these were the concerns (as well as my own misgivings as to the value and efficacy of contemporary social work practice), which acted as a catalyst and impetus for my specific area of research focus.

## **Rationale and Justification**

Within this thesis, I have chosen to explore care within social work practice (its potential value and impacts), with reference to the care home admission experiences of informal carers. As will be shown in the following sections there are several reasons why I feel that this study is important and relevant to the present time.

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<sup>2</sup> Managerialism introduced “tighter administration and appraisal” into social work practice, with the aim of improving organisational efficiency (Thompson and Wadley 2018, p. 710).

## **1. To Continue to Raise Awareness of the Challenges of Care Home Admission Experience from an Informal Carer Perspective**

Despite the primacy of discourses of ‘community care’ within current social care policy and practice (see Chapters Two and Three), the need for some form of residential or nursing home provision for older people will arguably remain inevitable (Nolan et al. 1996b) for two reasons:

### **i. Population Ageing**

The UK, along with many other Western countries, has an ageing population (Fekonja et al. 2021, p.1) and there are further predicted increases in life expectancy.

*In 2016, there were 11.8 million UK residents aged 65 years and over, representing 18% of the total population – 25 years before, there were 9.1 million, accounting for 15.8% of the population. ... by 2066 it is expected that there will be a further 8.6 million UK residents aged 65 years and over, taking the total number in this group to 20.4 million and making up 26% of the total population.*

(Office for National Statistics 2018)

Whilst many people live into older age without experiencing significant health issues, it is clear that the potential for developing chronic illness and for therefore needing some level of care provision, generally increases with age (Benziger et al. 2016). Milne et al. (2014) point out that people over the age of sixty-five years, constitute the largest group using both Local Authority and NHS services (p. 9).

Dening and Milne (in Dening and Thomas 2013) state that “the chance of being admitted to a care home increases with age” (p. 343). One reason for this increased likelihood is that the potential for developing dementia increases with age (Brown-Wilson 2017).

### **ii. The Increased Prevalence of Dementia**

Prevalence rates of dementia are increasing (Alzheimer’s Society 2017; Wittenberg et al. 2019). The World Health Organisation (2017) defines dementia as an “umbrella

term” (p. 2) covering a range of illnesses affecting memory, cognitive ability and behaviour. Examples of diseases categorised as dementia include Alzheimer’s disease, vascular dementia and dementia with Lewy bodies (NICE 2018). Dementia is sometimes categorised in ‘stages’ (mild, moderate and advanced) (Pulsford and Thompson 2013). In the early stages of the illness the majority of older people with dementia are cared for at home and by informal carers (Nolan et al. 1996a). At later stages of the illness, however, the prevalence of symptoms like wandering, agitation and restlessness (Toot et al. 2017) often means that informal carers are no longer able to maintain their caregiving roles and responsibilities. At this stage, some informal carers describe feelings of physical exhaustion (Toot et al. 2017) and have great concerns for the physical safety of the older person (Rodgers 1997). It is recognised that even with the most “enhanced support” (Welsh Government 2018, p. 25), the needs of some older people with dementia will not be met at home and admission to residential or nursing home care will be required.

It is important to state that when beginning this study, I had not intended to focus exclusively on the informal carers of older people with dementia (although I had acquired ethical approval for the inclusion of older people with dementia, should the need arise). In actual fact, however, all of the older people who engaged with this study had a diagnosis of dementia. This finding affirms that when an older person has dementia, the likelihood of needing a long-term care admission is significantly increased (Alzheimer’s Society 2013; Milne et al. 2014; Toot et al. 2017).

## **2. To Highlight the Particular Issues of Care Home Admission for Informal Carers in Wales.**

As will be stated later in Chapter Two, there has been very little study of informal carers’ experiences of care home admission in an explicitly Welsh context. The paucity of research study in this area is concerning for several reasons. Firstly, there is every reason to believe that residential and nursing home care will remain a significant area of service provision for older people in Wales. The population of Wales is ageing rapidly (Scourfield et al. 2008; Williams 2011; Welsh Government 2020; Hannigan 2022) with recent figures (2019) from the Older People’s Commissioner for Wales showing that 877,000 people (just over 30% of the population) were found to be aged 65 years and above. The numbers of people within

later old age (85 years +) is also expected to grow significantly and to more than double by 2040. In light of these statistics it is perhaps unsurprising that Wales has the highest number of informal carers within the UK (a figure of 370,000 is cited by Welsh Government (2021a), with many informal carers providing more than 50 hours of caring, per week). Secondly, it is also important to note that prevalence rates of dementia are higher amongst the Welsh population than elsewhere within the UK. The estimated prevalence rate of dementia in the Welsh population was 1.4% compared to 1.3% in the UK population (Alzheimer's Society 2015).

It is also the case that Wales has a unique “social and economic character” (Scourfield et al. 2008, p. 42). Williams (2011) highlights the significant levels of poverty in Wales. It has been argued that there are significant links between socioeconomic disadvantage and illnesses like dementia (Jones 2017) and between socio-economic circumstances and the potential need for care home admission (Grundy and Jital 2007; Giebel et al. 2020). As will be seen in Chapter Five, an informal carer's experience of care home admission is also negatively impacted by adverse socio-economic circumstances with the stresses of care home admission being eased for example, through informal carers having a choice of care home setting (Chentiz 1983). However, levels of choice are often significantly constrained by socio-economic circumstances.

Welsh Government has had devolved responsibility for policy related to health and social care, since democratic devolution (Williams 2011). The roles and tasks of social workers are shaped by welfare systems in significant ways (Phillips and Waterson 2002; Dustin 2007; Hyslop 2018). As such, it is important to consider the specific impacts of the Welsh policy landscape on the ways in which social workers work with informal carers within Wales. The legislative and policy context that shapes admission-related, social work practice is discussed in detail in Chapter Three of this thesis.

### **3. To Increase Knowledge of the Effectiveness of the Social Work Role in Care Home Admission**

Many professionals work in care home admission-related contexts. It is not unusual for older people to enter a care home from an acute hospital setting (Denning and

Milne (in Denning and Thomas 2013). As such, many health care providers work with older people and their informal carers at times of care home entry. Since the implementation of the National Health Service and Community Care Act 1990, social workers have undertaken the lead role in organising and managing residential and nursing home admissions. The legislation transferred the responsibility for funding care home admissions from the Department of Social Security to Local Authorities. In turn this resulted in social work practitioners undertaking needs-based assessments to determine an individual's financial eligibility for entry to long-term care (Johnson 2002, pp. 741-742).

Despite the primacy of the social work role in respect of care home admission, there has been very little research focused on the effectiveness of social work practice with informal carers at such times, especially in the UK (see Chapter Two). Moreover, it seems that there has not been any prior research undertaken on social work practice with informal carers, in relation to care home admission within Wales. The dearth of research on the roles of social workers with informal carers at times of admission, is concerning. Within this thesis, care home admission is conceptualised as a 'transition' (Zizzo et al. 2020) and as will be seen in Chapter Two, transitions are experiences that can be facilitated and eased with the right kinds of professional support and intervention. With this in mind, it is vital to establish what effective social work intervention looks like at times of admission. It will be seen that an *absence* of appropriate intervention and support significantly exacerbates the detrimental impacts of transition experiences (Meleis et al. 2000; Meleis 2010). It is anticipated that the findings of this study, will help address this important gap within the current research literature.

#### **4. To Raise Awareness of the Importance of Care in the Work of Formal Care-givers**

I argue that there has never been a more important time than the present, to reflect upon care and caring and to consider the importance of "authentic care" (Holstein et al. 2011, p. 128) within the work of formal care-givers including social workers. These formal care-givers face significant challenges in undertaking their work in "caring ways" (Engster 2005, p. 54). As stated by Holt and Butcher (2021), there has been a 3% decrease in the levels of social care funding in the UK since 2010. Staffing

issues are a significant concern and according to Read and Fenge (2018), have been exacerbated through the “UK’s departure from the European Union (Brexit)” (p. 676). It is also the case that the need for care (and hence pressures on health and social care services) has never been greater than throughout the coronavirus pandemic (covid-19). As I write up this thesis, the world is seemingly emerging from the grip of covid-19, which first became known in November 2019 and which has gone on to affect more than 82 million people globally<sup>3</sup>. I anticipate that the exploration of the potential of “authentic caring” (Holstein et al. 2011, p. 128) within this study, will produce findings that contribute to wider debates concerning the implications of the current crises within the health and social care sectors.

## **The Structure of the Thesis**

The thesis is organised as follows.

**Chapter Two** explores the research literature on the experiences of informal carers at times of care home entry, presenting a thematic review of the findings of the existing empirical research. I also highlight the main concepts and theories upon which I draw in appreciating the gravity of care home admission experience upon the lives and experiences of those providing informal care.

**Chapter Three** explores the literature used in understanding the fundamental qualities and characteristics of care and caring (namely, the ‘ethic of care’ literature). I also explore literature highlighting the characteristics of what I call *care-facilitative relationships* (that is, relationships conducive to caring). Within the second part of Chapter Three, I discuss the contemporary policy context of social work practice and explore its potential implications for levels of social work caring.

**Chapter Four** discusses the methodology used in undertaking the research and the approach used in analysing the data.

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<sup>3</sup> In 2020, 1.8 million deaths (worldwide) were reported as directly attributable to covid-19; this figure was estimated to rise to at least 3 million when taking into account those deaths indirectly linked to covid-19 (World Health Organisation 2021).

**Chapter Five** presents the first of the empirical findings of the study and uses the concept of ‘transition’ to explore the challenges faced by informal carers at the time of care home admission. It also considers the importance of practitioners undertaking their caregiving roles and responsibilities with care, at such times. In exploring care (its value and potential), the chapter specifically examines the importance of “attentiveness” (Tronto 1994, p. 127) within social work practice.

**Chapter Six** considers the kinds of relationships needed to increase levels of care within social work. The discussion draws upon the work of Buber (1970) whose distinction between “I-thou” and “I-it” relationships provides a useful analytic lens through which to view the qualities and characteristics of *care-facilitative relationships*.

**Chapter Seven** explores the importance of “authentic caring” (Holstein et al. 2011, p. 128) for older people with dementia and the significance of informal carer – care home provider relationships in facilitating the provision of effective care within long-term care settings. This chapter also explores the roles of social workers in promoting and maintaining these positive, collaborative, *care-facilitative relationships* within care home environments.

**Chapter Eight** explores the potential barriers to practitioners caring within their day-to-day work (with a specific focus upon the problem of time).

**Chapter Nine**, the final chapter, draws together the findings of the study in specific answer to the research questions; offers an interpretation of the findings (it considers their potential implications for social work practice); and makes policy and practise recommendations for increasing levels of social work care.

## **Chapter Two: The Trauma of “Turning it Over”<sup>4</sup>: Informal Carers’ Experiences of Care Home Admission**

### **Introduction**

The care literature is “voluminous” (Nolan et al. 1996a, p. 1) in size and covers many different aspects of both informal and formal care (see for example, Brechin et al. 1998; Phillips 2007; Milne and Larkin 2015; Larkin et al. 2018). This thesis focuses on specific elements of that literature. In this second chapter, I explore a “small corner” (Nolan et al. 1996a, p.1) of the literature on informal care; specifically considering that which explores the experiences of informal carers when an older loved-one moves into a residential or nursing home setting. Chapter Three then explores the literature examining the nature, character, qualities and attributes of “authentic” (Holstein et al. 2011, p. 128) care and caring, with a view to considering the efficacy of the formal (social work) care, provided to informal carers at times of long-stay admission.

Before moving on to discuss the literature related to each of these specific areas, I will briefly outline the strategy used in locating the literature discussed in both chapters two and three of this study.

### **Locating the Literature**

The literature search for this study was loosely undertaken in three phases. Within the first phase, I accessed the existing research on ‘informal carers and care home admissions’. This literature was drawn from studies undertaken both within the UK and internationally. When searching for this body of literature, I did not identify a specific time frame. I was aware that research focus in this area has been relatively recent (within the past thirty years or so) and I expected publications to come from within this reasonably manageable time frame.

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<sup>4</sup> “Turning it over’ (Nolan et al. 1996a, p. 109)

When exploring this literature, I looked for publications examining the roles and responsibilities of social workers in this area of practice. Finding very little on the roles and responsibilities of social work with informal carers at times of care home entry, I then broadened my search to explore wider elements of the social work literature (this constituted the 'second phase' of my literature search). Here, I focused on the literature related to social work with older people and informal carers, and paid particular attention to those sources published from 1990 onwards. As stated in Chapter One, this thesis is concerned with the impacts of managerialism (introduced via the National Health Service and Community Care Act 1990), on levels of caring within social work practice.

Thirdly, I engaged with the 'ethic of care' literature. This literature explores the purposes of care and its various dimensions, qualities and characteristics. The ethic of care literature offers an important way of determining the presence of care, in the work of formal care-givers. It also provides a significant means of understanding the impacts of care on the lives of care-receivers.

A number of key search terms were used in locating literature for the study and included: 'informal carer(s)', 'family carer(s)', 'residential home(s)', 'nursing home(s)', 'admission(s)', 'placement(s)', 'long term care', 'social work(ers)', 'care manager(s)', 'care management', 'social work care', 'older people' and 'elderly people'. These search terms were combined in a number of different ways (using 'Boolean operators') and used across several databases to access as many relevant publications as possible. The databases were carefully selected for their potential relevance to the subject area and included: 'ASSIA' ('Applied Social Sciences Index and Abstracts'); 'IBSS' ('International Bibliography of the Social Sciences') and 'SCOPUS', which enables access to scholarly journals within the social sciences; 'APA PSYCHINFO' (database of the 'American Psychiatric Association'), which focuses upon the health and behavioural sciences; 'Social Services Abstracts' (for literature on social work, social policy and gerontology); and 'Social Care Online' which lists government briefings, reports and websites.

As expected, the search strategy used produced high numbers of publications, a significant proportion of which were not directly relevant to my research. I worked through the various bibliographic lists produced within each database, examining

references firstly by key word and then as appropriate, by abstract. This process enabled me to draw out those publications of specific research interest to me. Due to the duration of my study (which was undertaken on a part-time and hence seven-year basis), I set an ‘alert’ within each database. This meant that I received monthly emails detailing new publications of relevance, which enabled me to keep abreast of emerging research in the field.

It is important to state that the search strategy, so far described, formed only the starting point in locating literature for this study. The identification and incorporation of relevant literature was in reality an on going (Ridley 2012) and evolving process (Bates 1989) that took place throughout the duration of my study. Having identified the substantive body of literature in this area, further appropriate reading materials were also accessed using the sorts of strategies described by Bates (1989) in her work. These included “footnote chasing”, “citation searching”, “subject-searches” and “author-searching” (pp. 201-202). It was through these processes, that I extended my reading into areas such as ‘transition’ (see Murray-Parkes 1971; Golan 1981; Selder 1989) and “family practice” (Morgan 1996: 2011). As will be seen in the findings chapters of this thesis (Chapters Five – Eight), the conceptual work on transition and family practice was very important in the subsequent analysis of my empirical data.

## **The Appraisal Strategy**

As stated by Ridley (2012), “peer review” is an important means of “quality assurance” (p. 200) when appraising the strength of published research findings. I aimed as far as possible, therefore, to focus on those publications subjected to processes of peer review. That having been said, I did not exclude either non-peer reviewed articles or the use of ‘grey literature’<sup>5</sup>, where such literature offered potentially important perspectives on issues of research relevance.

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<sup>5</sup> “Grey literature is a term used for any document that is not an academic journal article. Technical reports, commissioned research reports, working papers, government policy reports all come under the ‘grey literature’ umbrella” (Jesson et al. 2011, p. 54). These authors make the point that whilst ‘grey literature’ is viewed as traditionally lower down “in the hierarchy of knowledge sources” (p. 20), such literature can nevertheless offer potentially important insights on current and topical issues.

Having outlined my approach taken in locating the literature for this study, I now move on to discussing the key findings of my literature review.

## **The Care Home Admission Experiences of Informal Carers: Overview**

To reiterate, this chapter explores what is already known of informal carers' experiences of care home admission. Research interest in informal carers' experiences of care home admission has expanded significantly since the late 1990s and early 2000s. At that point, researchers drew attention to a *gap* within the existing literature, arguing that care home admission was usually studied from the perspectives of older adults, and rarely from the viewpoints of informal carers (Johnson et al. 1992; Kellett 1999a; Ryan and Scullion 2000; Pearson et al. 2004). Some 20 to 30 years later, this picture has changed and there is now a significant body of research focused on informal carers' experiences of care home entry.

In the following sections, I discuss key findings from this substantive body of literature. My intention is to 'paint a picture' of the care home admission experience, from an informal carer perspective. I then move on to outlining the concepts and theories I have used to (a) further my understanding of the emotional gravity of care home admission and (b) to increase my awareness of the importance of the continued caregiving roles of informal carers beyond care home entry. In the final sections of the chapter, I consider what is currently known of the effectiveness of the roles and tasks of social workers when working with informal carers in admission-related contexts.

### **Triggers**

A significant number of studies explore the reasons for long-term care admission (see Cahill 1997; Ryan and Scullion 2000; Gaugler et al. 2004; Graneheim et al. 2014; McGrath et al. 2021). The causes of care home entry are identified as "multifactorial" (Toot et al. 2017 p. 204), although it appears that the need for admission often arises because of a change in circumstances, which makes caregiving within the home (domestic) environment unsustainable. It might be, for example, the needs of the older person increase to the extent where they can no longer be safely supported within the

home setting (Lundh et al. 2000; Nolan and Dellagesa 2000; Penrod and Dellagesa 2001). The informal carer's own health might also deteriorate, making it impossible for them to continue to provide care at the required level (Ryan and Scullion 2000; Davies 2005; Buhr et al. 2006).

Numerous factors shape the longevity of caregiving within the home setting. These include for example, an informal carer's perceptions of caregiving; whether caregiving is seen as 'burdensome' or otherwise (Annerstedt et al. 2000). The sustainability of caregiving arrangements will also be influenced by the extent to which caregiving roles and responsibilities are shared amongst family members (Zarit et al. 1980; Liken 2001). Critically, it must be understood that whatever the circumstances leading to considerations of care home admission, decisions in favour of care home entry are usually delayed for as long as feasibly possible (Matthiesen 1989; Keefe and Fancey 2000; Ryan and Scullion 2000; O'Shea et al. 2014). Temporal studies of dementia show that many informal carers make every attempt to avoid care home admission (Willoughby and Keating 1991; Nolan et al. 1996a). If it is undertaken at all, care home entry is usually undertaken late in the caregiving "career" (Cronin et al. 2015, p. 89) and when all other forms of home-based, long-term care have been trialled and found to fail.

As stated in Chapter One, many informal carers undertake important decision-making roles at times of care home entry (Kellet 1999a), particularly where older people have dementia and may therefore lack the capacity for making such decisions independently (Afram et al. 2015)<sup>6</sup>. Within my reading, I paid particular attention to studies exploring the decision-making roles and responsibilities of informal carers at times of admission because it is often at times of decision-making, that practitioners are involved in working with older people and informal carers; during processes of social work assessment, for example (O'Sullivan 2010; Rogers et al. 2015). The experiences of informal carers when making decisions around care home admission are explored within the following sections.

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<sup>6</sup> The provision for informal carers to make such decisions is made in the Mental Capacity Act (2005) and through the execution of 'Lasting Powers of Attorney'.

# The Challenges of Decision-Making

## 1. Emotional Challenges

When informal carers discuss the decision-making process, they often describe intense feelings of emotional distress. Konietzny et al. (2018) describe care home admission as a “tumultuous” (p. 262) experience. When retelling their stories of care home entry, many informal carers discuss their feelings of anxiety, fear, stress, uncertainty, sadness, grief, loss, guilt and shame (Dellagesa and Mastiran 1995; Nay 1996; Dellagesa and Nolan 1997; Bramble et al. 2009; O’Shea et al. 2014). In a UK based study (Northern Ireland), Ryan and Scullion (2000) used semi-structured interviews to explore the care home admission experiences of ten informal carers. These informal carers described their feelings of: “guilt, helplessness, loss, regret and sadness” (p. 1192), when describing the care home admission process.

The challenges of making decisions in respect of care home entry might be better understood, when appreciating the kinds of losses experienced by older people and informal carers at such times. Working in Australia, Nay (1995) undertook semi-structured interviews with nineteen older people, to explore their experiences of care home admission. These older people described the multiple losses they experienced, when entering a long-term care setting:

*Everything went: home, possessions, friends, family, affection, pets, freedom, favoured locations and the environments, roles and lifestyles that were known and predictable (p. 322).*

It is not difficult to imagine the potential impacts of such losses. In highlighting the emotional impacts of losing one’s home, Brownie et al. (2014) state that a person’s home is far more than a physical place. These authors conceptualise home as an “affective place of belonging” (p. 1655). Similarly, Bokerman et al. (2012), view home as significant to an individual’s subjective well-being.

Nay (1995) also refers to the impacts of losing “family and friends” (p. 332) on the lives of these older people. For some informal carers the gravity of these relational losses is so significant that they have been likened to “bereavement” (Cheek and Ballantyne 2001). In her work, Tilse (1997) examined the impacts of relational loss

on the experiences of spousal informal carers. Also working in Australia, she conducted interviews with eighteen spouses following an admission to long-term care. These spouses described their feelings of “loneliness, grief and loss” (p. 203), when their marriage partner relocated to a care home setting.

Significantly, some informal carers also experience feelings of loss when losing contact with formal care providers (such as domiciliary care workers) at the onset of institutionalisation. These care workers might have visited an older person within their home environment for a substantial period of time before care home entry, developing good relationships and perhaps friendships with older people and their informal carers. Cronin et al. (2015) sought to understand the impacts of care home admission experiences and conducted focus groups and interviews with 40 informal carers, living in Ireland. The participants of this study highlighted the challenges experienced by informal carers when the “social network arising from medical appointments and services, suddenly dissipated” (p. 92) (see also Brown and Stetz (1999) who describe similar findings from their USA study).

An interesting area of exploration is the losses experienced by informal carers when relinquishing a caregiving role. (Kellett 1999a; 1999b; Larkin and Milne 2017). Early work on family or informal care tended to focus upon the burdens and stresses of long-term caregiving (Pitkeathley 1989; Opie 1994). From such a perspective, one might expect an informal carer to feel a sense of relief when relinquishing their caregiving roles and responsibilities. In more recent studies, however, the experience of informal care has been described more positively (Phillips 2007), meaning that losing a caregiving role is then seen as a possible source of anxiety and distress. Twigg and Atkin (1994) describe the reciprocity of caregiving relationships, stating that caregiving often meets the need of both care-givers and care-receivers. Motenko (1989), Courts et al. (2001) and Netto and Yap (2009) all explore the perceived benefits of caregiving from an informal carer perspective. Netto and Yap (2009) described the feelings of “personal growth” (p. 245) experienced by some informal carers, when caring for an older person with dementia. Courts et al. (2001) highlight the “positive feelings and enjoyment” (p. 49) described by their sample of informal carers when engaging with their caregiving roles and responsibilities. Nolan et al. (1996a) suggest that the caregiving roles of informal carers as a means by which they

express affection for their older loved ones and therefore affirm the value of cherished, filial relationships. These authors state that for some informal carers, caregiving provides them with a means for “expressing strongly held religious or personal beliefs” (Nolan et al. 1996a, p. 90) and as such, the opportunity to provide care is conceived as a source of great satisfaction. Larkin (2009) highlights the difficulties of the “post caring void” (p. 1026) for some informal carers and developed the concept of the “serial carer” (p. 1026). Serial carers actively seek new caregiving responsibilities to replace those that have ended.

Feelings of guilt and shame are common amongst informal carers at times of care home entry (Johnson and Werner 1982; Kellett 1999a; O’Shea et al. 2014). Such feelings often arise amongst informal carers because they feel that have failed in their familial duties and have “let down” (Ryan and Scullion 2000, p. 1193) those whom they love. There have seemingly been few studies undertaken on informal carers’ experiences of care home admission within Wales. The one study that I was able to find, evidenced the prevalence of guilt feelings amongst informal carers in Wales. Seddon et al. (2002) interviewed seventy-eight informal carers from North Wales whose older relative had recently been admitted to a residential or nursing home. These informal carers described experiencing significant feelings of guilt, which did not necessarily abate over time. In the words of one informal carer:

*It’s got worse as time’s gone by and it’s like I’m stuck in this downwards spiral of guilt and self-blame.*

(Seddon et al. 2002, p. 19)

In understanding these feelings of guilt it is necessary to appreciate the socially constructed nature of care (see Symmonds and Kelly 1998; Phillips 2007). As a social construction, ideals around care and caring are shaped in accordance with social and cultural expectations. Significantly, Henderson and Forbat (2002) highlight the ways within which social policy affirms expectations around the location and responsibility for care.

The literature discussed in this chapter has been drawn from both the UK and internationally, including for example, from the USA (Zarit and Whitlatch 1992); Canada (Bowers 1988; Konietzny et al. 2018); Australia (Tilse 1997; Bauer 2006);

and Sweden (Graneheim et al. 2014; Hertzberg and Ekman 2000). The findings of these research studies show that there are high levels of similarity (cross-nationally) in the care home admission experiences of informal carers. In many respects, these similarities are perhaps unsurprising. As observed by Davies (in Scharf and Wenger 1995), whilst there are inevitably differences in cross-national welfare policy, it is also the case that in practically all developed countries, community care policies have been adopted as an economic response to population ageing (see also Nolan et al. 1996b; Oldman and Quilgars 1999).

As will be discussed within Chapter Three, community care policies champion the care of older people at home, by family members. Such policies are embedded with notions of what Crist (2002) calls: “familism” (p. 366). Familism encompasses a belief that it is right and proper for adult children to care for those who have once cared for them; that the responsibility for the care of older people should rest with the members of one’s family and not with the State (Finch and Mason 1990). Crist (2002) demonstrated the power and influence of familism in her research with thirty-seven, informal carers of Mexican, American elders. During their interviews, these informal carers expressed strong, culturally based preferences for family care and as such, were highly resistant to receiving external support. In the case of eventually *accepting* support, many sensed that they had somehow failed in their filial responsibilities and experienced high levels of guilt and shame (Crist 2002, p. 372). According to Jack (1998), community care policies incorporate an explicitly “anti-residential bias’ (p. 26) meaning that they assert the “superiority of community care” (p. 26) over institutional care.

Whilst there are similarities in international, social care policy, Oldman and Quilgars (1999) argue that attitudes towards residential care within the UK have always been particularly negative (p. 363); perhaps therefore heightening the challenges of long-term care admission within a UK context. Institutional care within the UK has its origins in the “Poor Law” and subsequent workhouse provision of the nineteenth century (Means et al. 2008). It is beyond the scope of this review to explore the history of institutional care in the UK in detail (for a comprehensive discussion, see Jack 1998; Cowen 1999; Blakemore and Warwick-Booth 2013; Bochel and Daly 2014). Nevertheless, it is important to recognise the ways within which the attitudes

of many older people and informal carers towards residential and nursing home provision are adversely shaped by the origins of institutional care (Parker in Allot and Robb 2006). Criticisms of the negative aspects of institutional care also gained momentum in the 1950s and 60s through the work of writers like Goffman (1961) and Townsend (1962), which produced damning accounts of life within institutional settings. It was at this time that Goffman (1961) introduced the notion of the “total institution”, a place where individuals were “cut off from the wider society” and led “an enclosed formally administered, round of life” (p. xxi).

Nolan et al. (1996a) state that many informal carers derive a sense of satisfaction from keeping an older person *out* of long-term residential care. This is arguably particularly so, for women. The gendered nature of care is discussed extensively within the caregiving literature (see for example, Waerness 1984; Maclean and Groves 1991; Bauer and Nay 2003; Milne and Hatzidimitriadou 2003; Phillips 2007). These texts describe the ways within which women perceive themselves as having primary responsibility for caregiving within the domestic environment, with Graham (in Finch and Groves 1983), arguing that care constitutes the identity of women in Western society. According to Matthiesen (1989), the ‘gendered’ nature of care means that women often experience heightened feelings of guilt at times of care home admission; perceiving that they have especially failed in fulfilling their caregiving commitments. It is worth noting that according to writers like O’Neill (2011), women in Wales have traditionally been “strongly identified with the domestic sphere” (p. 47); their reputation critically dependent on the quality of care provided to other family members. Charles and James (2005) make the point that whilst patterns of employment have changed within Wales, ideas around the gendered division of labour have been slow to dissipate. It is not difficult to see how, when their roles and responsibilities are conceptualised in such ways, women in Wales may well experience high levels of guilt in connection with residential and nursing home admission.

In light of the challenges described in the previous sections, it is unsurprising that decisions in favour of care home admission are often held-off for as long as possible and made with the greatest levels of resistance. Even at the point of deciding that care home entry is needed, the challenges experienced by informal carers do not

necessarily ease. At such times, many informal carers experience very real practical challenges when trying to choose an appropriate care home setting and when engaging with complex, care home admission processes and procedures. It is to the practical challenges of care home admission that I now turn.

## **2. Practical Challenges**

### **i. The Challenge of Choice**

It is important to recognise that determining whether an older person enters a care home setting is not the only decision that informal carers make in respect of long-term care admission. Many informal carers also make decisions as to *where* an older person should live (that is they choose a care home setting). It is not unusual for informal carers to have little or no knowledge of life in a care home (Johnson et al. 1992) and to have very “limited criteria” (Nolan et al. 1996b, p. 761) upon which to base their judgements about the quality of care provided. This lack of knowledge and understanding makes the process of finding a *good* care home, extremely difficult. In an Australian study, Cheek and Ballantyne (2001) suggest that the identification of a suitable care home setting is more a matter of luck or “good fortune” (p. 225) than judgement. Here, twenty-five informal carers were interviewed to understand their experiences of identifying a care home environment on behalf of an older loved-one. The research highlighted the stresses and anxieties or “wear and tear” (p. 221) felt by these informal carers as they struggled to find an appropriate care home setting for their older loved-ones.

In the UK, there have been significant increases in the numbers of private sector, residential and nursing homes since the implementation of the National Health Service and Community Care Act 1990 (Phillips 1992; Carey 2015). As will be discussed in Chapter Three, these increases were intended to promote consumer choice and to increase the options available to older people and their families. In reality, however, it is arguable that these increases have also complicated the process of choosing *well*, from an informal carer perspective. In order to make an appropriate choice of care home setting, older people and informal carers need significant amounts of knowledge and understanding. They need to appreciate for example, the differences between different types of care home environment and between residential

and nursing home settings<sup>7</sup>. It is also the case that as highlighted by Andrews and Phillips (2000), care homes differ in important ways one from another and in accordance with the specialist interests and skills of registered providers. This means that even within the same ‘category of care’, there will be significant differences between alternative care home settings. The challenges of choosing a care home setting and the feelings of stress and anxiety experienced by informal carers at such times are highlighted elsewhere within the literature (see Matthiesen 1989; Berger: in Denning and Milne 2011; Pulsford and Thompson 2013; Fitzpatrick and Grace 2019).

## **ii. The Challenge of “System Navigation”<sup>8</sup>**

For many informal carers, these feelings of stress and anxiety are further exacerbated by the complexity of the care home admission process and the bureaucratic nature of the health and social care systems surrounding long-term care admission. Exploring informal carers’ experiences of care home admission in the UK, Phillips and Waterson (2002) state that: “admission is a complex process, involving different operators and procedures as well as multiple levels of decision making” (p. 174). In the course of any one admission, an informal carer is likely to encounter numerous different professionals (for example, social workers, health care providers, care home providers and staff from within housing and finance departments). There is evidence that informal carers do not always understand the roles and responsibilities of these different personnel and as a result, do not know where to turn for their much-needed assistance and support (Cheek and Ballantyne 2001; Zizzo et al. 2020). For many informal carers, “navigating the system” (Zizzo et al. 2020, p. 9) or “cutting through the maze” (Cheek and Ballantyne 2001, p. 228) is a confusing, frustrating and

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<sup>7</sup> As stated by Denning and Milne (in Denning and Thomas 2013) “a distinction is generally made between residential care homes and care homes with nursing (otherwise known as nursing homes)” (p. 343). Residential care homes provide assistance with daily living activities, such as “washing, dressing and giving medication” (p. 343), whereas those older people living in nursing homes generally have higher levels of physical needs and require the support of qualified nursing staff in maintaining their physical well-being.

<sup>8</sup> “System navigation” (Zizzo et al. 2020, p. 9)

emotionally exhausting experience (see also Wright 2000; Davies and Nolan 2003; Kelsey et al. 2010; Konietzny et al. 2018).

Given the anxiety, stress and distress (Dellagesa and Mastrian 1995) experienced by many informal carers when making decisions around care home entry, key theorists have sought to underline the professional assistance needed at this time.

### **Professional Intervention in Decision-Making Processes**

Some theorists have used the narratives of informal carers to develop models or ‘typologies’ of effective decision-making interventions. Nolan et al. (1996b) have developed one such model, which highlights the sorts of conditions and processes required when supporting informal carers in making decisions related to care home admission. The model and its dimensions are depicted within the following table:

<b><i>Anticipation:</i></b>	The extent to which the move into the facility is preceded by a period of rational thought and forward planning
<b><i>Participation:</i></b>	The extent to which the older person and the family are actively involved in choosing a home
<b><i>Exploration:</i></b>	The degree to which alternative options, including alternative homes and feelings and reactions to the move, are explored
<b><i>Information:</i></b>	The degree to which older adults and their families are provided with sufficient information to make informed decisions.

*Table 1. Adapted from Nolan et al. 1996b, pp. 269-271*

The model is important because it can be used as a tool for practitioners to help informal carers perceive the care home admission experience more *favourably*. Like

Chenitz (1983), Nolan et al. (1996b) state that informal carers' perceptions of the care home admission process are significant because they go on to shape and influence the success of subsequent levels of adjustment. The model shows that the assistance needed by informal carers when making decisions around care home entry, is both practical and emotional in nature. Thus for example, Nolan et al. (1996b) highlight the importance of information provision, and the need for informal carers to be provided with opportunities to talk through and to express their feelings and concerns around their care home admission experiences.

The types of interventions described by Nolan et al. (1996b), are well supported elsewhere within the literature. The findings of other research shows that the majority of informal carers *want* to be involved in making decisions related to care home admission (see Nolan and Dellagesa 2000; Ryan and Scullion 2000). Where levels of informal carer participation are limited, feelings of disempowerment arise (Davies and Nolan 2003). The extent to which informal carers are enabled to participate in decision-making processes is, however, dependent upon numerous other factors. For example, like Nolan et al. (1996b), many researchers draw attention to the importance of the quality of information provided to informal carers during decision-making processes (see Tipton-Smith and Tanner 1994; Nolan et al. 1996b; Davies and Nolan 2003; Johansson et al. 2014; Afram et al. 2015). According to Nolan et al. (1996b), it is also important that informal carers are given the time to digest and to reflect on the information provided, if they are to use that information *well* (hence the importance of the domain: "Anticipation"). It is considered unhelpful for decisions to be made hurriedly and at a time of "crisis" (p. 269), where the possibility of weighing up all available options for support is limited.

The model developed by Nolan et al. (1996b) is also a useful means of evaluating the effectiveness of current levels of professional intervention at points of decision-making. It is seen that there is much variability in the effectiveness of the professional interventions offered at such times and that many informal carers, do not receive the kinds of information conducive to successful decision-making outcomes. By way of example, Reed and Morgan (1999) interviewed seventeen informal carers in Ireland, to understand their care home admission experiences. These researchers learnt that many informal carers were given nothing more than a "list" (p. 823) of care homes

when attempting to choose a care home setting. A substantial amount of the literature in this area draws attention to the inadequacies of the time available for effective decision-making (Davies and Connolly 1995; Rodgers 1997; Victor et al. 2000; Strang et al. 2006; Sussman and Dupuis 2014; Fitzpatrick and Grace 2019).

Critically, the domain “Exploration” (Nolan et al. 1996b, p. 269) illustrates the importance of *relationships* and of shared and collaborative approaches to decision-making at times of care home admission. Through their work Nolan et al. (1996b), suggest that the majority of informal carers do not want to make decisions in respect of care home admission *alone*. Instead, they value the opportunity for mutual discussion with engaged and knowledgeable professionals. The importance of shared decision-making is affirmed elsewhere within the literature in this area (see Johnson and Werner 1982; Dellagesa and Mastrian 1995, Courts et al. 2001; Pearson et al. 2004, Fitzpatrick and Grace 2019). It is important to recognise that many informal carers derive emotional support from feeling that decisions are shared and where collaborative decision-making processes affirm the appropriateness and correctness of the decisions they make. Within such situations, feelings of anxiety and stress are alleviated (Dellagesa and Mastrian 1995; Davies 2005). Conversely, feelings of guilt are heightened when informal carers feel alone in making their decisions and when they do not have someone to validate and affirm the appropriateness of their decision-making outcomes (Flynn-Ruess et al. 2005).

The importance of practitioners “working together” (p. 436) with informal carers at times of decision-making was also highlighted in the later work of Davies and Nolan (2003), which built upon and expanded the processes identified within the framework of Nolan et al. (1996b). Davies and Nolan (2003) interviewed forty-eight informal carers in England, with recent experience of assisting an older person to move into a care home setting. Several different factors were considered important to the success of the decision-making process. The model (depicted below) highlighted the importance of factors like time, information and participation in promoting positive decisional outcomes:

<p><b>No Pressure</b></p> <p>Being encouraged to take time to make decisions, to be yourself, to say what you want to happen</p>		<p><b>Under Pressure</b></p> <p>Feeling the need to make decisions quickly, to conform, to conceal your needs</p>
<p><b>Being in the Know</b></p> <p>Having access to relevant information to play a full and active role in the life and care of the older person</p>		<p><b>Working in the Dark</b></p> <p>Lacking the relevant information to continue to play a full and active role in the life and care of the older person</p>
<p><b>Working Together</b></p> <p>Being able to work with health and social care staff to ensure best care for the older person</p>		<p><b>Working Apart</b></p> <p>Barriers to working together with health and social care staff or with family members</p>
<p><b>Being in control</b></p> <p>Being able to maintain ownership of decisions about your future and the future of your relative</p>		<p><b>Losing control</b></p> <p>Feeling that decisions have been taken out of your hands; that you can no longer influence events</p>
<p><b>Feeling supported</b></p> <p>Feeling that others are aware of the consequences of the move for you and your relative, they are willing to listen to you and are there for you</p>		<p><b>Feeling unsupported</b></p> <p>Feeling that your own experiences and / or those of your relative are of little consequence to others</p>

*Table. 2: "Relatives' experiences during phases of admission to a care home"*

*(Davies and Nolan 2003, p. 436)*

The presence or absence of the factors or domains identified within Davies and Nolan's model, was seen as critical to shaping overall perceptions of the decision-making process. These perceptions are 'mapped' in turn, on a continuum from positive to negative – left to right. The importance of collaborative relationships to decision-making is highlighted in the domain “working together” (p. 436), which makes explicit the need for informal carers to “work with health and social care staff to ensure best care for the older person” (p. 436).

Significantly, the importance of collaborative relationships can also be seen at all stages of the care home admission trajectory. Within their work, Davies and Nolan (2003; 2004; 2005) disaggregate the overall care home admission journey into a series of discrete phases. The first phase “Making the Best of Things” (Davies and Nolan 2003), discusses informal carers' experiences of decision-making processes. Within the second phase: “Making the Move” (Davies and Nolan 2004) the researchers focus on the experiences of informal carers at the *point of relocation* (that is, when an older person moves into a new care home environment).

In their application of the model to the third and final phase of the care home admission process: “Making it Better”, Davies and Nolan (2005) stress the importance of the presence of collaborative relationships between informal carers and care home providers in the time beyond care home entry. The reason that these relationships are so important, is that they influence the extent to which informal carers engage with their continued caregiving roles and responsibilities following care home admission (Bowers 1988; Hasselkus 1988; Sandberg et al. 2002; Gaugler 2005; 2006). The importance of the continued caregiving roles and responsibilities of informal carers is explored within the following section.

### **Informal Carer Roles and Responsibilities Beyond Care Home Admission**

A substantial number of studies have explored the ways within which informal carers continue to provide care to their older loved-ones within long-term care settings (Bowers 1988; Rowles and High 1996; Tilse 1997; Seddon et al. 2002; Pritty et al. 2020). Gaugler and Kane (2007) have explored the content of these caregiving roles and responsibilities and sub-divide caregiving into a number of categories including:

“personal care” (assistance with activities of daily living); “instrumental care” (the provision of help with for example, laundry tasks and the management of financial affairs); “socio-emotional support” (whereby informal carers seek to engage older people within social activities); and “monitoring and advocacy” (whereby informal carers oversee the quality of care) (p. 84). Rowles and High (1996) describe several different roles within which informal carers engage within care home environments, these include: “caregiving, pampering, comforting, educating, monitoring and mediating” (p. 24). Such studies show that whilst there may be alterations in the nature of an informal carer’s caregiving roles and responsibilities at times of care home admission (there may be less focus on “continuous hands-on care” (Zarit and Whitlatch 1992, p. 665)), many informal carers retain a level of caregiving involvement in the time following admission.

Some studies have paid close attention to the *purpose* of these caregiving roles and responsibilities. Chen et al. (2007) suggest that informal carers continue to engage with their caregiving roles and responsibilities as a way of alleviating their post admission anxieties and stresses. As stated in earlier sections, many informal carers distrust the quality of care provided in institutional environments. For these informal carers, undertaking “monitoring and advocacy” (Gaugler and Kane 2007, p. 84) roles within care home settings is critical, because it provides a means of assuring standards of caregiving (see Rodgers 1997). The importance of such roles and responsibilities should not be underestimated. Nolan et al. (1996a) draw attention to the perceived expertise of many informal carers. It is argued that because many informal carers have cared for older people for significant lengths of time ahead of care home admission, they have extensive knowledge of their physical and emotional needs. Rowles and High (1996) state that because of this knowledge, some informal carers have been able to “reveal concerns to staff, before they (might otherwise) become apparent” (p. 20).

It would of course, be inaccurate to state that caregiving within care home settings is of a *consistently* low standard. (See Meyer and Owen in Denning and Milne 2013, for a discussion of the ‘My Home Life’ project, which celebrates examples of good practise, within long-term care settings.) Nevertheless, there has been sustained criticism concerning what might be seen as low levels of care within care home

environments. Thompson and Thompson (2001) argue for example, that care homes have tended to focus on meeting the physical needs of older people at the expense of attending to their broader psychosocial needs (see also Nolan et al. 1995 and Perrin, 1997). At the far end of the spectrum, it is also the case that far too many older people have been mistreated and abused within long-term, institutional care (Penhale and Manthorpe: In Manthorpe and Stanley 2004; Burns et al. 2012; Milne et al. 2013; Ash 2014; Robinson et al. 2018). In Wales specifically, a major Gwent police investigation called ‘Operation Jasmine’, was set up to investigate sixty-three deaths in care homes and nursing homes (Welsh Government 2015a). The media publicity surrounding such high profile cases no doubt exacerbates informal carers’ anxieties around care home admission and increases their perceived need to monitor the quality of care provided, post institutionalisation.

Satisfaction with the quality of care provided to an older loved one is critical to the well-being of informal carers in the time following admission (Seddon et al. 2002). Additionally, Davies and Nolan (2005) state that the self-esteem of informal carers is enhanced when they feel able to contribute to the best quality of care of an older person (see also Fleming 1998 and Kellett 1998: 1999a: 1999b). (I will discuss the impacts of care home admission on the self-esteem of informal carers, more fully, in later sections.)

Kitwood’s (1997a) work on person-centred dementia care, offers important insights into the ways within which, informal carers potentially promote the quality of institutional care provided to older people with dementia. ‘Person-Centred Care’ and the roles of informal carers in the provision of such care, is discussed in the following section.

## **Person-Centred Dementia Care**

Traditional biomedical models have viewed dementia as a “dire condition” (Kitwood and Brendin 1992, p. 278) and a “terrible” (p. 278) illness in which a person inevitably experiences high levels of “ill-being” (p. 278). According to Morton (1999) it is not uncommon to suppose that those with dementia become a “shell of a person... losing those essential features that make (them) human” (p. 100). Put another way, dementia is often assumed to lead to the loss of an individual’s sense of

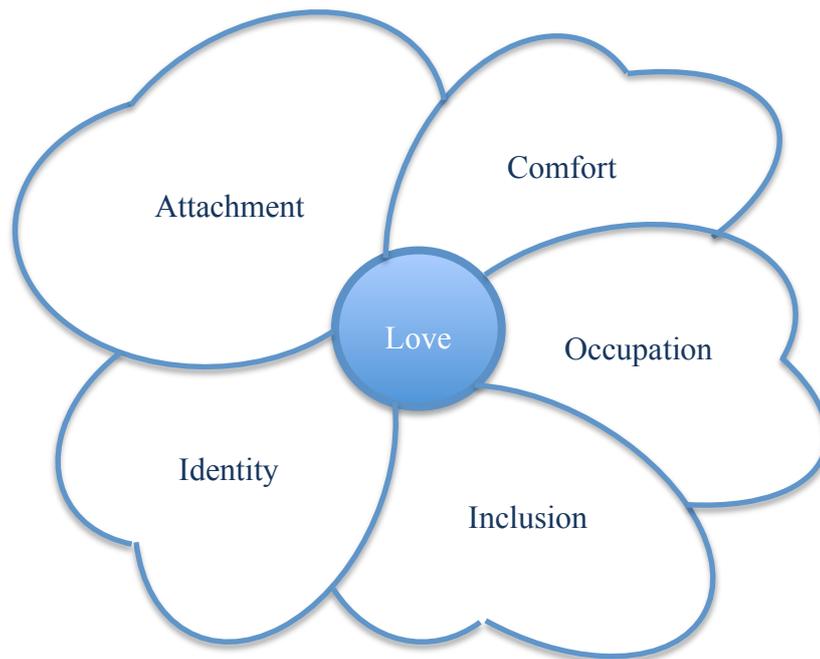
self or ‘personhood’ (Kitwood 1989: 1990: 1997a; Innes 2002; Brooker 2003; 2007; O’Connor et al. 2007; Hellstrom et al. 2007; Rosvik et al. 2013; Downs and Lord 2017).

Person-centred theorists argue, however, that the loss of a sense of self is not inevitable for those with dementia. It is important to recognise that such symptoms are not necessarily seen as characteristic of dementia per se, rather they are seen as arising within environments that fail to recognise the psychosocial needs of older people with dementia (Nolan et al. 1995; Perrin 1997; Milne and Hibbard 2011; Thompson and Thompson 2001) and where such environments fail to promote positive, social interaction (Kitwood 1997a; Morton 1999).

From Kitwood’s perspective, society plays a significant role in shaping inimical attitudes towards those with dementia and therefore helps legitimise negative behaviours and interactions (Kitwood and Brendin 1992). In a similar vein, Sweeting and Gilhooly (1997) make reference to the concept of “social death” (p. 93), which highlights the ways within which those with dementia (whilst biologically living), are sometimes treated as though dead and as therefore unworthy of meaningful social interaction (see also, Brannelly 2011).

Nevertheless, if selfhood is *denied* through low level care and negative social interaction, it is important to recognise that it can also be promoted through environments that foster “human interaction... activity and cooperation” (Kitwood and Brendin (1992 p.280); Perry and O’Connor 2002; Fazio et al. 2018). Kitwood and Brendin (1992) considered it possible to off-stay the deterioration of those with dementia and to help “stabilise” (p. 280) their condition through actions and interactions that promote personhood. Kitwood (1997a) defined personhood as “... a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust” (p. 8).

Kitwood (1997a: 1997b) identified five interrelated domains of psychological need, which are seen as fundamental to promoting the well-being of those with dementia. These domains are commonly depicted as follows:



*Figure 1. The main psychological needs of people with dementia - Kitwood (1997a)*

Whilst the psychosocial needs depicted in the diagram are no-doubt universal to the human condition, it is argued that they are often increased for those with dementia. Kitwood (1993) argues for instance, that those with dementia experience an increased need for comfort because “the psychological defences which give stability and protection ... are breaking or have broken down” (p. 57) (see also Hoffman and Platt 2000). I will discuss the domain “Comfort” in greater detail, to highlight the contributions of informal carers in meeting such psychosocial needs in care home settings.

Kaufmann and Engel (2016) state that “comfort” is derived by those with dementia, through engaging in relaxation and the “small pleasures of life” (p. 780). It is important to recognise, however, that *how* older people derive pleasure will inevitably differ in accordance with their unique personalities and preferences (Rowles and High 1996). As such, Kitwood (1997a) argues that if the well-being of those with dementia is to be promoted, then these psychosocial needs must be met in “personally significant” (p. 83) ways.

Individualisation is an important dimension of person-centered dementia care and involves “treating people as individuals (and) appreciating that all people have a

unique history and personality” (Brooker 2007, p. 44). Harvath et al. (1994) make the point that care home providers rarely have access to such individualised knowledge, at least not in the early stages of care home admission. As such, meeting the needs of older people with dementia in “personally significant” (Kitwood 1997a, p. 83) ways is inevitably dependent on the personalised knowledge of informal carers. Harvath et al (1994) refer to this personalised knowledge as “local knowledge”<sup>9</sup> (p. 29) and contrast the “local knowledge” (p. 29) of informal carers, with the generalised or “cosmopolitan knowledge” (p. 29) of formal care-givers. Formal care workers acquire cosmopolitan knowledge in the course of their professional training.

It is important to recognise that it is through such knowledge, that meaningful relationships between older people and care home providers are also promoted. Relationships are critical to the well-being of those with dementia (Milne 2020) and it is through warm, trusting relationships, that the psychosocial needs of older people with dementia are often met (Milne and Hibbard 2011). Kitwood (1997a) states for example, that older people with dementia are comforted when they feel “secure” and “close to” (p. 81) another. As care home providers meet psychosocial needs in “personally significant” (Kitwood 1997a, p. 83) ways, they are able to connect with older people with dementia and to build the kinds of relationships that inspire hope and promote self-esteem (Kitwood and Brendin 1992).

The work of Kitwood (1997a) makes explicit the advantages of collaborative informal carer – care home provider relationships, in caring for older people with dementia. Nevertheless, there are significant challenges to informal carers and care home providers “working together” (Davies and Nolan 2003, p. 436) in such collaborative ways. It is to the challenge of *working together* that I now move.

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<sup>9</sup> Harvath et al. (1994) refer to “local knowledge” whilst Dewar and Nolan (2013) refer to “relational knowledge” (p. 1247). Murphy and Skillen (2015) describe such knowledge as “soft knowledge” (p. 637) and “situated knowledge” (p. 637), whilst Clarke et al. (2003) refer to the wealth of “biological” (p. 697) knowledge possessed by informal carers.

## **The Challenge of Working Together**

Despite the perceived benefits of informal carers and care home providers working together to meet the needs of older people with dementia, it is also clear that some care home providers dissuade informal carers from engaging with continued caregiving roles and responsibilities (see Robinson and Thorne 1984; Bramble et al. 2009). Sandberg et al. (2002) argue that some care home providers lack the understanding and “empathic awareness” (p. 507) needed to appreciate the meanings that informal carers attach to their continued caregiving roles. This lack of understanding can lead in turn, to feelings of resentment on the part of care home workers and to family members being “cast ... in an adversarial role” (Bauer 2006, p. 45). Where involvement and participation is not facilitated, then relationships inevitably become “superficial and strained” (Sandberg et al. 2002, p. 406).

It is also important to recognise, however, that even where there is willingness to work together, that it is very difficult to “interweave formal and informal care” (Bulmer 2015, p. 172). Different models of collaborative caregiving have been trialled. Early models were based on the concept of ‘dual specialisation’ (Litwak 1985), where tasks were assigned on the basis of assumed areas of expertise. As observed by Duncan and Morgan (1994), care home providers were considered to have expertise in the provision of technical, hands-on care, whilst family members were considered to be more adept at providing socio-emotional support. Research by Shuttlesworth et al. (1982) has shown, however, that in reality, the demarcation between informal carer and care home provider tasks is far less clear-cut and that discrepancies and ambiguities within role-responsibility increase the potential for stress and relational conflict. It has also since been recognised that informal carers do not necessarily want to be restricted from involvement in the provision of technical care (Bowers 1988), that indeed, they want technical, instrumental care to be delivered in personalised ways and therefore see themselves as having a role in the provision of such care. Thus, Duncan and Morgan (1994) observe that relational tensions may arise when there is “too strict a division of labour” (p. 242) within care home settings.

Given the importance of informal carer - care home provider relationships, efforts have been made to explore those factors that facilitate productive relationships.

Briefly, communication is seen as critical to promoting and maintaining relationships (Hertzberg and Ekman 2000; Courts et al. 2001; Pritty et al. 2020; Harper et al. 2021). Brown-Wilson (2008a; 2008b; 2009) draws attention to the importance of styles of leadership and continuity of staff in promoting meaningful informal carer – care home provider relationships within long-term care settings. Montgomery (1982; 1983) suggests that care home providers can express a positive attitude towards the continued involvement of informal carers within care home settings in a number of ways. Attention is particularly drawn to the importance of levels of “family orientation” (p. 54) within long-term care policies and procedures. “Family orientation” is defined as the “extent to which residents are treated as members of a family, rather than isolated individuals” (1982, p. 54). Recognition of these strategies is important because, to reiterate, the self-esteem of informal carers is promoted when they feel able to contribute towards the provision of good care for their older loved-ones (Davies and Nolan 2005).

It is important to appreciate that the experience of care home admission has the potential to significantly *undermine* the selfhood and self-esteem of informal carers (Nolan et al. 1996b; Lloyd and Sterling 2011). This thesis draws upon the work of a number of transition theorists in understanding the impacts of care home admission (as a type of transition), on the selfhood and self-esteem of those providing informal care. The ideas of these transition theorists are presented in the following section.

## **Exploring Care Home Admission through the Conceptual Lens of Transition**

As stated by Grenier (2012), transition is an interdisciplinary area of study and constitutes a significant body of literature. As such, it is well beyond the scope of this review to discuss this literature in detail. Instead, I have drawn upon those strands of the transition literature that are most relevant to facilitating my understanding of the emotional impacts of transition, the challenges of adaptation and the complexities of transition experiences.

Analysis of the care home admission experience with reference to the concept of ‘transition’ is not entirely new. As stated by Zizzo et al. (2020), the experience of care home admission has been conceptualised *as* a transition since the 1980s and several

theorists working in this area have applied a transition framework to the conceptual analysis of their data (Olsson and McGlynn Shadick 1993; Brandberg 2007). Nevertheless, I have tried to use the work of transition theorists not hitherto referenced within this area of study (notably Murray-Parkes 1971; Golan 1981; and Selder 1989). The work of these transition theorists is particularly important in facilitating understandings of the impacts of transition on the *selfhood and identities* of informal carers.

## **1. Defining Transition**

The concept of ‘transition’ is often used within the health and social care literature to describe an individual’s movement between different areas of service provision (Geary and Schumacher 2012; Tanner et al. 2015). When transition is conceptualised in such ways, “transitional care” becomes, by implication:

*The care provided to (individuals) as they move from one care site (or one care level) to another and refers to care that aims to provide coordination and continuity of health across care sites.*

(Graham et al. 2009, p. 23)

Such literature focuses upon the roles and tasks of social workers and health care providers in facilitating smooth, efficient movement across these differing sites of care (Fabbre et al. 2011; Barber et al. 2015). (The issue of efficiency in social work practice, is discussed in detail, in Chapter Three.)

Tanner et al. (2015) argue that conceptualisations of transition as a “physical move between fragmented services” (p. 2057) are, however, limiting, because they pay insufficient attention to the “social, psychological and emotional aspects” (p. 2057) of transition. The work of the theorists upon which I draw in this thesis (Murray Parkes (1971); Golan (1981); Schlossberg (1981); and Selder (1989)), helps provide a more holistic conceptualisation of transition and one which recognises the deep, emotional impacts and significant challenges of life changing events in the lives of older adults and informal carers.

## 2. The Emotional Impacts of Transition

Blum and Sherman (2010) argue that transition is often initiated by situations of significant change. However, the concept of transition refers to the journey or “passage” (Golan 1981, p. 11) undertaken by individuals when adapting to these significant change events. The process of negotiating this “passage” (Golan 1981, p. 11) is often extremely challenging in the lives of individuals. According to Neimeyer (1999) and Goldsworthy (2005) change is challenging because all change involves a degree of loss. As stated previously, it is not uncommon for those engaged in care home admission to experience losses that are material (the loss of possessions for example), relational (as family relationships and wider social networks are altered and disrupted) and occupational (the loss of roles and responsibilities) (Nay 1995).

Murray-Parkes (1971) makes the point that the losses occurring within transition are experienced in what he calls the “life space” (p. 103). Drawing on the work of Lewin (1935), he defines the “life space” as:

*Consisting of those parts of the environment with which the self interacts and in relation to which behavior is organised; other persons, material possessions, the familiar world of home and place of work, and the individual's body and mind in so far as he can view these as separate from his self.*

Murray-Parkes (1971 p. 103)

Murray-Parkes (1971) argues that anything that an individual can call his or her own (such as “material possessions”, their “home and place of work” or “family” (p. 103)) constitute in effect, a part of him/herself. When these dimensions of selfhood are altered and diminished through transition experiences so too the individual loses a part of his or her identity.

As identity is lost, an individual may feel increasingly fragile (Selder 1989). He or she may begin to question how the world *is* and where he or she *fits* within it. At such times, all of a person's assumptions and prior expectations are challenged. Murray-Parkes (1971) argues that the “assumptive world” (p. 103) (that is the known or

familiar world of individuals) is significantly impacted by changes in the “life space” (p. 103). The “assumptive world” is defined as:

*... the only world we know and it includes everything we know or think we know. It includes our interpretation of the past and our expectations of the future, our plans and our prejudices.*

Murray-Parkes (1971 p. 103)

The loss of the “assumptive world” is highly disconcerting (Selder 1989). As stated by Harris (2010), the majority of us move through life without thinking about our “foundational assumptions” (p. 240). Since transition often challenges these assumptions it can result in a situation where the world as it known, no longer “makes sense” (p. 240). Bedar (2005) makes the point that a person’s known reality is critical to “grounding, stabilising and orientating” them (p. 255). The loss of a known reality provokes feelings of fear, anxiety, “uncertainty” and “disorder” (Zizzo et al. 2020, p. 2) (see also Selder 1989).

### **3. Adapting to Transition**

Adapting to the external “outer” (Golan 1981, p. 17) change events that initiate transition, demands that the individual negotiates significant processes of “inner change” (Golan 1981, p. 17). These “inner changes” occur at the deepest level and often involve an individual developing new ways of “looking at the world” (Golan 1981, p. 17). Amando and Ambrose (2018) describe the shift in “paradigms, values and other internal representations” (p. 4) that often occur as individuals accommodate transition processes. The process of accommodating transition is often referred to as adaptation, which generally occurs incrementally and *over time* (Grenier 2012).

Some theorists conceptualise the time taken in transition processes as segregated into a number of discrete phases. Within his classic anthropological work, Van Gennep (1960) envisioned transition as a process with a tripartite structure. Here, transition is seen as consisting of a “preliminal stage” whereby the individual is moved from his or her social situation; a “liminal” or in-between stage where the individual is in a state of ‘limbo’; and a “post liminal stage” where the individual adopts his or her new social situation (Tanner et al. 2015, p. 2058). Kralik et al. (2006) suggest that the

study of transition within the health care literature is often characterised by this three-part structure (see for example, Froggatt 1997). The work of Davies and Nolan (2003; 2004; 2005) discussed in earlier sections, adopts this three-part structure in terms of its analysis of care home admission experiences.

Studies of transition within the health care literature have explored the ways within which transitions are experienced temporally. A lack of consensus exists as to the ways within which time is 'played out' for those in transition. Whilst some theorists conceptualise transition as unidirectional, linear (Martin-McDonald and Biernoff 2002) and time bounded (Elmberger et al. 2002), others perceive transition experiences as more temporally convoluted with the process of adaptation occurring in a backwards and forwards motion (Glacken et al. 2001). Theorists like Meleis et al. (2000) and Schlossberg (1981) state that transitions are complex, multifaceted and highly unique experiences, shaped and impacted by numerous different factors. As such, the time needed for transition is often highly individualised and will differ from person to person (Selder 1989).

Meleis et al. (2000) studied a number of 'transition-types' in order to develop a 'middle-range'<sup>10</sup> theory of transition for nursing practise. These transitional experiences were broad-ranging and included, for example, "developmental transitions" (Meleis et al. 2000, p. 17) such as menopausal transition; "situational transitions" (p. 17) such as migration; and "health / illness transitions" (p. 17) such as those arising with the diagnosis of significant illness. Using the findings of these studies, these authors argued that transition experiences differ on the basis of a number of different factors called "transition facilitators" or "inhibitors" (p. 21). Transition "facilitators (or) inhibitors" include for example, structural factors such as socio-economic status, the levels of social or community support available to an individual and their levels of knowledge and skill (pp. 22-23). It is important to note that transitions are shaped by the "meanings" (p. 21) ascribed to them, which in turn

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<sup>10</sup> Roy (2014) states that middle-range theories differ from grand theories in terms of levels of abstraction and conceptualisation. Middle-range theories focus on a given phenomena and aim to influence practice in specific and concrete ways (p. 208).

are influenced by “cultural attitudes and beliefs” (p. 22) (see also Chick and Meleis: in Chinn 1986; Goldsworthy 2005; Amando and Ambrose 2018). Meanings matter, because they are likely to shape perception (Chick and Meleis: in Chinn 1986). When transitions are perceived negatively, the process of adaptation is often more complex and challenging. Meleis et al. (2000) make the point that transitions are often perceived in negative ways when they are related to stigmatised events. There is no doubt that care home admission is one such stigmatised event. As discussed in earlier sections, many informal carers experience feelings of guilt and shame in relation to care home admission, on account of the fact that families and more specifically, women, are expected to care for their older kin within contemporary British society.

According to Selder (1989), it is critical that individuals maintain the integrity of the self if they are to successfully adapt to transition experiences. Within this thesis, I explore the ways within which informal carers seek to maintain their sense of self at times of care home admission, through undertaking continued caregiving roles and responsibilities. In exploring the importance of continued caregiving, I draw upon the work of Atchley (1999), Selder (1989) and Morgan (1996; 2011).

### **Atchley’s Work on Selfhood and Continuity**

Within this thesis, I draw upon the work of Atchley for two main reasons. Firstly, Atchley (1999) draws attention to the importance of ‘continuity’ as a means of managing and maintaining selfhood within transition. Atchley focused his work on the transition of ageing but his ideas are arguably applicable to other types of transition experiences. From Atchley’s (1999) perspective, a loss of selfhood is not inevitable at times of transition provided that individuals maintain a level of consistency or “patterns of sameness” (p. 2) within their roles, responsibilities and relationships. Roles, responsibilities and relationships are elements of what Atchley (1989) calls “external continuity” (p. 185) and it is argued that in maintaining external continuity, individuals likewise maintain a level of “internal continuity” (p. 186). Atchley (1999) argues that individuals achieve a “psychic pay off” (p. 11) when they maintain consistency in their external roles and responsibilities. Significantly, selfhood and identity are components of “internal continuity” (p. 186).

Atchley's (1989) work also offers insight into the various dimensions of the self. These dimensions are relevant to understanding the impacts of care home admission, upon the selfhoods of informal carers. Atchley (1989) views selfhood as socially constructed; he argues that an individual has an "ideal self" (p. 186), that is, a self that he or she would like to be. Atchley (1989) argues that individuals engage in processes of "self evaluation" (p. 186), where they measure their performance, against their "ideal self" (p. 186). "Self esteem" (p. 186) is the outcome of "self evaluation" (p. 186) and will be positive or negative, depending upon the extent to which, a person feels they have lived up to their pre-conceived ideal. See also Atchley in Birren et al. (1991).

Atchley (1989) argues that an individual's "ideal self" (p. 186) is shaped by social and cultural expectations. It is argued that individuals are assigned roles and responsibilities in accordance with specific social attributes such as age, gender and social class (Atchley 1982; 1989). As such, what people "think and feel" (p. 186) when focusing attention on themselves, is significantly influenced by the extent to which they feel they have lived up to dominant social and cultural expectations. When integrated with the work of Morgan (1996; 2011) and Selder (1989), Atchley's (1989) ideas on selfhood make explicit the impacts of informal carers' relinquishing their caregiving roles and responsibilities, during institutionalisation. They also highlight the importance of providing informal carers with opportunities for engaging with continued caregiving, in the time beyond care home admission. The work of Morgan (1996; 2011) and Selder (1989) is discussed in further detail in the following section.

### **Care as a Normalised "Family Practice"<sup>11</sup>**

According to Selder (1989), the selfhood of individuals is maintained in transition as they engage with processes of "normalisation" (p. 450). Normalisation occurs as individuals undertake "behaviours that mirror the standard established by the core society" (p. 449). Socially and culturally, family members are expected to care for

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<sup>11</sup> The notion of 'family practice' is taken from the work of Morgan (1996; 2011), who sees families as more defined by their roles and activities than their living arrangements.

their older kin (Becker and Charles 2006; Ribbens-McCarthy 2012). As seen in earlier sections, the notion of family carries a moral dimension; it is often idealised and seen as a place where caring expectations are realised (Comas-d'Argemir and Soronellas, 2019). A perceived failure to care (as within situations of care home admission) is often associated with high levels of guilt and shame.

Within this thesis, care is conceptualised as a normalised “family practice”. The notion of family practice is drawn from Morgan’s (1996; 2011) work, which conceptualises the family within contemporary society as characterised more by ‘*doing*’ than ‘*being*’. Pylyser et al. (2018) discuss the ways in which the notion of doing family was derived from the more fully theorised work on “doing gender”; here gender was seen not as an innate quality, but as constructed in and through day-to-day social interaction (West and Zimmerman 1987). Changes in family structure mean that families are no longer identified through conjoined living arrangements, but rather through ‘family-type’ behaviours and interactions (Hertz 2006). Since care is conceptualised as a typical, family-type behaviour, informal carers who continue to care, are thus seen to behave in family-type ways. The result is that feelings of guilt and shame are then potentially alleviated.

The theoretical perspectives presented within the preceding sections illustrate the potential impact of care home admission as a type of transition on the selfhoods of informal carers. They also highlight the importance of the continued caregiving roles and responsibilities of informal carers, in enabling them to retain selfhood and self-esteem within the context of care home entry. In light of these theoretical insights, it is understandable that so many informal carers should experience increased stress when unable to continue with their caregiving roles and responsibilities. It is interesting to observe that the role of third parties in facilitating informal carer - care home provider relationships is rarely discussed within the existing literature. I would suggest that this is because the vast majority of the literature is drawn from research within the field of nursing and that few nurses remain involved in working with older people and informal carers, beyond the point of admission. Significantly, the international social work literature highlights the valuable roles undertaken by social workers in mediating productive, collaborative informal carer – care home provider relationships (see Schwartzben 1992; Hansen et al. 1988). The literature related to the

roles and tasks of social workers in respect of care home admission is discussed within the following, final section of this chapter.

### **Social Work, Informal Carers and Care Home Admission**

My aim within this thesis is to explore the roles and tasks of social workers in respect of residential and nursing home admission. It was striking to find that despite the primacy of the social work role in respect of care home admission (see Chapter One), there is so little research focused on social work with informal carers at times of admission. This research is especially limited in a UK context. It is anticipated that the findings of this study will help address this important gap in the research literature in this area.

The limited available research has tended to explore the social work role in countries such as Canada and the USA. Whilst the findings of these studies are important in highlighting the *potential* of social work practice in this area, it is important to recognise that social work is organised very differently within international contexts (Richards et al. 2014). As stated by Kaplan and Berkman (2011), it is not unusual for care homes in Canada and the USA to employ a resident social worker. Due to practitioners being physically located within care homes in these countries, the authors of such studies see social workers as having important roles to play in meeting the psychosocial needs of older people and informal carers in long-term care settings (Fields et al. 2012). They also highlight the important roles of social workers in undertaking interventions, which foster and facilitate positive, post admission relationships (Bogo 1987; Schwartzben 1992; Hansen et al. 1988). It has also been argued that because of its “value system” (Katan and Bergman 1988, p. 51) the social work profession is well placed to foster interventions that promote the participation of older people in care home environments. Katan and Bergman (1988) see participation as critical to promoting the “self respect, individuality and self-determination” (p. 52) of older people living in residential and nursing homes. Significantly, however, social workers within the UK are not routinely located within care home settings (Ray et al. 2015) and so are arguably more limited in being able to undertake the kinds of roles and responsibilities described.

To reiterate, there are very few studies of admission-related practice with informal carers within a UK context. Those that are available, show that it is *precisely* the context of UK social work, which is problematic to the effectiveness of social work intervention in this area of practice. By way of example, research by Cotter et al. (1998) and Phillips and Waterson (2002), explores the social work role with informal carers in relation to care home admissions from acute hospital settings. Both studies, undertaken in England, show limitations in the levels of psychosocial support offered to older people and informal carers at such times, stating that the focus on “assessment and care management” processes (p. 253), minimises the therapeutic input of practitioners.

The findings of the international literature suggest that social workers have important roles in facilitating positive informal carer – care home provider relationships and in promoting the meaningful participation of older people within care home settings. In a discussion piece, Scourfield (2007) highlights, however, the very limited potential for social workers to undertake such roles within the UK. Due to the time-pressures faced by such practitioners, the duration of post-admission relationships is often very short, with many practitioners not even undertaking a post admission initial ‘review’. As a result, valuable opportunities for facilitating the participation of older people in care home environments and for building positive informal carer – care home provider relationships are then lost.

It is important to state that my review of the existing literature did not locate any Wales-based research, related to social work practice with informal carers at times of care home entry.

## **Research Questions**

This chapter has drawn out the key findings from within the existing literature on informal carers’ experiences of care home admission. It has explored the challenges of care home admission from an informal carer perspective, highlighting the very real stresses and anxieties experienced by many informal carers, both in the times preceding and following residential or nursing home entry.

As stated in Chapter One, care has a specific purpose, that of alleviating suffering and stress. As such, it might be argued that care home admission is a rich site for exploring practises of care within social work. This study aims to determine *how* exactly care works to ease the suffering and distress of informal carers within care home admission contexts and to explore the ways within and the extent to which, practitioners undertake their roles and responsibilities in “caring ways” (Engster 2005, p. 54). In line with these aims and objectives, I have developed the following research questions for the study:

1. What are the experiences of informal carers as they assist an older person to move into a long-term residential or nursing home setting? What sorts of roles and responsibilities do informal carers undertake at this time?
2. How might a care approach to social work practice make a difference to informal carers as they engage with care home admission processes?
3. To what extent do social workers approach their work with care? What factors might limit care within the contemporary context of social work practice?
4. What changes need to take place at both a policy and practice level to make social work more consistently caring?

As stated in Chapter One, care is an ambiguous, elusive and nebulous concept (Morse et al. 1990; Souriel 1997; Phillips 2007). In order to appreciate the potential of care to positively shape admission-related, social work practice with informal carers, it is necessary to explore the qualities and characteristics of care in fuller detail. Within Chapter Three, I move to explore these qualities and characteristics, through the specific lens of ‘ethic of care’ theory. I also examine the attributes of *care-facilitative relationships* and consider the social policy and legislative challenges to caring within social work practice.

## Chapter Three: The Character of Care

### Introduction

This chapter focuses on the work of formal care-givers and primarily considers what it means for social workers to undertake their caregiving roles and responsibilities *with care*. The body of literature related to ethic of care theory, has been fundamental to the work of this thesis. It has enabled me to think deeply about the purposes of care (*what* care aims to achieve), and to consider the significance of the qualities and characteristics of care in fulfilling these purposes. As stated in Chapter One, care is seen as having an “obligatory” (Vanlaere and Gastmans 2011, p. 161) character. Within this chapter I examine the characteristics of care and consider the ways within which these characteristics potentially lead to caring outcomes. I also begin to reflect upon the potential impacts of care, for admission-related social work practice.

It will be seen that care is delivered in and through relationships (Barnes 2012; Habran and Battard 2019) and this chapter considers the kinds of relationships upon which care is dependent. In exploring the attributes of what I will call *care-facilitative relationships*, the discussion draws upon the work of Buber (1970). Buber (1970) makes a distinction between two different modes of relating (“I-it” and “I-thou”), which offers a useful way of understanding the types of relationships potentially present within the context of contemporary social work practice.

Tronto (1994) argues that care is always shaped by context and the discussion considers the impacts of neoliberalisation upon levels of social work caring. In so doing, it pays particular attention to the ways within which time-pressures in social work have the potential to undermine the caring endeavours of practitioners. Here, I draw upon Adam’s framework for “the rationalisation of work time” (cited by MacBride-Stewart 2013, p. 560), through processes of “commodification”, “compression” and “colonisation” (Adam 1990; 1995; 2004). Within the final sections of the chapter, I draw on the ‘critical gerontological social work literature’ to consider what is known of the impacts of diminished care on older people and their informal carers.

## A “Care Full”<sup>12</sup> Approach to Decision-Making

Within the ethic of care literature, care is conceptualised as both an “ethical framework” and a “practical activity” (Holland 2010, p. 1665). As an “ethical framework” (Holland 2010, p. 1665), care is seen as a specific approach to decision-making and to begin this chapter, I consider the qualities and characteristics of care, which lend themselves to the effective resolution of complex, ethical dilemmas.

The ability to make good and effective decisions is a fundamental element of social work practice and is arguably particularly important at times of care home entry. As discussed in Chapter Two, many informal carers value shared and collaborative decision-making processes within situations of care home admission; they appear to want professionals to be actively involved in decision-making processes. That having been said, effective decision-making within such circumstances is not always easy from a practitioner perspective. The making of such decisions is often “complicated” (Tronto 1998, p. 17) and requires a balancing of “moral... technical... and psychological judgements” (Tronto 1998, p. 17) in intricate ways. The importance of a care approach to decision-making and to the resolution of complex, practice dilemmas has been highlighted elsewhere within the social work and ethic of care literature (see Vonk 1999; Clifford 2002; Juujarvi et al. 2020).

“The genealogy of care ethics” (Barnes 2012 p. 25) lies in the work of Gilligan (2003), who conceptualised care as an approach to moral decision-making. Gilligan (2003) described what she saw as gender-based differences in the resolution of complex, ethical dilemmas and identified two different approaches to the resolution of moral issues. As observed by Phillips (2007), Gilligan saw boys as resolving ethical dilemmas through a notion of rights and what Held (2006) calls the “fair and consistent application” of “abstract principles” (p. 15). Girls on the other hand, were seen as attentive to contextual detail when making such decisions; they adopted a “particularistic perspective” (Moore 1999, p. 1) and took account of the specific

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<sup>12</sup> “Care full” (Barnes 2012, p. 9)

features of an individual's circumstances. Gilligan (2003) termed the male approach to moral deliberation "an ethic of justice" and the female approach "an ethic of care".

Critically, an ethic of justice and an ethic of care adopt entirely different positions as to the importance of relationships in decision-making processes. In the interests of perceived objectivity and impartiality, the ethic of justice demands that decisions are made from a position of interpersonal detachment (Sevenhuijsen 1998). In contrast, those who approach their decisions with care are seen to prioritise relationships in a number of important ways. Firstly, Gilligan (2003) argued that those who make decisions with care, are mindful of the need to *preserve* relationships. Gilligan (2003) recognised the importance of relationships to psychological well-being and argued that decision-making processes should sustain (rather than undermine) the "web of connection" (p. 44); the relationships that individuals have, one with another. "Care full" (Barnes 2012, p. 9) decision-makers make decisions with a view to reducing the conflict that would otherwise cause longer-term harm to relationships (Wolfinger et al. 1999; Juujarvi et al. 2020).

Secondly, Gilligan (2003) saw relationships as the very *means* for resolving complex, ethical dilemmas. In Chapter Two I argued that the anxieties and stresses of informal carers were eased when they believed that they had made the right and best decision on behalf of their older loved ones. From Gilligan's perspective, relationships enable care-givers to contribute to decision-making processes, because they constitute a vital source of *understanding*. The discussions taking place within the context of relationships, were considered critical to shaping moral action because they promoted deep levels of insight and enabled decision-makers to grasp the specific details of the situations and circumstances of others. Dewar and Nolan (2013) refer to the kinds of discussions that lead to such understanding, as "caring conversations" (p. 1247), whilst Blaug (1995) highlights the importance of what he calls "communicative reasoning" (p. 429) in promoting effective, decision-making outcomes.

Gilligan also argued, however, that right decision-making outcomes depended not only on discussion and communication, but also on *feeling and emotion*. Understanding was seen as facilitated through the feelings and emotions generated within mutual, reciprocal relationships (see also Polkinghorne 2004; Held 2006). The ability of one individual to feel or to *experience* something of the pain and suffering

of the other is termed ‘empathy’ and empathy is seen as critical to genuine insight (Todres 2008). The importance of subjective empathy to understanding is numerously discussed within the care literature (see McKinnon 2018; Jeffrey 2020) with van Dijke et al. (2019) stating that: “empathy is a unique way to connect with others (and) to understand what is at stake for them” (p. 1282). From the perspectives of van Dijke et al. (2019), the understandings acquired through subjective empathy are fundamental in helping “to... guide moral deliberation” (p. 1282).

Gilligan’s (2003) work has not been without its critics. Insofar as care is seen as the province of female thinking, feminist writers have viewed her theories as “essentialist” and as reinforcing gendered stereotypes (see Tronto 1994; Williams 2001). In recognising the importance of relationships and relational empathy to decision-making however, Gilligan’s work has challenged long-held assumptions concerning the importance of interpersonal detachment in moral decision-making. Ingram and Smith (2018) state that prior to Gilligan’s work, Kantian<sup>13</sup> notions of morality, which stressed “rational thought and self-determined action” (Banks (2021, p. 46) had stood almost unchallenged (see also Tronto 1994; Sevenhuijsen 1998; Parton 2003; Featherstone in Gray et al. 2010). Building on Gilligan’s work, others have since advocated the virtues of “relational autonomy” (Sherwin and Winsby 2010, p. 182), which recognises the “socially embedded nature” (p. 182) of decision-making processes.

### **“Care Full” Caregiving Practises**

As a practise, care is concerned with the direct actions needed in meeting the needs of individuals (Tronto 1994). Care ethicists claim that if practises of care are to achieve the *purposes* of care, then they must do much more than simply meet the “basic physical needs” (Engster 2005, p. 53) of care-receivers. Instead, it is argued that

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<sup>13</sup> Kant developed a “moral philosophy based on human reason, founded on the ultimate principle of respect for persons” (Banks 2021, p. 46). From a Kantian perspective, we should treat others as those with choices and desires. We should also conceive of them as *capable* of making decisions, consistent with those choices and desires (Banks 2021)

caregiving should also ease “suffering or pain” (p. 53) and promote the “well-being” (p. 51) and “flourishing” (Barnes 2012, p. 9) of individuals and families.

In highlighting the ethical characteristics of caregiving *with care*, I draw upon the work of Tronto (1994). Tronto developed a framework for maintaining the “integrity” (p. 136) of care. This framework has been used by other theorists in the analysis of care in social work practice (see Brannelly 2006; Holland 2010). I discuss these ethical principles in some detail because I draw on them in my subsequent data analysis.

Tronto (1994) conceptualised care as a process, comprised of four interrelated phases within which are embedded four ethical virtues or principles:

<b>Phase of Caring</b>	<b>Ethical Virtue</b>
“Caring About”	“Attentiveness”
“Taking Care of”	“Responsibility”
“Caregiving”	“Competence”
“Care-Receiving”	“Responsiveness”

Table 3. Tronto (1994) Framework for Ethical Caring (pp. 105 – 134)

The first ethical virtue to which Tronto refers is that of “Attentiveness” (p. 127). Attentiveness highlights the importance of the *ways* that care is given. From Tronto’s perspective, care must be given in such a way that care-givers show that they genuinely “care about” (p. 106) those with whom they work. Indeed, it is these expressions of care that are considered fundamental to alleviating an individual’s feelings of suffering and distress (Gray 2010).

Like other care ethicists, Tronto sees care as about more than care-givers undertaking instrumental tasks, to meet physical need. Whilst these tasks may be important, they

are not sufficient to maintaining the overall “integrity” (p. 136) of care. Tronto (2015) uses the example of a child who falls and hurts his knee. She argues that the purposes of care are not achieved simply through a care-giver bandaging the child’s injured knee. On the contrary, if the care-giver is to care *well*, they must also attend to the child’s likely feelings of emotional distress at having sustained a physical injury:

*“...the skinned knee of a child who fell off his bike isn’t only about scrapes and germs, it is also about creating the conditions for him to feel safe in the world”.*

(Tronto 2015, p. 4)

Tronto (1994) conceptualises attentiveness in terms of noticing or recognising the needs of others. She states that if “we are not attentive to the needs of others, then we cannot possibly address those needs” (p. 127). As illustrated in the above extract, Tronto (2015) sees a care approach as maintained when care-givers recognise and attend to the emotional needs of individuals as well as to their physical harms; when they “create the conditions” (p. 4) for those persons “to feel safe in the world” (p. 4). It is important to recognise that some needs are more visible than others (physical needs might be more immediately noticeable than psychological needs, for example) (Hall 1990). Attentiveness to the full impacts of a person’s situation (both physical and psychological) shows “caring about” (Tronto 1994, p. 106) because in a “complex modern” (1994, p. 127) world, there is great potential to overlook the needs of others. From Tronto’s (1994) perspective, ignoring these needs would constitute a serious moral failing.

Klaver and Baart (2011) elaborate upon the ethical concept of attentiveness, seeing it as a multi-faceted concept with various dimensions. Here, the word “attentiveness” is used qualitatively and as a way of describing a care-giver’s approach to undertaking their caregiving tasks. When performed attentively, such tasks are undertaken with focus, perseverance and “diligence” (p. 688). To borrow from Tronto’s (2015) earlier illustration, the care-giver attending to the injured child would bandage his knee in a careful, heedful and thoughtful way. He or she would ensure that the task was undertaken to the best of his or her ability, so as to maximise the potential for physical healing. In attending to the task in such a way, the care-giver would arguably show

“caring about” (Tronto 1994, p. 106) the well-being of the child; he or she acts in such a way, so as to minimise the risk of longer-term, physical harm.

Klaver and Baart (2011) also describe what they see as “beneficent attentiveness” (p. 690). Beneficent attentiveness is not instrumentally-orientated; it is simply attentiveness for the sake of attentiveness” (p. 690). It is a way of care-givers *being* in interaction with others. When care-givers act in beneficently attentive ways, they seek to show concern and solicitude towards others and to act in ways that express the perceived value and worth of that other person (Swanson-Kaufman 1986). Thus, the care-giver might, for example, speak kindly to the injured child when bandaging his knee (to soothe and comfort). He or she might also engage in “small acts of kindness” to help show the child that he is “valued” (Hay 2019, p. 269), such as offering the child a sweet, for instance. Acts of beneficent attentiveness constitute a visible means of practitioners expressing “caring about” (Tronto 1994, p. 106) within their work, and are often associated with a “gift of care” within the ethic of care literature (Bolton 2000; Brinkman 2008; MacBride-Stewart 2014).

Expressions of care are important because they show that care-givers *understand* the anxiety-provoking circumstances of others (the care-giver shows that s/he understands that the child is frightened because he has fallen, for example). Understanding helps achieve the purposes of care; it helps alleviate suffering and distress because it enables care-receivers to feel less alone within their situations. Benner and Wrubel (1989) make reference to a “gift of understanding” (p. 13) within their work, arguing that understanding eases feelings of fear and anxiety because it “moves back... walls of isolation” (p. 11). The importance of understanding as a caring attribute is highlighted elsewhere within the care literature, with Halpern (2001) and Peacock and Nolan (2000), drawing attention to the therapeutic or cathartic impacts of understanding.

The work of Tronto (1994) and Klaver and Baart (2011) shows that care is about both doing *and* feeling, action *and* affect. To care well, care-givers must feel something for those with whom they work; they must have concern and compassion for their situations. The importance of emotion and affect to effective caregiving is discussed extensively within the care literature (Graham in Finch and Groves 1983; Waerness 1984; Vonk 1999; Lachman 2012; Hirvonen and Husso 2012; Tronto 2015; Molterer

et al. 2019), and is encapsulated in Hochschild's (1983) concept of "emotional labour" (p. 7). Emotional labour refers to as the work or labour needed "to induce or suppress feeling" (p. 7) with the aim of promoting the correct emotional climate for care.

Klaver and Baart (2011) make reference to "practitioners of presence" (p. 687). These practitioners aim, above all else, to build meaningful relationships with those with whom they work. They do so, through a "presence-orientated approach" (p. 687), which embodies caring, attentive behaviour. Practitioners of presence show that they care because they engage wholeheartedly with the concerns of others. These expressions of care are then critical to building meaningful relationships (Tronto 1994). Reid et al. (2015) argue that relationships are built within situations where care-givers show "caring efficacy" (p. 905) towards those with whom they work. "Caring efficacy" is defined as the "ability... of a person to convey a caring orientation and to build up caring relationships" (p. 905). Tronto (1994) sees relationships as critical to caring, because they ensure the enactment of the other caring virtues or ethics to which she refers within her work. These other ethics are: "Responsibility" (p. 131), "Competence" (p. 133) and "Responsiveness" (p. 134)).

Responsibility has to do with the extent to which practitioners involve themselves in their caregiving roles and tasks. Not all caregiving tasks are undertaken with the same level of care, thus Lachman (2012) refers to a "continuum" (p. 122) of caring. In a similar vein, distinctions are sometimes made between a "duty of care" (Moss et al. 2015, p. 276), which meets needs and maintains safety at a minimum level, and ethical caring, that goes the "extra mile" (Hay 2019, p. 365). For Lachman (2012), a care-giver's location on the "continuum" (p. 122) of care will depend upon their feelings for and their "emotional involvement" (p. 112) in the experiences of the other. According to Brannelly (2006) the *feelings* of care-givers are critical to moving their work "beyond minimum standards" (p. 200) and to the point of caring "well" (p. 200) for individuals and families.

In ways analogous to the work of Gilligan (2003), Tronto (1994) sees emotion as a source of insight and understanding (see also Polkinghorne 2004; Held 2006; Todres 2008). Critically, as insight and understanding are increased, so too care-givers feel more *drawn* to care (Nortvedt 2001; Nortvedt et al. 2011). Levinas (1998) suggested

that individuals experience an increased sense of moral responsibility towards others within the context of feeling-generating, face-to-face relationships. He argued that whilst “all (persons) are responsible for one another” (p. 107), it is in the “face” (p. 107) of the other that feelings of moral obligation are awakened. The more a care-giver is drawn to care, the more he or she engages in caring action. As caring action is increased so too, the needs of the care-receiver are better met. In similar ways, Noddings (2003) states that caregiving that achieves the purposes of care, is given when one individual “feel(s) a stir of desire or inclination” (p. 9) towards another.

The ethic “Competence” (Tronto 1994, p. 133) is concerned with the outcomes of caregiving and the extent to which needs are genuinely met. In ways similar to Gilligan (2003), Tronto (1994) sees the competence of care-givers as increased, through the understanding acquired within discursive relationships. Tronto’s (1994) framework says much about the characteristics of relationships conducive to effective caregiving. Care-givers develop the kinds of understanding leading to competent care, through relationships that are mutual and reciprocal and that allow for the exchange of ideas on equal terms. It is argued that if caregiving is to be truly competent, care-givers must understand the needs of care-receivers *from their own perspectives*. Tronto (1994) expressed concern about power imbalances within practises of care, which are seen to increase the potential for “paternalism” (p. 145) (paternalism arises where care-givers assume superior knowledge and expertise and therefore ignore the perspectives of care-receivers). As stated by Kittay (2011) mutual, reciprocal relationships are fundamental to countering the potential for paternalism; they democratise caregiving through ensuring that care-receivers have an equal voice in the caregiving process.

The ethic “Responsiveness” (Tronto 1994, p. 134) is the fourth ethic of care to which Tronto (1994) refers in her work. It builds upon competence and states that we can only know whether care is *good care*, through evaluating it from the perspectives of those receiving that care. As such, Tronto (1994) sees reciprocal conversations and the relationships within which they are embedded, as on going and continuing over time. Since care is viewed as a process and as iterative in nature, Tronto (1994) argues that effective care demands “listening to and including (the perspectives) of care-receivers” (p. 172) *at all stages* of the caregiving process.

It is important to recognise that the needs of many individuals are transient and changing. As such, good care is achieved through on going, “situated assessment” (Molterer et al. 2019 p. 96) and through “processes of tinkering” (p. 96), which adjust caregiving in line with the altered needs and preferences of individuals and families. In a similar vein, Mol (2008) argues that care is not a “product” but an “action that goes back and forth” (p. 21) over time:

*Care is not a transaction in which something is exchanged (a product against a price); but an interaction in which the action goes back and forth (in an on going process).*

(Mol 2008, p. 21)

The ethic of responsiveness recognises that not all care is necessarily good care and it pays serious attention to the harms potentially arising, through inadequate caregiving. It is acknowledged that inadequate caregiving potentially exacerbates the vulnerabilities of care-receivers. As such, Tronto (1994) argues that care-givers must take responsibility for both recognising *and* challenging the conditions that undermine care in the course of their work.

Critically, Tronto (1994) sees the authenticity of care at the micro level, that is, at the level of face-to-face interaction, as shaped by macro level, socio-political and economic contexts (see also Dustin 2007). From such a perspective the extent to which care achieves its purposes is dependent, for example, upon political ideologies and the level of resources allocated to care. Within contexts where care is under-resourced there is potential for “parochialism” (Tronto 1994; 2010). Parochialism occurs when there are simply not enough resources to go around and where practitioners then perform their work with differing levels of care, in accordance with the quality of their relationships.

Whilst early care ethicists like Gilligan (2003) and Noddings (2003) saw care and justice as opposed (see Fine 2007), Tronto (1994) and others (Barnes 2012) view care and justice as inexorably linked. From the perspectives of these so-called ‘political care ethicists’, disparities within the quality of caregiving are unacceptable; they see *all people* as having the right to give and to receive good care. Within her later work (2013) Tronto added the principle “Solidarity” (p. 157) to her framework. As stated by Brannelly (2016), adherence to the principle of “solidarity” (p. 157) demands that

care needs are met in ways “consistent with (a) democratic commitment to justice” (p. 307). Care-givers who practise in accordance with the principle of solidarity seek out and challenge the injustices and inequalities that undermine the potential for “authentic caring” (Holstein et al. 2011, p. 128). The principle of “solidarity” (Tronto 2015, p. 36) demands that those who care “care enough *about* care to start caring *for* care” (p. 38).

Thus far I have argued that if care is to achieve its purposes, it demands adherence to certain ethical principles, largely enacted through the establishment of certain kinds of relationships. In light of the importance of relationships to care, I feel it is important to examine the qualities and characteristics of *care-facilitative relationships* in further detail. Before moving on to explore these characteristics, however, I will briefly discuss some of the literature on ‘relationship-based social work’. This body of literature is important because it highlights the significance of relationships to effective social work practice, in ways consistent with ethic of care theory. It is to the literature on ‘relationship-based social work’ that I now turn.

## **Relationship-Based Social Work**

Advocates of relationship-based social work view relationships as a critical source of understanding within social work practice (Howe 1998; Sudbery 2002; Trevithick 2003; Ruch et al. 2010; Munro 2011; Ingram 2013; Ingram and Smith 2018). Relationship-based theorists see relationships as fundamental to promoting the understanding of social workers in several ways. This work acknowledges for example, that it is often difficult for individuals to express their deepest feelings and emotional concerns in the absence of relationships. Howe (2008) argues that “safe” (p. 6), affective, caring relationships are fundamental to enabling individuals to express the kinds of sensitive emotions that might otherwise remain hidden:

*One of the hallmarks of a good relationship is that our feelings, however dark and distressing are recognised, understood and accepted by the other. If the relationship is a place where we can feel safe, then we can explore the thoughts and feelings that are distorting and disfiguring our lives.*

(Howe 2008, p. 6)

These expressions of feeling are clearly important in enabling practitioners to understand and to appreciate the impacts of the experiences of others.

Writers like Trevithick (2014) also emphasise, however, the importance of “gut feelings” or “intuition” (pp. 296-297), “attunement or empathy” (p. 294) to social work understanding. Empathy is defined as: “the ability to imaginatively feel the world from the other’s point of view and to successfully communicate that understanding” (Trevithick 2012, p. 194).

Due to its potential to heighten levels of understanding, empathy is considered important to the effectiveness of practitioner interventions. Hingley-Jones and Ruch (2016) make the point that when practitioners affectively feel something of the situations and experiences of another, they are more likely to respond to their needs with creativity and ingenuity:

*Adopting a stance that allows and encourages practitioners to ‘look beneath the surface’ in order to understand – to feel – the affective, irrational and unconscious aspects of practice and to simultaneously ‘think outside the box’.*

(Hingley-Jones and Ruch 2016, p. 236)

It is also important to note that as practitioners experience something of the feelings and emotions of others, so too their desire or motivation to act in caring ways is heightened. Perlman (1979) states that “it is no mere word play to recognise that ‘motivation’, ‘movement’ and ‘emotion’ all stem from the same Latin root, *movere*” (p. 71). Consistent with the ethic of responsibility within the work of Tronto (1994), feelings and motivations are considered integral to increasing levels of caregiving action from a relationship-based perspective.

Such writers also see relationships as an important means of addressing the emotional needs of individuals and families. Perlman (1979) states that if the needs of individuals are to be met in potentially satisfying ways, it is necessary for practitioners to be “sensitively responsive to the emotions with which the person’s

problem is charged” (p. 51). Drawing upon psychodynamic theory, Sudbery (2002) views relationships as critical spaces for psychosocial recovery. He argues that since many of the problems experienced by individuals are located within early relationships (particularly childhood relationships), relationships that are affirmative and responsive have significant corrective and restorative potential. Drawing on the psychodynamic concept of “transference” (p. 155), Sudbery (2002) argues that when individuals re-enact aspects of previously difficult encounters within the context of safe and accepting relationships (and when they receive a positive, assenting response to their emotions and behaviours), self-confidence will grow and therapeutic healing will take place.

The literature on ‘relationship-based social work’ makes explicit the importance of relationships to practitioners undertaking their roles and responsibilities “in caring ways” (Engster 2005, p. 54). It is important to understand, however, that not all relationships are *care-facilitative* and indeed, that some relationships explicitly undermine caring. Ferguson et al. (2022) recently made the point that relationships have “effects” (p. 2), for either better or worse. Consistent with this perspective, Broadhurst and Mason (2014), argued that there is never a time where the relationship (the “embodied occasion” (p. 584)) does not count. Relationships are always “co-constitutive” (p. 584) and each and every encounter has the potential to work either for or against the alleviation of suffering and stress. Within the following sections, I explore the characteristics of *care-facilitative relationships* with reference to the work of Buber (1970).

## **The Characteristics of Care-Facilitative Relationships**

In ways consistent with ethic of care theory, Buber (1970) saw relationships as having the potential to promote high levels of insight and understanding. For Buber, understanding within the context of relationship was critical to ensuring the avoidance of action on the basis of assumption. He argued that our assumptions are inevitably limited by our own experiences and are not therefore, conducive to meaningful action in the lives of others (“when we walk our way and encounter a man... who comes towards us walking his... way, we know our way only and not his...” (Buber 1970, p. 124).

However, Buber was also explicit that only *certain kinds* of relationships have the potential to lead to understanding and that other sorts of relationships actively work against genuine understanding. Buber (1970) makes reference to two modes of relating or interaction within his work, termed “I-it” and “I-thou” relationships. I-it and I-thou relationships are seen to differ significantly, both in terms of linguistic characteristics and in terms of levels of presence.

Linguistically, I-thou relationships are characterised by two-way, reciprocal modes of communicating. In order to explicate the linguistic characteristics of I-thou relationships as compared to I-it relationships, I make reference to research undertaken by Westerhof et al. (2013). The research was undertaken using participant observation and sought to explore the differing kinds of relationships existing between care-givers and older people living within nursing home settings. The authors identified two communication styles used by these care home providers when interacting with residents. The first, termed “person-centred communication” (p. 354) resembles the kind of reciprocal, two-way conversations characteristic of I-thou relationships. Here it is argued, that discussions are initiated with the intention of demonstrating “true interest in the uniqueness of the other person” (p. 356) and are “mutual, free (and) immediate” (p. 356). Zerwech (1997) refers to such dialogue as “genuine dialogue” (p. 260). “Task-centred” (Westerhof et al. 2013, p. 354) communication on the other hand is characteristic of I-it modes of relating, and is undertaken for the sole purpose of the completion of the task at hand. It is limited, perfunctory, pragmatic and “uni-directional” (p. 356).

Buber (1970) is explicit that relationships of understanding are relationships of *presence* (see also Candlin and Candlin 2018). Presence is an important concept within this thesis and may be understood in a number of ways. Being *physically present* over time is clearly important to the development of relationships (Olsson and Sundh 2019; Hay 2019). Time also allows for the continuation of the types of “caring conversations” (Dewar and Nolan 2013, p. 1247) discussed within earlier sections and therefore promotes practitioner understanding. As observed by Malone (2003), “physical proximity” (p. 2318) leads to “narrative proximity” (p. 2318), which in turn, leads to increased care-giver insight. However, when Buber writes of presence he is not referring to an individual simply being *physically* present within the physical

context of another; rather, he is speaking of a certain kind of intersubjective presence. Buber envisions I-thou relationships as “borderless” (p. 55), where one person enters the emotional, subjective world of the other. It is through these borderless relationships that an individual develops a deep, inner “connection” (Itzhaky and Hertzanu-Laty 1999, p. 19) with another, and that levels of subjective insight are then increased. Buber uses the term “encounter” or “confrontation” (p. 66) to refer to the high levels of intersubjective presence within I-thou relationships.

In exploring the impacts of differing levels of presence upon caring within social work practice, I refer to the work of Osterman and Schwartz-Barcott (1996). These authors describe a continuum of presence which moves from mere physical presence at the one end (where a person might be bodily present but psychologically absent from the context of the interaction), to a mid-point “partial presence” (p. 25) and ultimately, to “full presence” (p. 25). Those who are partially present use the encounter instrumentally; here, relationships are used for the purposes of fulfilling a practical function, but psychological distance is maintained. Those engaged in I-it relationships are partially present; they are “cool and distanced”, focused primarily on the task at hand and are preoccupied with their own agendas. Fully present practitioners on the other hand, “drop everything, their own agendas and priorities, prejudices and assumptions” (Schmidt Bunkers 2012, p. 10), to focus exclusively on the concerns of the other. There is much overlap between the concepts of presence and attentiveness (Osterman and Schwartz-Barcott 1996; Klaver and Baart 2011). Osterman and Schwartz-Barcott (1996) make the point that when interacting in “fully present” (p. 25) ways; practitioners show interest and genuine concern for those with whom they work through engaging in “attentive, listening behaviour” (Osterman and Schwartz-Barcott 1996, p. 25).

Whilst “partial presence” (Osterman and Schwartz-Barcott 1996, p. 25) is seen to impact negatively on psychosocial well-being, leaving individuals feeling interpersonally “disconnected and isolated” (p. 26), “full presence” is seen to have positive psychosocial effects. Here, the care-giver is seen as being both “there” and psychologically “with” (Fredriksson 1999, p. 1167) those for whom they care, with the result that feelings of isolation are diminished. Insofar as “being with” (Osterman and Schwartz-Barcott 1996, p. 26) alleviates feelings of fear and anxiety, Naef (2006)

views relationships of presence as *ethical* encounters. Naef (2006) describes those who are ‘with’ others in their distress, as “bearing witness” (p. 146) to that distress; such persons are seen as “present and attentive to the truth of another’s experiences” (p. 146).

It is important to recognise that it is not necessarily easy for practitioners to be “fully present” (Osterman and Schwartz-Barcott 1996, p. 25). Mitchell and Bunkers (2003) argue that there are emotional risks inherent in entering into and experiencing the worlds of others. Some practitioners will therefore withdraw from fully present relationships. The potential for “partial presence” (p. 25) within contemporary social work practice, is considerable. This thesis pays particular attention to the challenge of time within social work and to the ways within which time pressure, significantly shapes and impacts the quality of social work relationships. The challenge of time within social work is discussed in the following section.

## **The Challenge of Time**

Within the following sections, I explore the potential constraints to care within social work practice through the theoretical lens of time. Discussions of a perceived problem of time dominate much of the contemporary social work literature (Postle 2002; La Valle and Lyons 1996; Harlow 2003; Dustin 2007). However, the majority of this work fails to explore time *conceptually* and as a result, the true nature of the time-problem within social work is not sufficiently explored. This study adds to the limited social work literature adopting a conceptual analysis of time (see Holland 1999; Siegel 2001; Fahlgren 2009; Roberts 2017).

### **1. The Social Construction of Time**

Cipriani (2013) states that it is extremely difficult to grasp the concept of time because time constitutes such a taken-for-granted part of our daily lives (Adam 1990; 1995). However, it is necessary to appreciate that what has come to be seen as *time* within contemporary Western society (that is, time as linear, clock time (Adam 1995)) is in fact, a socially constructed *version* of time. Time theorists numerous draw attention to the ways within which specific constructions of time within individual

societies, enable the members of those societies to make sense of the different worlds within which they live (Davies 1990; Lovgren et al. 2010).

Conceptualisations of time as we know it, as: “regular, absolute, marching from left to right, from the past to the present, to the future” (Davies 1994, p. 277), arose with the emergence of industrial capitalism and later, wage-labour (Davies 1990). Time became a means of regulating the work of others (Lovgren et al. 2010; Olsson and Sundh 2019) and was considered critical to “productivity and performance” (Davies 1990, p. 27). Adam (1990; 2004) makes the point that time within Western capitalist society is “commodified” (or equated with money) and states that when time is seen as an economic resource, the pressure to save time (money) increases. With reference to the work of Adam (1990; 1995; 2004), time is seen as saved within industrialised contexts in two important ways. Firstly, time is “compressed” (Adam 1990) (time compression occurs where there is a sense of time literally speeding up (MacBride-Stewart 2013); the result is that workers experience a need to do more work, within less time (Brannen 2002). Secondly, time is “colonised” (Adam 1990), which means that time is conceptualised *only* in linear, chronological ways and the subjective dimensions of time are ignored within workplace policies and practises.

## **2. The Subjectivity of Time**

Stone (2012) makes the point that time as we live it, or “lived time” (p.1), is experienced *subjectively* and therefore differs from person to person; the lived experienced of time, is referred to as *temporality*. A child waiting for Christmas Day night, for example, experience time as ‘dragging by’. On the other hand, a person juggling the demands of paid employment and child-care may experience time as ‘flying past’; they perceive having too little time on their hands to do what needs to be done (Jones 2001). The perceived pace of time is referred to as “tempo” (Jones 2001, p. 156) and as the examples show, tempo will differ in accordance with “mood and occasion” (Hall 1983, p. 151). A further aspect of temporality is that of “timing” (Jones 2001, p. 155). Cipriani (2013) draws attention to the temporal concept of “kairos” (p. 9) or *when time*. As observed by Adam (1995), individuals inevitably live with a sense of time *when*; that is, a time when certain events *should or should not* take place, for example. *When* time is sometimes referred to in ways, which suggest that individuals intuitively know *the right time* for an event to take place.

### 3. Time and Care

Care theorists highlight the importance of time to care, with care often seen as a time-consuming activity (Davies 1990). The relationships upon which care is dependent both need and take time to develop (McMullin in McColgan and McMullin 2017). Habran and Battard (2019) make the point, however, that whilst there is a general acceptance of the importance of time to relationships, the “temporal dimension remains surprisingly absent from studies on caring relationships” (p. 78).

This study aims to address this gap in the research literature in this area. It draws upon Davies’ (1994) concept of “process time” (p. 277), to illustrate the importance of practitioners using time in specific ways, to build the kinds of relationships conducive to care. Davies (1994) argues that if care-givers are to undertake their roles and tasks with care, they must approach those roles and tasks with temporal *flexibility*. Gibson (1994) states that the ways within which care-givers use time, conveys important messages about what they value. It is argued that those with a “caring orientation” (Reid et al. 2015, p. 905) express value for those with whom they work, through attuning to their temporal subjectivities and performing care in accordance with their unique, subjective pace and timings (Klaver and Baart 2011, p. 687). It is this expression of care through time that then assists in the building of *care-facilitative relationships*.

It is also the case, however, that time is rarely used in “process time” (Davies 1994) ways, in contexts of institutional caregiving (see Jones 2001; Lovgren et al. 2010; MacBride-Stewart 2013; Hirvonen and Husso 2012; Tufte and Dahl 2016). Olsson and Sundh (2019) refer to the “commodification” of time within social work, which increases perceptions of work pressure and hence practitioner stress. Yuill and Mueller-Hirth (2019) refer to the ways within which the commodification of time within social work practice has increased “paperwork time” and hence diminished “compassionate time” (p. 1532). The result is that practitioners are seen as less able to perform their roles and responsibilities in relational, caring ways. Yuill and Mueller-Hirth (2019) highlight a “temporal conflict” (p. 1533), (a ‘clash’) between organisational or institutional time and the time needed for effective caregiving.

It is important to recognise that the extent to which social workers care in the course of their work, is influenced by *'the time'* and context of their particular practice (Yuill and Mueller-Hirth (2019). Yuill and Mueller-Hirth (2019) make the point that there was a time when social workers had “much greater freedom” (p. 1539) and far greater temporal flexibility in undertaking their work. These authors draw attention to the “looser and more fluid temporalities” (p. 1539) of social work in Britain in the 1970s, prior to the “neoliberal restructuring of welfare systems” (Ward in Barnes et al. 2015, p. 45).

Social work is not a static endeavour; rather it is shaped and is “constructed through political processes” (Payne 2000, p. 82) (see also Phillips and Waterson 2002; Harris 2003; Hyslop 2018). As stated in Chapter One, this thesis focuses on the changes in social work arising through the neoliberal projects of the New Right<sup>14</sup> Conservative government. Matarese and Caswell (2018) define neoliberalism as “an ideology that manifests itself in many ways, including privatisation, decentralisation and integrating business ideologies and market rationalities in non-businesses” (p. 715). This study explores the impacts of neoliberal ideologies upon levels of social work caring; focusing in particular, on the ways that such ideologies, have reshaped social work relationships (see Postle 2001; 2002; Harlow 2003). It is to the impacts of neoliberalisation on social work that I now turn.

## **Care in the Time of Neoliberal Social Work**

The National Health Service and Community Care Act 1990, was introduced by the neoliberal, New Right, Conservative government and applied to both England and Wales. It provided a critical means for the ‘outplaying’ of neoliberal ideologies and

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<sup>14</sup> The ‘New Right’ is a political philosophy associated with the Conservative government (1979-1997). The New Right advocated many neoliberal ideals; it rejected the role of the welfare state for example, seeing this as undermining competition and creating dependency (Denney 1998) and advocated free market principles (Baldock et al. 2003). However, the New Right Conservative government also combined neoliberal ideologies with “neoconservative” (Lister 2010) principles. From a neoconservative perspective “social institutions such as the family and community and values and responsibility” (p.42) are considered critical, to upholding morality.

imperatives. As stated in Chapter Two, the legislation fundamentally challenged existing ideas about responsibility for care. Ward (in Barnes et al. 2015) states that the Act: “eroded the conditions of the post-war social contract between states and citizen” (p. 45), replacing ideals of collective welfare responsibility with notions of self-care or self “responsibilisation” (Shamir 2008, p.1).

The New Right, Conservative administration had gained power in 1979, at a time of great economic uncertainty (Rogowski 2010) and the need to control public spending was high on the political agenda. The welfare state, premised upon Keynesian economics<sup>15</sup>, was seen as wasteful and inefficient (Harris 2003) and was therefore targeted in this ‘cost-cutting’ exercise. Dickens (2016) notes that neoliberal ideologies have their roots in the political philosophies of eighteenth and nineteenth century “libertarianism” (p. 40), which advocated a “minimalist... non-interventionist state” (p. 40). ‘Community care’ focused, health and social care policies diminished the role of the state in the provision of welfare and placed the responsibility for care firmly at the feet of family members, who then became an integral part of the so-called “mixed economy of care” (Hastings and Rogowski 2015, p. 24). As observed by Tronto (1994), the role of the State was to step in and provide support, only in situations where families were considered to fail in their caring responsibilities.

Neoliberal ideologies altered both the relationship between the State and its citizens (Ward in Barnes et al. 2015) and the nature of micro-level social work interactions, through processes of managerialism. Following the implementation of the National Health Service and Community Care Act 1990, these relationships were described as “impersonal and brief” (Harlow 2003, p. 33) and as “time constrained and task-orientated” (Tsui and Cheung 2004, p. 440). As stated by McLaughlin in McColgan and McMullin (2017), “new public management, also known as ‘managerialism’, first

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<sup>15</sup> Keynesian economic thinking underpinned the post-war welfare state and viewed economic investment as the most appropriate means of overcoming economic challenge. Here, the economy was ‘pump-primed’ through for example, the payment of pensions, which was then seen as allowing a significant proportion of the population to re-invest in goods and services; hence promoting economic growth (Johns, 2011).

came to prominence in the UK under the New Right, Conservative government” (p. 33). It was seen as an “organisational model for implementing neoliberal ideology” (Matarese and Caswell 2018, p. 715). Tsui and Cheung (2004) suggest that managerialism has three main ‘strands’: *markets*, *managers* and *measurement*. In the following sections, I explore the ways within which the elements of managerialism (markets, managers and measurement) have reshaped relationships within social work practice.

## **Markets**

Consistent with traditional liberalism, neoliberalism advocated the virtues of the “self-regulating function of the market” (Pendenza and Lamattina 2019, p. 102) as the most secure means of ensuring economic prosperity. In reducing the costs of welfare, the Conservative government sought to break the perceived monopoly of public services and introduced quasi-markets into welfare provision (Harris 2003). Local Authorities were reconceptualised as commissioners rather than providers of services (Juujarvi et al. 2020) and efforts were made to promote a “flourishing independent sector” (Department of Health 1989 p. 5) in an attempt to ensure cost-efficiency (Tsui and Cheung 2004, p. 438). Competition between providers was seen as critical to ensuring that the costs of service provision were driven down (the place of any provider within the economic market depends upon their ability to deliver goods and services more effectively and efficiently than their next competitor) (Johns 2011).

The ideological appeal of welfare markets was promoted through reconceptualising individuals and families as social care consumers. These consumers were seen as having the power to choose between services and to identify those most appropriate to their particular needs and circumstances (Ward in Barnes et al. 2015). Critically, the success of the social care market depended on conceiving individuals as “unattached, self-responsible market players” (Pendenza and Lamattina 2019, p. 100). Markets work because individuals are seen as able to make decisions and choices autonomously; in a spirit of competitiveness, they are seen as able to act in their own best interests with minimal, outside interference (Barnes 2012).

Ideologies of managerialism, arguably render the need for discursive, relationship-embedded decision-making processes, obsolete. Insofar as individuals are conceived

as autonomous decision-makers, the role of social workers within decision-making processes is seen as a simple provider of information. Mol (2008) states that: “the ideal of patient choice presupposes the need for professionals who limit themselves to presenting facts” (p. 14).

## **Managers**

Proponents of managerialism believed that good management was key to the efficiency and effectiveness of organisations (Harris 2003; Tsui and Cheung 2004; Rogowski 2010). As stated by McLaughlin in McColgan and McMullin (2017), managerialism transported “business techniques and practise from the private sector to the public sector” (p. 33) with the aim of promoting value for money.

As an approach to social work practice, managerialism was seen to maximise efficiency through what Blaug (1995) calls, the increasing “bureaucratisation of social work practice” (p. 424). Blaug (1995) points out that “bureaucratisation” (p. 424) became a means of governing the work of practitioners; it sought to “flatten out the differences between individual performances” (p. 426) through standardising assessment processes, and functioned as a means of removing partiality and emotionality from decision-making processes (Meagher and Parton 2004). Rogowski (2010) and others (Lymbery 2001; Carey 2003; Harris 2003) highlight the ways within which social work assessments became a means of ensuring that practitioners were drawn into a ‘money-saving’ mind-set and worked in cost-sensitive ways. Lymbery (2001) argues that social workers were allocated a “gate keeping” or “rationing role” (p. 275) and Simic (2008) observes that in undertaking their work in accordance with the demands of budgets, practitioners needed to acquire certain kinds of “hard bargaining skills” (p. 12). Completing their tasks in such ways demanded that practitioners maintain relational distance and “impersonality” (Meagher and Parton 2004, p. 13). Thus, it is stated that:

*The ideal new manager remains distant and controlled. He takes a critical stance towards the arguments presented and the established practises of others, drawing his own conclusions based on designated general decision rules (risk assessment, cost benefit analysis and so on)*

(Meagher and Parton 2004, p. 14)

It is important to recognise that managerial practises were also introduced to address the perceived inadequacies of practitioner decision-making, which was considered to be “insufficiently rigorous” (Munro 2010, p. 12). As stated by Blaug (1995), the profession had faced several high profile, public enquiries into the deaths of children. Due to its potential for standardising the work of practitioners, managerialism was seen as fundamental to reducing the discretion of social workers and was therefore considered a vital means of controlling uncertainty and minimising risk (Dustin 2007; Trevithick 2014).

Meagher and Parton (2004) argue that social work in the neoliberal era, functions in accordance with a “masculine” (p. 13) ethic of justice, rather than a feminist ethic of care (see also Holland (2010) and Juujarvi et al. (2020)). “The bureaucratic approach emphasizes formality and distance in rational decision-making” (Meagher and Parton 2004, p. 13); it prizes “impartiality and impersonality” (p. 13) and marginalises “the relational and contextual dimensions” (p. 13) of the work of practitioners. Indeed, it has been argued that within contexts, which prioritise “objectivity and the technical aspects of social work” (Alexander and Charles 2009, p. 6) warm, reciprocal, empathic relationships might appear inconsistent with “ideals of professional behavior” (p. 5) (see also Muzicant and Peled 2018).

It is important to state that managerialism also strengthened the power of managers, through the introduction of what McLaughlin in McColgan and McMullin (2017) calls “a technology of care, known as care management” (p. 34). As stated by Dustin (2007), care management took apart the “component elements” (p. 23) of the social work task, with individual social workers (often in different teams) each then being given responsibility for a part of the overall process. The disaggregation of work roles and responsibilities in such ways was considered important in improving overall efficiency (Dustin 2007). Nevertheless, it was also considered a means of “managers gaining power” (p. 23). As observed by Dustin (2007), when work is organised in such ways, managers “are the only ones with a perspective on the whole process” (p. 23). It is important to recognise, however, that the division of social work tasks between individuals and teams, has also resulted in the fracturing of social work relationships, in ways that potentially undermine the provision of effective care (Carey 2015).

## Measurement

Finally, organisational efficiency was also ensured through processes of measurement. Following the introduction of managerialism, organisations were subjected to a “raft of disciplinary measures” (Ellis et al. 1999, p. 267) such as “performance indicators, cost centres (and) customer surveys” (p. 267); all designed to ensure that they worked in efficient and cost-effective ways. Carey (2003) states that “bureaucratic procedures” (p. 128) were a fundamental part of care management processes and enabled middle managers to oversee the work of front-line, social workers. The “completion of forms” (Carey 2003, p. 128) allowed a “surreptitious but effective form of surveillance” (p. 128).

Many social work theorists have highlighted the fact that practitioners faced significant increases in their administrative responsibilities following the implementation of the 1990 legislation. These increases in paperwork tasks were seen to detract from the time available for building relationships with individuals and families. Broadhurst and Mason (2014) state that many practitioners were “tethered to their computer workstations... at the expense of investing in the skills of direct work” (p. 579). Such findings are strongly affirmed elsewhere within the social work literature (see Lewis et al. 1997; Stanley 1999; Postle 2001; Weinberg et al. 2003).

The effects of managerialism have been enduring, persisting to the present day through the policies and practises of successive governments (see Meagher and Parton 2004; Butler and Drakeford 2005; Stepney 2006; Banks 2011; Burrows 2018). Nevertheless, it is important to recognise that there are important differences in the social care policy landscapes of England and Wales since democratic devolution. As I stated in Chapter One, one of the aims of this thesis is to consider the care home admission experiences of informal carers, living in Wales. These experiences are inevitably shaped by the practises of social workers in Wales and as I have argued in the previous sections, the practises of these social workers in turn, are influenced by the political contexts within which they operate. The potential impacts of the Welsh social policy context are discussed in the following section.

## **Welsh Social Policy Context**

As stated by Williams (2017), the Social Services and Well-being (Wales) Act 2014 (Welsh Government 2014), was an “early Act” (p. 175) of the National Assembly of Wales after acquiring its primary law making powers. Some commentators have suggested that Wales “has adopted a more social-democratic (and less neoliberal) style of politics” (Williams 2011, p. 11) than its English counterpart. It has been argued for example, that whilst “choice and competition have been central planks of the English government’s health reforms and modernisation programme” that “Wales... (has) chosen a different path” (Hunter 2009, p. 489). There appears to be a greater commitment in Welsh policy to the principle of universal services fundamental to the post-war welfare state (Drakeford 2005). This post-devolution commitment to the provision of universal services may be seen for example, in the provision of free prescriptions in Wales (Welsh Assembly Government 2007).

There has been a particular emphasis in Welsh social policy on raising awareness of, and addressing the issues facing older people in Wales. In 2003, the then Welsh Assembly Government introduced a ten-year strategy for older people, which focused on increasing the voice of older people in decision-making (Welsh Assembly Government 2003). This strategy led to the development of a National Service Framework for Older People (2006) (Welsh Assembly Government 2006a), which sought to challenge age discrimination and notions of dependency, and to promote well-being and person-centred care. Wales was also the first country in the world to establish the role of an Older People’s Commissioner (Welsh Assembly Government 2006b). The role of the Commissioner is to champion and uphold the rights of older people in Wales.

At its introduction the Social Services and Well-being (Wales) Act 2014 (Welsh Government 2014), was greeted with a degree of optimism by social work academics (see Pithouse et al. 2018). With reference to older people in particular, the legislation required that services should have due regard for the United Nations Principles for Older Persons 1991 (United Nations 1991), which demanded a commitment to the participation of older people in society and the provision of respectful, dignified care.

It could be argued that there are other ways within which the legislation advocated principles that were broadly ‘care consistent’. The 2014 Act focuses for example, on the need for the participation of individuals and families in the planning and provision of care (encapsulated within the principle of “co-production”) (Welsh Government 2014). The principle of co-production champions a discursive and dialogic approach to assessment and social work intervention. Emphasis is also placed upon the importance of the quality of relationships between practitioners, individuals and families. The White Paper to the 2014 Act (Welsh Assembly Government 2011) states that relationships are critical to “enabling people to make the changes they need in their lives” (p. 24). Significantly, the 2014 Act pays attention to not only the physical needs of individuals and families, but also to their psychological and emotional well-being (as I discussed in earlier sections, care takes account of the emotional well-being of care-receivers, as well as their physical and instrumental needs). It is also the case, however, that despite the Welsh Assembly Government citing care management as “outmoded” (Welsh Assembly Government 2011, p. 24), and despite the aspirations of the 2014 Act aiming to improve social work practice, Burrows (2018) suggests that a care management approach still predominated in social work in Wales. I left social work practice in 2019 and concur with his views; care management still remained a key feature of the work of practitioners.

It has not been possible for me to evaluate the impacts of the 2014 Act as a part of this thesis. I undertook my fieldwork for this study in 2016, the point at which the aims and objectives of the then new legislation were being implemented into the work of the Local Authorities. As such, the practitioners engaged in this study, were still working in accordance with the requirements of the National Health Service and Community Care Act 1990. Nevertheless, the findings of this study remain important in highlighting the issues *faced* by practitioners at the time of the Act’s implementation. These findings also make explicit the problems to be addressed in making the aspirations of the Social Services and Well-being (Wales) Act 2014 (Welsh Government 2014), a reality in the practise of social workers. I continue my reflections on some of the social care policies of the Welsh Government in Chapter Nine of this thesis.

In the final sections of this chapter, I move on to considering the impacts of reduced care on social workers, older people and informal carers.

## **Reductions in Care from a Social Work Perspective**

There has been sustained criticism concerning the impacts of managerialism on social work (see for example, La Valle and Lyons 1996; Postle 2001; 2002; Carey 2003; Harlow 2003; Dustin 2007; Ray et al. 2009). Hyslop (2018) argues for example, that there has been a reduction in the “emancipatory elements of social work” (Hyslop 2018, p. 20). According to Drakeford (2014) and Hyslop (2018) there have been reduced opportunities for social workers to engage in practises like advocacy, which help tackle issues of social injustice. Challenging issues of social injustice is considered a defining feature of social work practice<sup>16</sup>. A loss of such roles is therefore seen to have had a significant impact on the identity of the profession.

Some commentators have raised concerns about the impacts of reducing caring, on practitioners. Dybicz (2012), Clouston et al. (2018), Hay (2019) and Engen et al. (2021) all state that caring has been central to the profession of social work since its inception, with Featherstone (in Gray 2010) arguing that the majority of would-be practitioners enter the profession because they have an interest in building relationships with and caring for others. A loss of opportunities for “authentic caring” (Holstein et al. 2011, p. 128), has therefore been associated with practitioners feeling

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<sup>16</sup> Brandon et al. (1995) argue that when social workers advocate for those with whom they work, they “press their case with influential others” (p. 1). Social workers may advocate either about “situations which either affect (individuals) directly” (p. 1) or they might champion the cause of wider issues, which if left unchecked, would adversely impact the well-being of individuals / groups within society. Brandon et al. (1995) make the point that advocacy has a ‘consciousness-raising’ and an ‘empowerment’ dimension; it should “increase the individual’s sense of power; help them to feel more confident, to become more assertive and to gain increased choices” (p. 1). Likewise, Scourfield (2021) states that advocacy involves both “influencing others” (p. 8) and increasing an individual’s “sense of power” (p. 8) over their lives. Practices of advocacy were “revitalised in the 1970s and 1980s as part of a new emphasis on human rights and active civil involvement” (Schmid 2019, p. 818).

highly dissatisfied in their work. Ingram and Smith (2018) argue that the inability of practitioners to make decisions in care-embedded ways, that is, through flexible discussion and dialogue and with feeling and *discretion*, has resulted in practitioners feeling deskilled and experiencing a loss of professional status.

Insofar as social work is orientated “towards and guided by ideals of care” (Engen et al. 2021, p. 34), an inability to care on the part of practitioners has been found to lead to heightened levels of what Fenton (2015) calls “ethical stress” (p. 1415). Ethical stress arises in situations where social workers are unable to practise in accordance with the core values and principles of their profession (see also Fenton 2020).

### **The Critical Gerontological Social Work Literature**

Advocates of critical gerontological social work see social work as theoretically well placed to meet the needs of older people and informal carers at times of transition (Small 2001; Asquith et al. 2005; Milne et al. 2014; Ray et al. 2015). Social workers are seen as having a “particular skill and knowledge set” (Ray et al. 2015, p. 1296), which enables them to work in situations of complexity and to assist individuals when facing emotionally challenging experiences. As stated in Chapter Two, transitions are both complex and emotionally challenging events. I argued there that the ways within which individuals respond to transition experiences are highly individual and will differ significantly, one from another. The interpersonal skills of social workers are critical to their developing the kinds of “deep” (Lloyd et al. 2014, p. 322) situated and contextualised understandings of a person’s circumstances, which enable them to respond appropriately to the needs of older people and informal carers, at such times.

However, it is arguably social work in its more ‘traditional sense’ that enables practitioners to ease the transition experiences of older people and informal carers in such ways. Ray et al. (2009) state that: “a managerialist model of social care (has) led to an erosion of the traditional values, skills and knowledge base of social work” (p. 3). Whilst managerialism has inevitably impacted all forms of social work practice, it is argued that its negative effects have been most fully experienced within the field of adult social care (McLaughlin in McColgan and McMullin (2017); Lymbery and Postle 2010). According to Ray et al. (2015), the “straitjacket of care management... (has) had the effect of suffocating practice with older people” (p. 1299).

Critical gerontological social work recognises the disadvantage experienced by many older people on account of ageist attitudes and assumptions. It has been argued that practises of managerialism exacerbate the already significant challenges faced by older people when accessing health and social care services (see for example ‘The King’s Fund’ 2000; Courtney et al. 2020). It has been argued that the ‘tick-box’ (Blaug 1995 p. 428) style assessments introduced via processes of managerialism, have detracted from the kinds of discussions that facilitate genuine understandings of the needs of older people and their informal carers. This lack of understanding makes it more likely that resulting social work interventions will be “inappropriate and unwelcomed” (Ray et al. 2015, p. 1304). There is also evidence that the pressures of financial restraint and the demand for adherence to strict eligibility criteria, have resulted in risk-dominated assessments of need. These assessments have focused on the “disability and dysfunction” (Sullivan 2015, p. 338) of older people and their situations at the expense of their strengths, resilience and coping mechanisms.

Ray et al. (2015) highlight the importance of the traditional “rights-based orientation” (p. 1304) of social work in countering such practises. At the micro level, critical gerontological social work advocates that practitioners build relationships with older people and their informal carers to allow for “care full” (Barnes 2012, p. 9), inclusive decision-making processes. More broadly, however, it also calls upon social work to become a more ‘campaigning profession’ and to develop the skills and capacity to challenge inequality and to promote the rights of older people at the macro level of social policy. Theorists highlight, for example, the profound risks of discourses of “successful ageing”. It is argued that in an effort to promote ‘self-care’ and ‘self-responsibility’, these discourses carry significant “moral connotations” (Lloyd et al. 2014, p. 326) and place “the onus” (Phillips and Burholt 2007, p. 189) for health and well-being, on older people themselves. Critically, they ignore the impacts of life-long structural inequalities upon the health and well-being of older populations (see also Wu et al. 2018; Doheny and Jones, 2021). Such literature sees social workers as having a vital role to play in challenging the adverse impacts of policies and practises that disadvantage older people and that systematically ignore the impacts of structural inequality upon their situations and circumstances.

In equipping social workers to practise in such ways, the critical gerontological social work literature is explicit regarding the vital roles of social work educators. According to Ray et al. (2009) the content of the social work curriculum has neither facilitated “interest in (working) with older people” (p. 14), nor has it prepared would-be practitioners to adopt the kinds of “rights-based” (Ray et al. 2015, p. 1304) perspectives critical to challenging the discrimination and oppression of older people. In countering this situation, Ray et al. (2009) advocate for the inclusion of the *critical* gerontological literature within the social work curriculum. Concerns have been raised that perspectives from ‘traditional’ gerontology, reinforce negative stereotypes (Baars 1991; Ray et al 2015) of ageing and construct processes of ageing as a social “problem” (Sullivan 2015, p. 335). This literature tends to ignore the ways in which negative attitudes towards older people are shaped in society. The critical gerontological literature, in contrast adopts what Silverstone (2005) describes as a “person-in-environment” (p. 337) perspective and seeks to “contest” (p. 355) the problematisation of ageing. Such literature reframes the experience of ageing; it takes account of the strengths, resilience and contributions of older people and illuminates the ways within which ageing processes, are complicated through negative stereotypes and ageist assumptions.

## **Summary**

Within this chapter, I have considered what it means for formal care-givers to undertake their roles and responsibilities *with care*. With reference to the ethic of care literature I have explored the ethics and virtues of “authentic caring” (Holstein et al. 2011, p. 128); the kinds of relationships upon which care is dependent; the potential constraints to practitioners caring within their day-to-day work; and the potential impacts of neoliberalisation in reducing levels of caring within social work practice. In the final sections of the chapter, I explored the potential implications of diminished caring from the perspectives of social workers, older people and informal carers.

Just as care must be given with care from an ethic of care perspective, so too it is important that research is undertaken in “care full” (Barnes 2012, p. 9), care-considerate ways. In Chapter Four, I now outline the methodology for the study, discussing the ways within which I sought to ensure a care-consistent approach to undertaking the research for this study.

## **Chapter Four: A Care-Embedded Research Praxis**

### **Introduction**

The ontological and epistemological positions described in this chapter have been influenced by (1) my intention to undertake social work research in ways consistent with the values of the social work profession, and (2) my aim to conduct my research in accordance with the principles and ethic of care. As stated by Herron and Skinner (2013), it is “paradoxical” (p. 1697) to *do* research about care without ensuring that research methodologies are embedded *with* care (see also Ward and Gahagan 2010; Brannelly 2018).

This chapter discusses the perceived advantages of a constructivist research methodology in ensuring a social work compatible and care consistent approach to undertaking social science research. Reflexivity is critical to ensuring that research is undertaken ‘with care’ (Herron and Skinner 2013) and in the discussion I make reference to the work of Barrett et al. (2020) to illustrate the ways within which I adopted an intentionally reflexive approach to both my data collection and analysis. The chapter discusses the specific methods of data collection used in undertaking the study, the process of seeking ethical approval, the ethical sensitivities and challenges encountered in undertaking the research, and my approach to data analysis.

### **Ontology and Epistemology**

Fisher (1991) and others (Braun and Clarke 2013) have compared and contrasted the ontology and epistemology of positivist, objectivist research with that of constructivist research. Research undertaken within a positivist, objectivist paradigm is embedded with certain assumptions about the nature of reality (“ontology”) and the most appropriate means of obtaining knowledge in relation to the social world (“epistemology”). As stated by Braun and Clarke (2013) positivist, quantitative research is underpinned by “realist” ontology (p. 27):

*Realism assumes a knowable world, which is comprehensible through research – that the truth (and there is only one) is ‘out there’ and can be accessed by the appropriate application of research techniques.*

(Braun and Clarke 2013, p. 27)

Positivist approaches to social science research acquire knowledge through “carefully constructed tools of... measurement and scaling” (Smith 2009, p. 39), with the aim of ensuring “accuracy... and replicability” (Smith 2009, p. 35). In an attempt to achieve perceived objectivity, such approaches advocate relational distance and separation between researchers and participants (Braun and Clarke 2013).

Realism is contrasted with “relativism” (Braun and Clarke 2013, p. 27). Relativist ontology underpins ‘constructivist’ approaches to social science research wherein realities (*plural*) are seen as “constructed (with) experience” (Fisher 1991, p. 15). Whilst there may be commonalities in experience, constructivists nevertheless see the ‘reality’ of a shared experience or “common environment” (Thyer 2010, p. 580) as inevitably differing in accordance with the unique perspectives of individuals (Rodwell 1998). The aim of constructivist research is to understand and to make known these differing perspectives and viewpoints (Thyer 2010, p. 580). Since the reality of an experience is often different from person to person, it cannot be understood apart from *engagement* with those persons. Thus Rodwell (1998) states that “useful understanding” (p. 8) is derived through researchers fully engaging with the experiences of “stakeholders and the context of the social problem under investigation” (p. 8).

I chose a constructivist approach to this study firstly, because I see a link between what Rodwell (1998) calls the “epistemological perspective of constructivism” (p. 4) and “the social work frame of reference” (p. 4). Like social work practice, constructivist approaches to social science research see reality as situated and contingent. Experience is seen as “context-bound” (Rodwell 1998, p. 8), with the recognition that the ‘reality’ of a given experience will differ from person to person and in accordance with the presence or absence of multiple mitigating factors. Both constructivist research and social work theorists also advocate the importance of discursive relationships in the process of knowing and understanding. As stated in Chapter Three, the importance of relationships in knowledge acquisition is championed by advocates of relationship-based social work. In contrast to positivist enquiry, there is no relational separation (“no subject-object dualism” (Rodwell 1998, p. 17)) within constructivist research. The researcher becomes the “primary data

gathering instrument” (Rodwell 1998, p. 57) and seeks to build a relationship with the research participant with the aim of ‘co-producing’ knowledge (Fisher 1991)<sup>17</sup>.

Secondly, constructivist approaches embody an ethic of care and are therefore consistent with “a feminist philosophy of social science” (McCormack 1980, p. 1). Webb (1993) makes the point that feminist research is not “simply the study of women” neither is it necessarily “undertaken by women” (p. 416), rather it is an approach to research that embodies a specific “set of (caring) principles” (p. 416). In maintaining consistency with “feminist values” (Fonow and Cook 1991, p. 89), constructivist research champions non-hierarchical, egalitarian relationships. As stated within the previous section, constructivist approaches actively seek to build upon the perspectives of those with direct experience of a situation or set of circumstances. From a care perspective, it is considered impossible to understand a situation or experience without firstly seeking the viewpoints of those directly involved within that situation or experience (Tronto 1994). Campbell and Wasco (2000) state that “emotionality” (p. 786) is also considered a specific trait of feminist modes of research enquiry. In contrast to positivist methodologies, emotional identification is seen as a critical means of understanding within constructivist research. As stated by Scott-Jones and Watt (2010), qualitative research draws upon

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<sup>17</sup> The activity of social work research is surrounded by debate concerning the best and most appropriate means of acquiring knowledge (Butler 2003; Parton 2003; Qureshi 2004; Smith 2009). Some social work researchers have questioned the legitimacy of positivist approaches to social work research (drawing attention to perceived inconsistencies between quantitative methodologies and the ethical values and principles of the social work profession (Everitt et al. 1992; Butler 2003; Strier 2007)). Webb (2001) argues that positivist methodologies are at odds with a profession where action is taken on the basis of “reflexive understandings (and) contestable meanings” (p. 68). It should be noted, however, that I am neither personally adopting this position nor dismissing the potential importance of quantitative methods to social work research. In the case of this study, qualitative methods enabled me to gather the kinds of rich, exploratory data critical to understanding the care home admission experiences of informal carers from their own perspectives. Much has nevertheless been written concerning the value of quantitative methods in social work research. For example, Teater et al. (2017) state that quantitative methods provide social workers with a “more rounded understanding of the scale, scope and impact” (p. 19) of the issues facing individuals and families. Such methods also help ensure the efficacy of intervention outcomes.

the emotions of researchers and these emotions are considered fundamental in ensuring a genuine appreciation of the experiences of others. The importance of “reflexivity” (Campbell and Wasco 2000, p. 786) is also highlighted within such research.

Herron and Skinner (2013, p. 1698) see reflexivity as critical to maintaining the integrity of “care full” (Barnes 2012, p.9) research. Barrett et al. (2020) conceptualise reflexivity as having two important elements. Firstly, a reflexive approach demands “a continual process of (researchers) engaging with and articulating (their) place... (within) the context of the research” (p. 9). Researchers inevitably bring their own preconceived ideas to the research process and must be explicit regarding both the “intended and unintended” (Barrett et al. 2020, p. 10) consequences of their “histories, values, assumptions and perspectives” (Braun and Clarke 2013, p. 37) upon the outcomes of their studies.

According to Barrett et al. (2020), reflexivity is especially important for those conducting “insider research” (p. 11). As stated in Chapter One, I had practised as a social worker for many years before commencing PhD study and had been involved in many situations of facilitating long-term care admissions. Whilst there are many potential benefits of insider research including for example, “a profound understanding of a particular phenomenon of the context in which it occurs” (Barrett et al. 2020, p. 11) (see also Fuller and Petch (1995) and McLaughlin (2007) for a discussion of the potential advantages of social work practitioner research), there are also possible risks aligned to such research. Delamont and Atkinson (1995) argue that ‘insider-researchers’ can be over-familiar with the context of the research to the extent that it can be difficult for them to ‘see’ what really lies in front of them. In countering this problem, Hamersley and Atkinson (1989) argue that practitioner researchers must develop strategies to make the familiar, “anthropologically strange” (p. 8). My strategies for distancing myself from the research and for ensuring a reflexive approach to undertaking this study are discussed in later sections.

Secondly, and as highlighted by Barrett et al. (2020), “challenging and articulating (the) social and cultural influences and dynamics” (p. 9), which shape particular

research contexts, is a fundamental part of reflexivity. Webb (1993) highlights the fact that as a post positivist methodology<sup>18</sup>, feminist research expresses a commitment to issues of social justice and seeks to examine the impacts of wider social structures on experience. Brown-Wilson and Clissett (2010) state that: “the constructivist paradigm (views) perceptions of reality (as) located in time and space” (p. 678). I wanted to ensure that this study adopted an authentically “person-in-environment” (Sullivan 2015, p. 337) perspective, one that acknowledges the ways in which subjective experiences are subject to the “social contexts in which (they are) formed” (Everitt et al. 1992, p. 20). I therefore adopted an intentionally critical and reflective stance towards the analysis of my research data, drawing on the “situational analysis” approach of Clarke (2005). A full account of my approach in analysing the data for this study is discussed within the “analysis section” at the end of this chapter.

## **Data Collection**

I used the following methods of data collection:

### **1. Ethnography**

According to Hammersley and Atkinson (2019), ethnographic research often requires that researchers spend significant lengths of time in the everyday settings of participants “watching what happens (and) listening to what is said” (p. 3). The process of “watching what happens” (p. 3) (that is, observation), is central to ethnographic modes of research (Bryman 2004; Gomm 2008). I identified observation as an important method of data collection within this study for several reasons.

Firstly, the majority of studies exploring informal carers’ experiences of care home admission have used in-depth interviews as a method of data collection (see Chapter Two). The literature review for the study showed that observation is very rarely used in researching the admission-related experiences of informal carers. It is also the case

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<sup>18</sup> Post-modernists state “it is no longer possible for a single methodology to be appropriate to study all topics, and call for a recognition of the limitations of traditional ways of doing science” (Webb 1993, p. 418)). Ways of knowing are seen as “inherently culture-bound and perspectival” (p. 418).

that ethnography has certainly not been used as a method of exploring social work practice with informal carers at such times, in a UK context. As such, this study makes an important and distinctive methodological contribution to knowledge.

Secondly, the use of observation as a means of data collection is seen as having numerous methodological advantages. According to Brewer (2000) observation within the context of ethnographic research allows researchers to “capture (the) social meanings and ordinary activities” (p.10) of the population under study, therefore, promoting a depth of understanding. Scott-Jones and Watts (2010) likewise draw attention to the quality of research data gathered through observational research, making reference to “a wealth of thick data” (p. 7). Proponents of ethnographic research, point to its potential to overcome some of the limitations of other methods of data collection. It has been argued, for example, that what people say they do within interview, and what they *actually* do in reality, can often be very different (Gomm 2008). Mulhall (2002) argues that observation helps expose areas of discrepancy between what is said and done, and therefore generates greater levels of insight and understanding.

In social work specifically, Ferguson (2016) makes the point that research has often “stopped short of getting close enough to practice to produce understandings of what goes on between social workers and service users” (p. 154). Observational methods have been seen as a viable means of enabling researchers to get ‘closer’ to the everyday realities of practice encounters (Ferguson 2016). The need to ‘get closer’ to what practitioners actually do is especially important when seeking to understand care practises within social work. As stated within Chapter One, much of the literature on care within social work is “speculative” (Banks 2008, p. 1243), meaning that there has been little focus upon actual performances of care within social work encounters (Hay 2019). I see observational and ethnographic methods as an important means of addressing this theoretical and methodological gap within the current research literature.

Scott-Jones and Watt (2010) make the point that from an ethnographic perspective, understanding is seen as acquired not only through observation but also through *participation* in the everyday lives and activities of individuals. It is important to clarify what is meant by participation within the context of ethnographic research.

Traditional ethnography has tended to conceptualise participation in accordance with models of the “fully immersed researcher” (Scott-Jones and Watt 2010 p. 7). When a researcher is “fully immersed” (p. 7), he or she becomes a complete participant in the context of the research study. In reality, however, the degree to which participation is possible will be dependent upon the context of the research and the subject matter of enquiry. As a researcher with a social work background, I was very mindful of the need to undertake participation *with care* in the course of this study. There were inevitably limitations to the extent to which I could participate in the care home admission experiences of informal carers and I did not feel it appropriate, for example, to accompany informal carers on visits in choosing a care home setting. These visits would no doubt have been insightful in supporting my understanding of the challenges of choosing a care home environment. It is important to state, however, that due to the geographical location of my research, there was every possibility of my already knowing some of the care homes and care home providers in a professional, social work capacity. In such situations, I anticipated it would be very difficult to remain impartial and to avoid influencing the decision-making processes of informal carers, if I had prior knowledge of potential ‘issues’ and difficulties with a specific care home setting.

My observations were instead intentionally focused upon discrete yet differing elements of the care home admission process. **Appendix A** provides details of the various observations undertaken during the course of data collection for this study. These observations included, for example: assessment visits; multi-disciplinary meetings; reviews of residential and nursing home admissions; monitoring visits; and safeguarding meetings. Two observations were also focused upon ‘Local Authority Panel Meetings’ where decisions were made regarding eligibility for funding at a Team Manager level. I felt it was important to include these observations in data collection as I wanted to determine the impacts of context (for example, financial austerity) upon care home admission, decision-making and authorisation. In various combinations, these observations involved participants from across each of the stakeholder groups (that is, informal carers; older people; social workers; care

managers<sup>19</sup>; managers of care home settings; and health care providers). In total, I undertook 18 separate observations between December 2016 and September 2017. The average duration of these observations was 1 hour 45 minutes (with the total accumulated ‘observation time’ for this study reaching 32 hours).

Observational research methods are not of course without their limitations. It is possible, for example, that participants will alter their behaviours when they are aware of being ‘observed’ and are in the presence of a researcher; the so-called “Hawthorn effect” (Goodwin et al. 2017). Mulhall (2002) also points out that ethnographers have extremely high levels of “freedom and autonomy” (p. 308) in the undertaking of their research and they are often unrestrained in terms of “what they choose to observe, how they filter that information, and how it is analysed” (p. 308). As a result, observational methods carry a high potential for *misinterpretation*. According to Hammersley and Atkinson (2019), the validity and reliability of research outcomes are increased when researchers employ multiple methods of data collection. In using multiple data collection tools, it is possible to “triangulate” the data (Denzin 1978). Triangulation refers to the process of “checking inferences drawn from one set of data by collecting data from others” (p. 198). Within this study (and in an attempt to overcome some of the issues highlighted), I combined observation with the use of semi-structured interviews and a small amount of documentary data.

## **2. Interviews**

As part of the process of data collection, I undertook interviews with informal carers, social workers and care managers, team managers and with a small group of care home managers. Undertaking interviews with different groups of participants was important and meant that I could compare and contrast (that is, triangulate) different stakeholders’ perceptions of the same or similar events.

A separate interview schedule was developed for each participant group, with slightly

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<sup>19</sup> Within the Local Authority where the research was undertaken, the title of ‘care manager’ was given to practitioners who undertook ‘social work-type’ roles but who had not undergone formal social work training.

differing areas of focus (see **Appendix B** for details of interview schedules). The interviews typically lasted between 30 minutes and an hour and a half in duration. Written consent was obtained from all participants prior to interview (including specific consent for audio recording). The interview was then transcribed verbatim for analysis. In total I interviewed twenty-eight people for this study.

### **i. Informal Carers**

Ten interviews were undertaken with informal carers and were an important means of capturing their “voices and stories” (Hennink et al. 2020 p. 117) within the research process. Whilst I developed an interview schedule for these informal carer interviews, it is important to state that this guide was used simply as a prompt and to remind me of the types of areas of discussion that might be important in shaping my understanding. My starting point in undertaking these interviews was to ask informal carers to simply talk about their experiences in their own ways (that is, what led to the care home admission, who was involved, what the admission ‘felt like’ at the time and afterwards, and so on). This type of interview is consistent with what Baver and Gaskill (2000) call “narrative interview” (p. 60). Baver and Gaskill (2000) argue that within narrative interviews, participants will focus upon what matters *to them* and that these interviews have high potential for “relevance fixation” (p. 60)). This allows researchers to see what is important from the perspectives of key stakeholders engaged in an event or particular set of circumstances and helps researchers to avoid imposing their own expectations upon an area of research enquiry. It is also important to state that these interviews were mostly undertaken following an informal carer’s participation in a research observation. This was important because it enabled me to ask questions about what I had seen and observed within those observations and therefore to check consistency with my own interpretation and understanding of the event.

### **ii. Social Workers, Care Managers and Team Managers**

As a part of this study, I also undertook interviews with six social workers and three care managers. I developed an interview schedule for these interviews and asked specific questions of the social workers and care managers with a view to understanding their perspectives of working within contexts of care home admissions.

These questions were framed as openly as possible in order to encourage practitioners to ‘talk freely’ about their experiences.

Later within the study, I recruited two additional social workers for interview. These social workers had a role exclusively focused on facilitating discharges from acute hospital settings. The purpose of the additional interviews was to give a more in-depth perspective of the experience of supporting care home admission from within the context of a health care environment. On the basis of my prior discussions with social workers and care managers within the generic adult social care teams, I had learnt that there were particular stresses associated with facilitating care home admission from acute hospital settings. I therefore wanted to explore these stresses (their source and means of resolution) in greater detail.

I also recruited two Team Managers to the study for the purposes of interview (up until that point, Team Managers had been engaged in the study for observation only). I wanted to explore some of the thinking behind the decision-making processes of Team Managers. I had witnessed these processes of decision-making in my observations of panel meetings, and I wanted to discuss in further detail their thought processes in allocating and approving requests for care home admission.

My recruitment of these additional participants was the outcome of processes of “theoretical sampling” (Birks and Mills 2015, p. 10). As stated by Charmaz (2014), when researchers engage in “theoretical sampling”, they “seek and collect pertinent data to elaborate and refine categories in (their) emerging theory” (p. 192). “Theoretical sampling” (Birks and Mills 2015, p. 10) is discussed in further detail in the “Analysis” section of this chapter.

### **iii. Care Home Managers**

I also undertook interviews with a small group of five care home managers. I felt that discussion with this group of stakeholders would offer important insights into the needs of informal carers at times of care home admission and beyond and the potential effectiveness of the roles of social workers within situations of care home entry. I also wanted to determine how care home providers saw their own roles in relation to informal carers (whether they appreciated an informal carer’s need for continued caregiving beyond care home admission, for example).

### **3. Documentary analysis**

The research involved analysis of a small amount of those documents produced by practitioners in the context of their admission-related work. In this case, documents were related to observed visits and included assessments, care home contracts, care plans and case recordings completed and relevant to the care home admission. It was anticipated that an analysis of the documents produced by social workers and care managers would offer insights into the meanings and motivations underpinning social work actions and interventions. (See **Appendix C** for details of documents analysed within the course of the research.)

#### **Access and Ethical Approval**

The processes of seeking appropriate ethical approval and negotiating access for the study were complex. On the basis of my own social work experience, I anticipated I would need to be present at a number of different observation sites when observing the admission-related work of practitioners (for example, in the homes of older people and their families, in hospital settings, and in residential and nursing home settings.)

Permission to undertake this study was sought from the relevant Local Authority and was authorised following meetings with the ‘Service Manager for Adult Social Care’ and discussions with the ‘Head of Service’. Since I had envisioned (and this was borne out in reality) that some of the observations would need to be undertaken within hospital-based settings, I also sought ethical approval from an independent Research Ethics Committee (REC) and from the local Research and Development (R&D) group within the relevant University Health Board. I had anticipated REC approval would be needed because some of those older people participating in the research might lack the capacity to consent to research engagement. My years spent as a practitioner within Adult Social Care, had taught me that many older people admitted to care home settings were diagnosed with dementia and were often at the more advanced stages of this illness. As previously discussed, the literature pertaining to residential and nursing home admission also makes explicit that the later symptoms of dementia are often a ‘trigger’ to care home entry (Annerstedt et al. 2000; Buhr et al. 2006; Hennings et al. 2013).

Due to anticipated issues around mental capacity, I decided against conducting interviews with older people as a part of this study. I was concerned that a formal ‘question and answer’ type interview might provoke anxiety amongst some of these older people. I nevertheless wanted opportunities to appreciate their perspectives regarding, for example, the importance of informal carers’ continuing caregiving beyond admission. In this respect, observation worked well. It allowed me to witness first-hand the very obvious pleasure of many of these older people when visited by informal carers and demonstrated the value they placed on continued contact with family and close friends. In the context of observation, I was also able to ask questions of some of these older people in a gentler and less direct way. These discussions help to provide important insights into the care home admission experiences of older people with dementia.

The Mental Capacity Act (2005) states that research involving those without the capacity to make informed consent is permissible, provided that there is clear justification for their involvement within the research study. The Code of Practice accompanying the Act defines “justifications” as potential improvements in the quality of care available to such individuals on account of the research being undertaken (p. 207). I anticipated that the involvement of these older people in the study, could lead to improvements in their care in a number of ways. Observation of the interactions between older people and informal carers following care home admission highlighted for example, the importance of the continued roles and responsibilities of informal carers within care home settings (see Chapter Seven). I was then able to make recommendations for social work practice in this area (Chapter Nine).

Where an older person was regarded as unable to make informed consent for research engagement, then in line with the requirements of the Mental Capacity Act: Code of Practice (2005), consent was sought from a ‘consultee.’ The Code of Practice defines a ‘consultee’ as follows:

*The consultee must be involved in the person’s care, interested in their welfare and willing to help. They must not be a professional or paid care worker. They will probably be a family member but could be another person (p.210)*

For the purposes of this study, it was decided that the informal carer of the older person with dementia would also act as ‘consultee’ in terms of consenting to the engagement of that older person within the study (specific information sheets and consent forms were devised for this purpose). However, in adopting this position, I also recognised the need for caution. Whilst it was accepted that in most cases, an informal carer would act in the best interest of the older person in terms of making decisions regarding participation within the study, I was nonetheless concerned that the needs of an older person might be overlooked where an informal carer was both ‘participant’ and ‘consultee.’ I considered, for example, that the prior wishes of an older person regarding research engagement might not be fully acknowledged when an informal carer was strongly motivated towards study participation. To help resolve some of these concerns, I adopted additional strategies of what Dewing (2007) calls “process consent” (p. 11). “Process consent” involved finding out about the older person’s preferences before research engagement and seeking to ascertain what he or she was able to understand of the research (its aims and objectives) (Dewing 2008, p. 62). It also involved monitoring for signs of ‘objection’ to my presence throughout the research process, such as considering whether individuals appeared in any way uncomfortable or distressed. I ensured that all participants were aware that if I felt that the older person objected to my presence, then I would withdraw from the site of the research observation. In actual fact, this situation did not arise and all of those older people engaged within this study appear contented with my presence throughout research observations.

As highlighted within **Appendix D**, the study involved a number of different groups of individuals who were involved in various different ways. Due to the different levels of involvement of participants, I designed and submitted to the REC for approval, a participant information sheet and consent form for each group of participants reflecting their individual levels of involvement. This included those participants who whilst not actively engaged within the research, might, nevertheless, be present within the site of a research observation (this included for example, Health Care Providers). (See **Appendix E** for information sheets and consent forms for each participant group. The details of the Local Authority and other potentially identifiable features have been redacted for the purposes of ensuring anonymity.)

The relevant authorisations needed for undertaking this study were granted by the REC in November 2016 (See **Appendix F** for REC and R&D approval documents). **Appendix G** contains the authorisations for the additional social work and team manager interviews, discussed within the preceding section. Identifiable features have been redacted from the approval documents for the purposes of ensuring anonymity.

## **Recruitment**

It was difficult to determine how many participants would be engaged within the study at the outset of data collection. Whilst I anticipated undertaking approximately 20 separate observations in respect of care home admission, it was impossible to know exactly how many participants would be present within the context of these observations (how many informal carers might be present, for example). As seen within **Appendix D**, more than one informal carer was present in a number of those observations undertaken.

Six social workers and three care managers were recruited from within the identified Local Authority. The participants were located within three adult social care teams. Meetings were undertaken within the teams to discuss the aims and objectives of the study and expressions of interest sought. All of these practitioners were “self-nominated” (Berg 2006; Emmel 2013) in the sense that they contacted me directly to state that they were willing to become involved in the research, following the initial information-giving session. Individual meetings were then undertaken with each potential participant to discuss their role in relation to the research and should they wish to proceed, to distribute written information sheets and consent forms. Each of these nine participants engaged with the study for the purposes of both observation and interview. In agreeing to participate within the study, these social workers and care managers agreed to refer two or three admission-related observations to the study and to allow me access to the documents produced in relation to the observed visit (it was agreed that the practitioner would obtain consent from the older person where appropriate (otherwise ‘consultee’) and informal carer, before ‘referring in’). Interviews were generally undertaken with each practitioner after observations had been completed. This allowed me to ask questions concerning different aspects of the observations and to ‘follow up’ on areas of interest.

A total of 24 informal carers were recruited to the study (some for observation only, some for interview only and some for both observation and interview). The study involved (1) informal carers either actively considering care home admission or involved in care home admission processes at the time of data collection; and (2) informal carers of older people who had already relocated to a residential / nursing home setting (and where a phase of adjustment to care home admission might have potentially been reached).

As highlighted within Chapter Two, individuals progress through the phases of transition and reach adaptation at different rates of time. As such, there is no real knowing where within the transition trajectory an individual might *be* on the basis of duration. For the purposes of practicality, a period of up to 3 years post admission was identified as an appropriate criterion for study inclusion. It was anticipated that within a period of three years post-admission, informal carers (whilst possibly still in the process of transition) would have made some progress towards adaptation. At the same time, it was important that informal carers were still in a position to reflect upon and recount their experiences of the admission process in detail and with some degree of accuracy. I did not feel it feasible therefore, to involve informal carers where long-term care admission had occurred in excess of a three-year period and where, for example, their recollections of the experience might have diminished with the passing of time.

It is important to state that due to the limitations of time and resources, the study is cross-sectional in design. As stated by Wang and Cheung (2020) “cross sectional studies analyse data from a population at a single point in time... (they)... do not follow up individuals over time” (p. 65). The potential limitations of cross-sectional research methodologies will be discussed in Chapter Nine.

In planning the study, other methods of informal recruitment were also trialled. I felt this was important because I was using a “self-nominating” (Berg, 2006; Emmel, 2013) sample of social workers and care managers. The potential for bias within such samples must be recognised because for example, practitioners might only refer “positive” scenarios to the study (wherein they would be presented in particular ways). Posters were placed within two local nursing homes within the Local Authority and leaflets distributed via two agreeable voluntary agencies. Both the

posters and leaflets were focused upon inviting informal carers to nominate themselves for interview through making direct contact with me (**Appendix H**). However, this strategy had only very limited success in terms of informal carer recruitment as it resulted in only one informal carer participating in the study.

One of the most difficult aspects of the study to manage was ensuring that timely, informed consent was obtained from those whom I will call ‘ancillary participants’ (for example, those wider professionals such as health care providers and staff within residential and nursing homes) who, whilst not actively recruited to the study, might nonetheless be present within the context of a research observation. Within such situations, it was necessary to ensure that all individuals, irrespective of the extent of their research involvement, were made fully aware of and consented to my presence within the research setting.

Since I anticipated that observations could potentially take place within any number of health care or residential or nursing home settings across the Local Authority, I understood that I needed to devise a strategy for raising awareness of and for ensuring the early dissemination of study information across these multiple sites. There are in excess of 30 residential and nursing homes in the Local Authority where the research was undertaken and the process of disseminating information to each care home individually was potentially problematic in terms of the time available. At the start of the study, my strategy for resolving this issue was to attend a ‘Providers Forum Meeting’ where study information and consent forms could be provided to care home managers in ‘one go’ (it was anticipated that these care home providers could then disseminate the information amongst their members of staff). However, the forum meeting did not arise at an opportune time and so it became necessary to make contact with and to visit the managers of care homes individually as a referral for observation was received. The recruitment of care home managers for interview was undertaken on an individual basis. I directly approached the managers of 4 separate residential and nursing homes within the Local Authority and invited them to participate in an interview.

As for hospital settings, I intentionally chose a hospital with a small number of wards (thus reducing the numbers of staff to be reached in terms of the dissemination of information). Meetings were arranged with the Senior Nurse Manager, the Ward

Managers and the Head of Therapies to discuss the study and to provide written information. It was agreed that the Ward Managers and Head of Therapies would distribute copies of the information sheets and consent forms to their relevant staff and that I would then contact ward staff and therapy staff directly as observations brought them within scope.

## **Maintaining the Integrity of the Research**

The Research Governance Framework for Health and Social Care (Department of Health 2005) highlights a number of key elements for consideration in terms of maintaining the welfare of research participants. These elements include, for example: a need to ensure “informed consent” (p.7); to appropriately ensure respondent confidentiality; and to maintain the security of data gathered within the research process (p. 8). The need to consider areas of ‘risk” (p.8) arising from within the research process and to assess the potential impact of these risks on participants, is further highlighted. In the case of the latter, it is imperative that research should do “no harm” (Braun and Clarke 2013, p. 63) to those participating within it.

In maintaining confidentiality, participants were assured that all data would be anonymised (that is, personal identifiers were removed as interview recordings were transcribed). As seen within **Appendix D**, pseudonyms were used to maintain the integrity of the narrative. The participant information sheets contained information regarding the confidential storage of data which I collected in line with the Data Protection Act 1998<sup>20</sup>.

In designing this research study, I was very aware of its potential sensitivities. Having worked within this area of practice for many years, I knew that admission to a residential or nursing home setting can often be a difficult and emotionally costly experience for both the relocating older person and his or her informal carers. I

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<sup>20</sup> Following the period of data collection, the Data Protection Act (1998) was replaced with the Data Protection Act (2018). The data for my study was retained during and following the change in legislation and so I was careful to familiarise myself with the contents of the new Act (so as to ensure that I was compliant with its requirements too).

understood, therefore, that strategies would be needed to safeguard the well-being of participants at all times as they engaged within the research process.

The risk of participants becoming upset when engaging within the research was also acknowledged at the outset. It was made explicit, for instance, within visits to informal carers for study discussion and was included within written information sheets. Prior to the commencement of both observations and interviews, I reiterated to participants that they were free to stop the process of data collection at any point, should they find the subject matter too distressing. I also ensured that I developed awareness of different support services, so that informal carers could be ‘signposted’ for additional assistance if necessary.

## **Reflecting on Challenges**

As stated in previous sections, ‘practitioner research’ (Fuller and Petch 1995) can be challenging. In many respects, my familiarity with the area of practice meant that I was able to anticipate and hence plan for some of the challenges that might arise during the course of my fieldwork. I considered for example, the ways in which the context of the study might result in limits to confidentiality. I understood that should issues of ‘adult protection’ arise during the course of my data collection, then my professional responsibilities as a social worker would outweigh my commitment to other aspects of the research process (in this case, assurances of respondent confidentiality and anonymity could not be maintained). To that end, limits to confidentiality were explicitly discussed with research participants at the outset of their research involvement.

Nevertheless, I became acutely aware of other – perhaps less anticipated – difficulties of ‘practitioner-research’, early within the process of data collection. It was through my contact with participants that I realised, for example, the extent to which I routinely used terms and phrases which are typically part of ‘social work parlance’, but which had different meanings for those outside of the profession. Take the term ‘informal carer’ for instance. In undertaking my social work role, I had often referred to those family and friends caring for older people as ‘carers’, ‘informal carers’ or ‘family carers’. However, and as argued elsewhere (Phillips 2007; Larkin et al. 2018), such phrases are contentious because many family members do not perceive

themselves *as carers* when supporting other family members. I became very aware of the dangers of using such phrases in an uncritical way during a conversation with ‘informal carer’, Bryony. As I interviewed Bryony, I realised that she did not conceive of herself as a ‘carer’ at all (even though, I would have seen her in that role). Since Bryony did not consider herself ‘a carer’, she informed me she had therefore excluded herself from services *for carers* (such as carers support groups):

*People like me, who are not the carers full-time – Dad didn’t live with me, I wasn’t looking after everything for him, I didn’t have power of attorney – you think of carers as somebody who is devoted... you know... like a wife looking after her husband with dementia, or the other way round; I didn’t feel like that was me, so I’d never belonged to any sort of – or had any contact with any sort of – Carers’ Support, because I didn’t think of myself as a full-time carer.*

**(Interview with Bryony – IC07)**

Following this conversation, I questioned whether the terminology used within my posters and leaflets for example, had resulted in some participants excluding themselves from the study, simply because they did not consider themselves as occupying a caring role. This incident made me very aware of my need to avoid ‘professional jargon’ in undertaking the research for this study.

There was also a second reason why ‘stepping back’ from ‘professional jargon’ was important in this study. Critically, I wanted to avoid being seen *as* a social worker by study participants. I was concerned that if I was seen as having a social work role, then this might potentially change the dynamic of my interactions with research participants. In undertaking this study, I considered it ethically right to be explicit about my practitioner status; information regarding my ‘dual status’ as both a social worker and researcher was contained within all participant information sheets. However, I was also careful to explain that my role within the study was one of a researcher, and *not* a social worker. I was very aware that there were potential consequences associated with my being *seen* as operating in a social work capacity. Alston and Bowles (2003) state that from a participant perspective, researchers who are also social workers, may well be perceived as retaining a level of power within research relationships. Participants may therefore worry that a researcher has the

potential to influence “access to resources” (p. 112) and may feel obliged to consent to research involvement. I sought to overcome this issue through ensuring that information sheets contained assurances that access to services and support would not be compromised in any way, should individuals decline from participation or choose to withdraw from the study.

I also experienced a number of occasions where I was aware of being perceived as another social worker *by social work participants* within the context of data collection. There were times where for instance, those practitioners engaged within the study, sought to ‘use’ me as a social work colleague for the purposes of their own assessment. By way of example, I recall being asked by a practitioner for my opinion concerning the mental capacity of an older person when making a practice-related decision. Within such circumstances, it was necessary for me to refrain from engagement within such decision-making processes and to reiterate my role (as a researcher and observer) within observed visits.

One of the most challenging aspects of the study, was to avoid ‘*thinking like*’ a social worker. In undertaking my fieldwork particularly in the ‘early days’, I found it difficult not to ‘slip into’ the role of social worker and offer direction in terms of service provision and strategies for support. Whilst much has been written regarding the overlap and transferability of social work skills to research contexts (Fuller and Petch 1995), I had to constantly remind myself that the roles of researcher and social worker are not the same (McLaughlin 2007) and must be kept separate. Indeed, a blurring of these roles, could have unintended consequences in terms of viable research outcomes. I realised, for example, that I needed to avoid assuming understandings of care home admission processes and instead, needed to develop the habit of asking sometimes seemingly obvious questions regarding care home entry procedures. It has to be said that I did not always find this process easy; there were times where I felt that practitioners were confused as to why I was asking questions to which I surely, already knew the answer (I was an experienced social worker after all). Nonetheless, in asking such questions, I began to access some of the thinking behind practitioner actions and decision-making. In doing so, I was then able to ‘step back’ and to think more critically about what was seen and heard throughout the observation process.

In order to ‘distance myself’ from my study, to stand back and to view my data critically, I used adapted versions of some of the strategies to which Barrett et al. (2020) refer to within their work. Thus, for example, I kept a “research diary” (p. 11) to reflect on the process of undertaking my research and its emerging findings. I kept detailed notes of my observations, thoughts and feelings when reading the existing literature related to social work practice in this area and ‘journalled’ the challenges I encountered in setting up and undertaking my fieldwork. During the process of data collection I was especially careful to revisit my field notes and interview transcripts for the purposes of writing critical annotations and memos. In so doing, I developed the habit of ‘questioning myself’ (my thoughts, conclusions and so on), with the intention of deliberately and consciously considering alternative perspectives.

Barrett et al. (2020) suggest that reflexivity is promoted when researchers hold regular meetings with the ‘research team’ for “reflexive discussion” (p. 11). Whilst I did not theoretically undertake my research as a part of a ‘team’, I nevertheless routinely engaged my supervisors in processes of data discussion. I shared ‘slices’ of my annotated data with my supervisors, which were then discussed in detail within supervision sessions. These interactions also provided me with an opportunity to check and to challenge my own perspectives.

## **Analysis**

A ‘grounded theory approach’ to data analysis dates back to the work of Glaser and Strauss (1967) and as observed by Urqhart (2013) has been adopted in multiple variations (p. 3). Proponents of grounded theory see its promise as lying in its ability to generate theory from data, through methods of comparing different elements of the data (Hammersley and Atkinson 2019). Whilst I used elements of grounded theory in my approach to data analysis, it must be acknowledged that I did not (and could not have) adhered to its principles rigidly, on account of my prior social work practice in this area. Purists of grounded theory argue that those conducting such research should enter the field without pre-conceived ideas (Charmaz 2014). My knowledge of the subject area meant that it was simply impossible for me to approach ‘the field’ without any preconceived ideas.

The elements of a grounded theory approach to my data analysis were nevertheless, visible in a number of other ways. For example, I combined data collection concurrently with analysis and I wrote annotated memos throughout the process of data collection (Clarke 2005), which helped document my thinking and allowed for a type of “progressive focussing” (Hammersley and Atkinson 2019, p. 163). Progressive focussing arises as researchers attach particular importance to specific elements of the data and intentionally begin to search for other related and relevant data instances in support of the developing of theory. The intentional gathering of data in accordance with emerging phenomena of research interest is achieved through a process of “theoretical sampling” (Birks and Mills 2015, p. 10). Birks and Mills state that when using theoretical sampling, the “researcher makes a strategic decision about what or who will provide the most information-rich source of data to meet their analytical needs” (p. 10)

As stated previously, I used ‘theoretical sampling’ within this study when recruiting two additional hospital discharge social workers to the study for interview and when seeking additional ethical approval to undertake two ‘team manager’ interviews (**Appendix G**). To reiterate, I became increasingly aware of a perceived problem of time-pressure amongst practitioners during the period of data collection; particularly when care home admissions were undertaken from hospital-based settings. I began to question what it might be like to work continually within a hospital environment from a practitioner perspective and whether this environment might change the approach of practitioners to their work. These additional interviews were undertaken with the intention of exploring these issues.

As for data coding, this commenced following the completion of data collection and was undertaken as follows: I (a) undertook a thorough re-reading of all my data, writing further notes and analytic memos to capture my thoughts and developing ideas. As a result of this process, I began to develop a sense of the “initial codes” (Birks and Mills 2015, p. 7) that I wished to attach to the data. I then (b) selected a small sample of the total number of interviews to ‘trial’ the potential and effectiveness of these initial codes (that is, to what extent did they capture all of the phenomenon of interest within the research data). I began working through these interview transcripts

to label small sections of the data with the initial codes and in so doing, I became confident in their utility.

As a result of engaging in the above process, I found myself in a position of beginning to identify connections and interrelationships between different codes. Consequently, I was able to think more deeply about the nature and properties of these initial codes and in so doing, developed a sense of how one code potentially linked to and impacted upon another. Through continuing to develop my understanding of these interrelationships, I then devised a series of “intermediate codes” (Birks and Mills 2015, p. 12) or subcategories. Subcategories are generated when initial codes are aggregated on the basis of their commonalities or similarities.

When satisfied with the adequacy of my initial codes and subcategories, my entire data set was (c) entered into the NVivo 12 software package. I then mapped the data line by line, against each of the individual codes contained within their broader subcategories. In completing this process, the whole of my data was ‘densely coded’ (each segment of data mapped against multiple codes and subcategories). Attaching multiple codes to each data section as described, ensured that full account was taken of its richness and complexity. It also enabled me to expand my thinking about the connections and relationships between the various subcategories.

According to Rodwell (1998), “the goal of constructivism is to understand the network of relationships involved in the phenomenon under investigation” (p. 162). In order to develop my thinking around the “network of relationships” (Rodwell 1998, p. 162) (that is, the properties and meaning of specific subcategories and their connections and interrelationships with other subcategories), I wrote further, detailed analytic memos throughout the process of data analysis. At first, I wrote annotations and memos within the NVivo programme but after a short while, I chose to work outside of the software, finding that I could ‘think more freely’ and explore my ideas in more depth, when writing in simple Word documents.

When interrogating each of these ‘subcategories’ (and in order to expand my thinking around their various dimensions), I drew upon a version of Clarke’s (2003; 2005) approach to Grounded Theory analysis (called “situational analysis”). Clarke provides a number of prompts (headings) for researchers to think about when

examining their data. I found these ‘headings’ extremely useful when ‘probing beneath the surface’ of participant responses and when thinking about the broader structural, political-economic and cultural influences shaping and constructing care home admission experiences. The kinds of prompts suggested by Clarke (2005) include: “human elements (individual and collective); “discursive constructions of actors”; “nonhuman elements”; “organisational / institutional elements”; “spatial and temporal elements”; “political economic elements”; and “popular and other discourses” (p. 73).

Clarke (2003) saw a Grounded Theory approach to data analysis as potentially reductionist and as therefore over-simplifying research data; she was concerned that researchers should fully understand the subject of enquiry and that full account should be taken of all of those factors potentially influencing the perspectives, positions, actions and interactions of participants. Her approach spoke to my concerns to adopt an explicitly “person-in-environment” (Sullivan 2015, p. 337) perspective, in my approach to data analysis.

Clarke (2005) argued that “situational analysis” allows researchers to:

*...draw together studies of discourse and agency, action and structure, image, text and context, history and the present moment – to analyse complex situations of enquiry broadly conceived’*

(p. xxii)

As well as using the prompts suggested by Clarke (2005) in investigating each of the ‘subcategories’ (through the writing of ‘analytic memos’), I also followed the technique of drawing a “situational map” to ensure my understanding of all of the elements (human and non-human) relevant to and shaping the field of enquiry. The ‘situational map’ was especially important in allowing me to think deeply about the influence of context on the care home admission experience (the impacts of finance and budgets for example on the practises of social work and the impacts of discourses of ‘community care’ on the emotional reactions of informal carers at such times).

Through this process of memo writing (and through linking the various dimensions of subcategories, one with another), I was able to develop a series of overarching

categories (six in total), which enveloped all of the subcategories and codes throughout the entire data set. **Appendix I** offers a diagrammatic representation of the overarching categories and their constituent subcategories. It was through examining the interrelationships between these overarching categories, that I was able to develop the theories and understandings presented within the empirical chapters of this thesis.

## **Summary**

In this chapter I have discussed my approach to undertaking this research (I have explained the reasons for my chosen methodology and described my ‘tools’ for data collection). I have discussed the process of obtaining ethical approval for the study and my approach to recruiting research participants. I have also described some of the ethical challenges encountered in the process of undertaking the study and the efforts made, in resolving these issues. My approach to data analysis was then outlined in the final sections of the chapter.

I now move on to present the findings of the study, that is, the outcomes of the process of data analysis. These findings are discussed in Chapters Five through to Eight.

# **Chapter Five: Easing the Stresses of Transition through Caring Social Work Practice**

## **Introduction**

This chapter has two main areas of focus. Firstly, it adds to the existing literature exploring the challenges of decision-making around care home admission from an informal carer perspective. As stated in Chapter Two, it is at times of decision-making in respect of care home admission, that social workers are often involved in working with older people and their informal carers. It is therefore critical that practitioners have an understanding of the difficulties experienced by many informal carers when making decisions related to care home entry. I examined this decision-making process through the conceptual lens of ‘transition’ and ‘transition theory’ and with reference to the work of writers like Murray-Parkes (1971); Golan (1981); Selder (1989); and Meleis et al (2000). As a framework for conceptual analysis, transition (concept and theory) offers great potential insight into the emotional impacts of care home admission and is highly relevant to understanding the difficulties experienced by many informal carers when determining appropriate courses of action around long-term care.

Secondly, later in the chapter I consider the importance of practitioners adopting a care approach when working with informal carers during care home entry. As a ‘way in’ to understanding the benefits of practitioners working with care, the chapter specifically examines the importance of “attentiveness” (Tronto 1994, p.127) within admission-related, social work practice. As stated in Chapter Three, attentiveness is a fundamental element of care (Tronto 1994) and has the potential to significantly alleviate feelings of suffering and distress. This chapter draws upon the theoretical work of Tronto (1994), Klaver and Baart (2011) and Hay (2019), to explore the presence of attentiveness within the work of practitioners. It considers different instances of attentive social work practice and examines their impacts on informal carers, when engaged in care home admission processes.

# The Challenges of Decision-Making

## 1. Emotional Challenges

From the perspectives of transition theorists like Golan (1981) and Blum and Sherman (2010), transition begins with change. As a type of transition (Zizzo et al. 2020), care home admission often arises as a result of a change in circumstances, such as a deterioration in the health of the older person or informal carer. As stated by social worker, Sue:

*It's usually because... maybe the carer has had an accident or can't cope anymore, or the cared-for person is unwell.*

**(Interview with Sue – SW08)**

The types of altered circumstances described by Sue, may well give rise to the unsustainability of caregiving arrangements and legitimise a need for care home admission. Despite the significance of these changes, however, many informal carers still spoke of finding it extremely difficult to determine whether an older person should enter a long-term care setting. As stated by informal carer, Rose:

*It's been terrible... It is one of the hardest decisions to make in life.*

**(Interview with Rose – IC02)**

To give a sense of the emotional impacts of making such decisions, informal carers often described care home admission as: “*heart breaking*”; “*heart rendering*”; “*traumatic*”; “*horrendous*”; “*devastating*”; “*worrying*”; and “*stressful*”. Care home admission was sometimes likened to “*bereavement*”:

*It's like bereavement, really... Except you've still got your Mum 'somewhere'.*

**(Interview with Lynne - IC06)**

Indeed, for some informal carers, assisting an older person to move into a long-term care setting was considered even *more* challenging than losing a loved one through death:

*(The informal carer) expressed: 'I just wish he would die, it would be kinder for him'*

**(Data from Documents – Lindsay – CM03)**

Decisions in favour of care home admission were often made with the greatest reluctance. For many informal carers, admission to a long-term care setting was conceptualised as a “last resort” and undertaken only in the absence of all other viable alternatives (Stull et al. 1997; Rodgers 1997; Keefe and Fancey 2000; O’Shea et al. 2014). As stated by informal carer, Harriet:

*I'd always said I would never ever put either of my parents in a home; that was the last thing I'd do! [tearful] ... But I knew – I didn't want her to go anywhere, at all – but I knew she had to. I knew, really, deep down, I didn't have a choice.*

**(Interview with Harriet – IC04)**

Harriet makes clear that had she had any other “*choice*”, she would not have opted to “*put either of (her) parents in a home*”.

The concept of transition helps explain the reluctance felt by many informal carers when making decisions in favour of care home entry. Transition theorists make explicit that with change comes loss (Goldsworthy 2005) and in understanding the gravity of care home admission, it is important to appreciate the nature of the losses experienced at such times. Most obviously, care home admission results in the loss of a home or material possessions. The impacts of losing a home are described within the following extract from one of my observations:

*Ray and Mandy (informal carers) described how – on the day of the admission – Winnie (the older person) had stood at the top of the steps leading down to her house and had said: “Bye house.” Ray said: “We were in bits!” (Ray described how emotional he and Mandy (his wife) had felt in witnessing this experience.)*

**(Observation - Two)**

Ray describes very powerfully, how distressed he and his wife became when watching his mother say her farewells (says “*Bye house*” ) to the home in which she had lived for so many years. Ray states that he and his wife were “*in bits*”.

As an older person enters a care home setting, many informal carers also experience a loss of relationships and of roles and responsibilities (Nay 1995). These losses can be highly distressing from an informal carer point of view. By way of illustration, I refer to the following citation, taken from my interview with social worker, Chloe:

*He explained that his social circle very much was through her friendships, ... his wife had dementia – and when she had the dementia, the friendships sort of withered away, and there was just those two. Their daughter lives away. And you could see that he used to enjoy the visits that I used to do and we had a support worker in place and he used to enjoy that she... that’s the feedback I had from her, that he was very receptive to having visits; and you almost felt like it was the only social contact he was having. And then when she transitioned into care, and we’d done the review and... you know... I almost felt this sense of... of loss, really, from him... And I remember him saying ‘I don’t know what I’m supposed to do with my life, now’.*

**(Interview with Chloe – SW02)**

Chloe describes the relational losses experienced by a spouse, as his wife enters a care home setting. It is clear that this informal carer experiences relational losses on several levels; most obviously, his relationship with his wife is significantly altered as she moves out of their shared home. We also see that friendships “*wither away*”, given the informal carer’s “*social circle*” was very much connected to his wife’s “*friendships*”. Relationships and possible friendships are lost as formal care services are withdrawn at the onset of admission (see Brown and Stetz 1999 and Cronin et al. 2015, who describe the losses experienced by informal carers when formal care services are relinquished). These accumulated losses give rise to apparent feelings of uncertainty and a perceived loss of purpose; thus, the informal carer states: “*I don’t know what I’m supposed to do with my life, now*’.

Golan (1981) and Selder (1989) state that many people in transition experience feelings of significant confusion and disorientation. At times of transition everything that an individual knows and with which they are familiar, is thrown into upheaval and disarray. The disruption of an individual's "assumptive world" (Murray-Parkes 1971, p. 103), the disordering of their daily expectations and their hopes and plans for the future, lead to feelings of disorientation, destabilisation and confusion (Beder 2005, p. 255). It is arguably unsurprising therefore, that the informal carer described in the extract, appears 'in limbo'; he is uncertain of where to go "now" or what to do next.

According to Murray-Parkes (1971) the losses arising in transition occur in what is known as the "life space" (p. 103). As stated in Chapter Two, the life space is seen as consisting of "those parts of the environment with which the self interacts" (p. 103). Anything that an individual can call "mine" constitutes a part of the life space (for example, a person's possessions, relationships and their roles and responsibilities). The losses of the elements of the life space are seen to lead to a loss of selfhood or identity.

From such a perspective, when an individual loses his/her own home, they lose in a sense, a part of themselves (Murray-Parkes 1971). Given the impacts of such losses, it is arguably understandable why some older people vehemently resist leaving their homes to enter long-term, institutional care:

*Jean (the informal carer) said that the house did not have any heating or running water – she said that there was an outside toilet but that the roof of the toilet was "falling in..." Jean described how Sadie (the older person) would say: "they'll have to take me out of here in a box" (i.e. a coffin).*

**(Observation - Fifteen)**

Sadie's house might have looked like very little from the outside (indeed, it is described as being in a dilapidated state and without "heating or running water"). Nevertheless, for Sadie, the fact that this is *her* home is clearly meaningful, it is a part of who she is, and Sadie is not willing to leave her home, except *in a box*" (i.e. a coffin).

Likewise, some informal carers became extremely upset at the prospect of clearing out an older person's belongings when that person enters a care home setting. Informal carer, Lynne, stated:

*I had to clear out all her stuff and I wouldn't let my husband down there, because he would just say 'Oh, throw it out; throw it out!' but it wasn't! They were memories!*

**(Interview with Lynne - IC06)**

Whilst Lynne's husband sees her mother's "stuff" as items to be simply discarded or "thrown out", for Lynne, these items are precious, they are symbolic of her mother's past (they are "memories") and are constitutive of who she is (her own selfhood and identity).

Within this thesis, I pay particular attention to the impacts of losing a caregiving role, upon the selfhoods and identities of informal carers. A loss of role can have a significant impact on an individual's sense of self. By way of illustration, I draw on the following extract, taken from my interview with informal carer, Lois:

*Lois tells me that she has recently given up her job and talks about the impact of this decision upon her life. Lois said that she had "loved" her job; she said that she was the: "office clown" and that she would make everyone laugh; she also said that everyone came to her with their problems and concerns: "I knew everyone's problems." Lois said: "I am not being me at the moment."*

**(Interview with Lois - IC08)**

Making a decision to leave work had been very difficult for Lois and the perceived impacts upon her identity and loss of selfhood are clearly articulated in her statement: "I am not being me at the moment."

Lois had given up a job to take on a full-time caring role, but equally the *loss* of a caring role, has significant impacts upon the selfhoods of many informal carers. To appreciate the gravity of these impacts, it is necessary to reflect upon the *socially constructed* nature of the self (Atchley 1989; Atchley in Birren et al. 1991).

Atchley in Birren et al. (1991) states that individuals construct notions of an “ideal self” (p. 390) (that is, they conceptualise a self they would like to be or feel that they ought to be). When constructing an “ideal self” (p. 390), account is inevitably taken of broader social and cultural expectations. Within Chapter Two, I argued that discourses of ‘community care’ champion the concept of “familism” (Crist 2002, p. 366). The concept of “familism” (Crist 2002, p. 366) encapsulates a deep-seated belief that adult children should care for those who once cared for them and that responsibility for the care of one’s older kin should rest with the members of one’s family and not with the State (Finch and Mason 1990).

Many of those informal carers engaged within the study recounted their experiences in ways suggesting that they had absorbed societal expectations around the *right* and *proper* ways to care for older people. The influence of “familism” (Crist 2002, p. 366) could be seen in the language used by these informal carers when stating, for example, that they believed that they “*should*” care for their older loved-ones:

*You should be able to cope until they pass on.*

**(Interview with Rose – IC02)**

Rose also said:

*You know, they changed your nappies, you should do it for them.*

**(Interview with Rose – IC02)**

For some informal carers, caregiving was seen as an opportunity for them to repay an older person for their kindnesses of the past. Informal carer Phillip told me, for example:

*... that he and Connie (his mother) had been “very close”, as Connie had helped him raise his own son since his son was (a very young child).*

**(Observation - Eleven)**

In return for that past kindness, Phillip told me that he wanted to “*do (his) best*” for his mother:

*Mum's done the best to bring (us) boys up... she brought up my son since he was (small) ...she's done her best; so now, I should be doing my best (by her)*

**(Interview with Phillip - IC09)**

It is important to recognise, however, that some informal carers still provided care to an older person, even when they had *not* received care from that person in times past. During interview, informal carer David described having a very distanced relationship with his uncle. Nevertheless, when his uncle needed care, David described the ways within which he had 'stepped up' to provide care both within the domestic setting and later, within the care home environment. When I asked David *why* he provided this care (in the seeming absence of a meaningful relationship), he replied as follows:

*David: Well (pause) I dunno, really... Because it's not for what I get out of it, because it's nothing.*

*AC: Because you said he's not necessarily chatty with you, or...*

*P: No, he's... like... and anything that he's got to say, it's never anything... to sort of give you a spur on then, to help him more... So that I... I think well why... why do I bother, like? [Laughs] you know? But I do it, anyway.*

**(Interview with David - IC03)**

David believes that he gets “*nothing*” out of caring for his uncle (he describes a lack of recognition or appreciation). I would argue, however, that in reality, David probably gets *much* out of caring for his uncle in such ways. Insofar as family members are *expected* to care within contemporary society, the provision of care enables informal carers to enact behaviours consistent with social expectations and therefore to feel satisfied with their behaviours.

Atchley in Birren et al. (1991) argues that the “ideal self” (p. 390) constitutes a standard against which a person measures his or her actions. When a person feels that they have lived up to social demands and expectations, feelings of satisfaction and self-affirmation are experienced. As stated by informal carer Ruth:

*I decided to finish work, to look after (him).... in a way I was so glad I'd given up work, because he only lived 3 years after.... I thought, 'Well I did the right thing' because I could take him to all his appointments and various things for those 3 years... spend as much time... you know... And I could sit with him all that time... you know... so I was glad.*

**(Interview with Ruth- IC10)**

On the other hand, a perceived failure to provide care leads to feelings of guilt, shame and low self-esteem. The prevalence of guilt as a reaction to care home admission is highlighted elsewhere within the literature (Johnson and Werner 1982; Johnson et al. 1992) and was very much a feature of the narratives of those informal carers engaged within this study:

*And then, I felt guilty. 'What am I doing putting my mother in there, when I'm perfectly able to care for her?'*

**(Interview with Lynne - IC06)**

*The guilt is...is heart rendering. The guilt of having to put her in; thinking you can't cope.*

**(Interview with Rose – IC02)**

My discussions with participants evidenced that it was through their interactions with others, that cultural expectations surrounding the provision of care were reinforced. By way of illustration, I refer to the following extract taken from my interview with Anne (Anne is both a social worker and an informal carer, with personal experience of care home admission):

*Anne described an incident (shortly after her Mother's admission into long-term care), Anne said that she was out one day and 'ran into' an acquaintance. Anne said that the acquaintance had asked after her Mother (believing her Mother to be in hospital). Anne said that she had explained that her Mother was no longer in hospital but that she had now been admitted to a care home. Anne spoke of the reaction of the*

*acquaintance to this: (“I’d never put my Mother in a care home!”) Anne described feeling very hurt at this comment.*

**(Interview with Anne - SW07)**

Anne’s comments illustrate the power of social interaction, in affirming and perpetuating ideas as to the perceived *right way* to care for older people. They also show that an informal carer’s possible feelings of guilt and shame around care home admission are likely to be exacerbated by the responses of others. Anne describes feeling “*very hurt*” when her acquaintance tells her that she would “*never put (her) Mother in a care home!*”.

From a Local Authority perspective, informal carers were very much seen as the primary providers of care. The following extract is taken from my observation at social care panel<sup>21</sup> and shows that decisions related to the allocation of resources, firstly took into account the *availability* of informal carers:

*Team Manager, Ross explains the service user has a daughter but states that she is at “breaking point” and “can’t manage without extra support”. Ross also notes that there is a neighbour but that the neighbour “can’t provide the extra help”. The request for additional support is approved.*

**(Observation – Three)**

Here, it can be seen that the agreement of additional services is contingent upon other sources of informal care having firstly been considered and then effectively *ruled out*. There was certainly evidence that informal carers had awareness of their perceived roles as primary care-givers. As illustrated within the following extract, some informal carers certainly *anticipated* that health and social care professionals expected them to care for their older loved-ones, irrespective of the difficulties that they would likely encounter in the provision of such care:

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<sup>21</sup> Social Care Panels are meetings of Team Managers where decisions related to the allocation of resources are reached.

*I've got a (situation) now, where I've got a gentleman in hospital, he's in his 90s, his wife is in her 90s, she's had rheumatoid arthritis and other health issues and is very... her vision is very poor, and in effect he's been ... her carer. And now, all of a sudden, he's failing and has ...been in hospital ... and she's sort of sitting there, in her wheelchair, in the Discharge Planning meeting ... crippled with arthritis – saying, 'I can't have him home' and like... no-one's telling her she's got to have him home, but she's... telling herself, really, 'I can't have him home; I couldn't cope' you know?*

**(Interview with Anne - SW07)**

Whilst Anne makes clear that the older person here would certainly *not* be expected to provide care for her spouse, it is probable that she (the spouse) *perceives* that she *will* be expected to take on a caring role; a possibility that leaves her feeling anxious and distressed. Significantly, when informal carers no longer feel able to provide care for an older loved one, many will work hard to convince *others* of the legitimacy of their decision. Thus, the informal carer in the above extract seeks to explain and to justify her position by stating “*I can't have him home; I couldn't cope' you know?*”. Further, some informal carers even described feeling that they had to “*justify*” themselves to me (as a researcher) when recounting their decisions in favour of care home entry. Such statements clearly indicate the feelings of guilt, shame and embarrassment accompanying decisions around long-term care admission.

It is also important to recognise that society does not have equal expectations of all its members when it comes to care. As stated in Chapter Two, the responsibility for caregiving is overwhelmingly assigned to women within Western society, who are then seen as having their selfhoods and identities ‘wrapped up’ with care (Graham in Finch and Groves 1983; Waerness 1984; Phillips 2007). As such, it can be very difficult for women to relinquish their caregiving roles and responsibilities. As stated by social worker, Anne:

*I think... it's an issue for women particularly; they've been mothers, they've been household managers [laughs wryly], they've taken on the caring role then... (they've)been in that 'giving' role all (their) life! And*

*although part of (them) may be very relieved it's not to happen anymore, (they may then ask)... 'What is there for me now; what do I do?'*

**(Interview with Anne - SW07)**

Selder (1989) argues that individuals maintain their sense of self at times of transition, through “engaging in behaviours that mirror the standard of the core society” (p. 449); a practise that she refers to as: “normalisation” (p.449). Insofar as care is seen as a normalised “family practice” (Morgan 1996; 2011) particularly for women within contemporary British society, it is unsurprising that some women actively sought opportunities to continue caregiving beyond care home admission. Indeed, informal carers like Kate went to great lengths to find ways of continuing caregiving after an older person had entered a residential or nursing home setting:

*Kate (informal carer) told me that following Lorna's (the older person's) admission into the care home that she has taken up a job in another nursing home. Kate talked about enjoying this job; she also talked about taking care of (another family member). We discussed Kate's involvement in caring roles and she said that this is something that she had always done: "I am that way anyway."*

**(Observation - Sixteen)**

Kate very much saw her identity as intertwined with the undertaking of caregiving roles and responsibilities. Kate describes having had multiple caregiving roles and implies that it is almost ‘natural’ for her to care because caring is a part of who she is, she states: *“I am that way anyway”*. When the time comes for Lorna (the older person) to enter residential care, Kate refers to taking up *“up a job in another nursing home”*. In avoiding relinquishing caregiving, Kate adopts the position of what Larkin (2009) calls the “serial carer” (p. 1037) wherein care-givers replace lost caregiving roles, with new caregiving roles.

As discussed in Chapter Two, Atchley (1999) views “continuity” as an important strategy for managing the impacts of transition upon selfhood. Roles and responsibilities are elements of what Atchley (1989) calls “external continuity” (p. 185) and it is argued that maintaining a degree of external continuity is prerequisite to

maintaining “internal continuity” (p. 186); of which selfhood and identity are a part. In enacting caring roles and responsibilities consistent with her perceived sense of self, Kate will experience what Atchley (1999) calls a “psychic pay-off” (p. 11); her hoped-for or “ideal self” (Atchley 1982, p. 390) will be actualised. I continue my discussion of the importance of the ongoing care-giving roles and responsibilities of informal carers in Chapter Seven.

According to Meleis et al. (2000), transition is far more challenging when it is related to a stigmatised event. The feelings of guilt experienced by many informal carers are of course, exacerbated by pervasive, negative attitudes towards care provided in institutional settings. Many informal carers were seen to have a deep-seated distrust of the quality of care provided in residential and nursing home environments. Thus, informal carer Lynne said:

*Whatever you say about care homes – however good they are – they’re not perfect. They don’t do what I’d do for my Mum, obviously*

**(Interview with Lynne – IC06)**

As highlighted within Chapter Two, institutional care has its origins in the nineteenth century workhouse and there was suggestion that the legacy of the workhouse still dominated the thinking of some older people. As observed by care home manager, Chris:

*When you think, the generation that we are looking after... they’ll remember workhouses.... You know? And there’s still that ‘you’ll never put me in one of those, will you? You’ll never put me in a workhouse?’*

**(Interview with Chris – CHM03)**

It is very difficult to change negative attitudes towards residential and nursing home care because, as stated by team manager Ross, care homes tend to exist “*in isolation*” rather than being integrated into the wider community:

*I think care homes... just needs to be a huge part of the community... They kind of just ‘exist in isolation’ in a way. I think our care homes at the moment are very separate to communities, which they exist in.*

**(Interview with Ross – TM03)**

Some participants also saw the media as fuelling this negative public perception of care home settings, and highlighted the need for much more positive publicity. As stated by care home manager, Dawn:

*I mean, you know what it's like; the press that people get, it's always the bad press that's on TV and in newspapers; you very rarely see the good stuff that goes on, and... you know... we've had some phenomenal letters and cards sent to us from relatives, praising the care; praising the staff. I feed that back to my staff, you know, but it's always the bad press that's out there. So, I think the good stuff needs to be promoted a lot more.*

**(Interview with Dawn – CHM05)**

My discussions with informal carers made clear that at the present time, their anxieties around the quality of care in care home settings, made it very much harder to choose an appropriate care home setting for their older loved ones. Given their feelings of distrust, many informal carers were preoccupied with the need to find a *good* care home for their older loved-ones. As stated by Rose:

*It's a point of 'where's the best place for her'. Wherever I can find the best place for her, that's where she will be. It won't be about 'well, I can't get on a bus to visit' or 'I'm going to find it difficult to go down there'. It'll be whatever is the best place for her....*

**(Interview with Rose – IC02)**

Nevertheless and as will be seen in the following sections, the task of identifying a good care home setting is far from straightforward and illustrates the very real, practical difficulties experienced by many informal carers when making decisions around care home entry. It is to the practical difficulties of care home admission that I now turn.

## **2. Practical Challenges**

The interviews and observations with informal carers revealed from the outset that the experience of decision-making in respect of care home admission is fraught with

practical difficulty. This is a finding that is well supported by the existing literature (Cahill 1997; Ryan and Scullion 2000; Zizzo et al. 2020). Tilse (1997) and others (Fleming 1998; Kellett 1998; 1999a; 1999b) make the point that for many informal carers, feeling that they have chosen a good home (that is, a home with a good standard of care), is fundamental to offsetting some of the feelings of distress, anxiety and guilt experienced at times of admission. However, many informal carers had little prior experience upon which to draw (they emphasised that this was the “*first time*” they had been in this position) and that they did not therefore know how to make the best choice of care home environment. Rose like several other informal carers engaged within this study, described simply not knowing how to choose a care home for her mother and described feeling uncertain as to how to judge the quality of care on offer (“*I can’t find.... like good care homes*”). Rose was not alone in feeling this way. During interview, care home manager Michael, told me that the majority of informal carers do not know what questions to ask when choosing a prospective care home setting:

*People’s first words to me, when they ... first come in to look around the building...see what the ethos of the place is... one of the first things they say to me is, ‘I’m new to this... I don’t know what to ask... I don’t know what to look at... I don’t know what to do. I’ve been given three or four care home names and... I don’t know what to do so I’m just going around all the homes and seeing what is on offer’.*

**(Interview with Michael – CHM02)**

It is also the case of course, that what constitutes a good care home, is somewhat subjective and will differ in accordance with the personalities and preferences of older people. Individual care homes were seen to have markedly different characteristics, meaning that they might suit some older people but not others. As stated by Care Manager, Carole:

*It’s like some homes have got animals and, you know, that might have been really important to someone who was in the community and they’ve always had dogs, you know – that would let them settle in more if they*

*knew there were animals there. Whereas somebody on the other hand would hate it if there were cats and dogs running around the home!*

**(Interview with Carole – CM02)**

Elsewhere, Carole makes the point that it is not always easy for informal carers to appreciate the differences between specific care home environments. As a result, it can be very challenging to ensure that an older person's personality and preferences are well suited to a particular care home setting.

Some theorists argue that choice is critical to promoting positive transition outcomes (Chenitz 1983). As stated in Chapter Two, however, informal carers need significant amounts of knowledge and understanding to distinguish between different care home environments and to make a satisfactory choice of care home on behalf of their older loved-ones. Within the Local Authority where the research was undertaken, care homes were 'grouped' into a number of broad categories of care<sup>22</sup>, depending upon their registration and the nature of the care provided. Informal carers therefore had to ensure that they chose a home within the appropriate category of care.

Many informal carers also faced significant, choice constraining factors when seeking to identify a care home setting. These constraints significantly shaped the options available to them. It could be seen for example, that the degree of choice available to older people and informal carers was dependent upon levels of vacancy:

*I phoned one today.... It's like they said, 'we haven't got any beds'.*

**(Interview with Rose – IC02)**

Degrees of choice were also limited by socio-economic circumstances. For some informal carers, their socio-economic circumstances meant that certain care homes were 'off-limits' on account of the size of their 'third-party payments' or so-called

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<sup>22</sup> Care homes were segregated in accordance with the care they were able to provide on condition of their registration. Thus for instance, some care homes focussed upon providing physical, nursing care to older people and could not accommodate older people with care needs explicitly related to dementia.

“top-up fees”<sup>23</sup>. Within interview, Lynne described a previous experience of choosing a care home setting on behalf of another family member. Lynne made clear that the process of choice within this situation had been far easier on account of the older person having a higher level of income:

*Lynne: My (relation) was different... she had more money – she had her own bungalow...*

*AC: What was the difference, do you think?*

*Lynne: The fact that she could choose and pay for it, I think, that would be... Yeah. She had enough income... without touching savings, to pay for her home. So she could... and I said ‘Oh, we’ll go round; we’ll find a nice one’.*

*AC: So it gave her greater choice?*

*Lynne: Yes, yeah.*

**(Interview with Lynne - IC06)**

Lynne’s comments suggest that whilst having choice might be seen as important (older people are then in a position to find a “nice home” of their liking), in reality, genuine choice is perhaps, only available to the more affluent. Lynne’s mother is not in a position of having “money” and so her choice of care home setting is inevitably more limited.

It was not uncommon for some informal carers to receive very little practical support in respect of their decision-making process. Informal carer Rose, described being left largely to her ‘own devices’ when trying to find a suitable care home for her mother.

During interview, she said:

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<sup>23</sup> Top up fees – some care homes charge fees above the agreed Local Authority rate. Within such situations, family members or informal carers often find themselves in the position of ‘making up’ the financial shortfall.

*I've been trying to find help on web sites and that... that's the part I'm finding difficult, is sourcing out help.*

**(Interview with Rose – IC02)**

A feeling of not knowing how to choose an appropriate care home environment was a source of significant anxiety and stress. As stated by informal carer, Jackie:

*The stress of actually choosing a care home – she says that it is difficult to know what to look for.*

**(Observation Four – Jackie IC05)**

Both Rose and Jackie spoke in ways indicating that they found the care home admission process complex, confusing and anxiety provoking. Rose referred to feeling as if she was “*floundering in the dark*”). Jackie described feeling that she was in a “*tunnel*”, with no idea of how to find her way out:

*And it's like... we don't know what's actually...you know... what's... ok, 'Well what happens from here; what happens from there?' because we're... this is the first time we've been in the tunnel, it... you know... you don't know what steps there are!*

**(Interview with Jackie – IC05)**

In the process of choosing and then making arrangements for an older person to enter a care home, many informal carers found themselves interacting with various different stakeholders, many of whom did not necessarily share relevant information, one with another. As stated by informal carer, Bryony:

*All of these people are involved in the transition ... especially if somebody's got housing benefit or any extra support... you do need somebody to guide you through it; not because... everybody knows their bit – everybody. We used to call it 'working in silos' – a 'silo mentality' – and that's what it seems like to me; everybody's in their little silo, and they're all ticking their little boxes, and they're all getting it right; but nobody pulls it together and gives the person in the middle the whole picture.*

**(Interview with Bryony – IC07)**

From Bryony's perspective, these different personnel work in separate "silos"; a situation that she clearly finds frustrating. Bryony tells me that as far as she is concerned, there is "nobody" who "pulls it together" and assists the "person in the middle", that is, the informal carer, through the overall care home process. Elsewhere within the interview, Bryony referred to the system as a "nightmare" and a "circus". Her "resentment" at being left to deal with this system on her own is evident within the following extract:

*But that transition... I probably... you probably gathered that, in our conversation, so... I feel very resentful about that, and I don't envy anybody in the same position, at all! In fact, I don't know how other people cope. They probably stumble through it the same as me.*

**(Interview with Bryony – IC07)**

Interestingly, however, not all informal carers appeared to have had the same experience. Indeed, some informal carers described the interventions of the social worker (and hence their experience of care home admission) in far more positive ways. Informal carer Ruth told me, for example, that she "could not praise the system enough" and that the input of the social worker (Chloe) had "lifted a weight off (her) shoulders".

Significantly, this very clear difference in experience gave me a 'way in' to beginning to explore the possible impacts of a care-approach to social work practice. Given Ruth's noticeably more positive comments, I decided to examine the extent to which Chloe (her social worker) had approached her roles and responsibilities *with care*. Specifically, I explored the extent to which Chloe adopted an *attentive* approach to her practise, when working with Ruth.

As stated in Chapter Three, "attentiveness" (Tronto 1994, p. 127) is a critical component of "authentic care" (Holstein et al. 2011, p. 128). It is fundamental to achieving the purposes of care (that is, the alleviation of suffering and distress) because it enables practitioners to show that they "care about" (Tronto 1994, p. 106) those with whom they work. When practitioners show "caring about" (p. 106), they

communicate to informal carers that they are genuinely ‘on side’ and this, in turn, helps alleviate feelings of fear and isolation. Within the final sections of this chapter, I explore expressions of attentiveness in the work of Chloe and other practitioners. I also consider the potential importance of these expressions of attentiveness from an informal carer perspective.

## **The Value of Attentive, Caring Social Work**

In examining the impacts of attentiveness on the admission-related experiences of informal carers, I draw on the theoretical work of Tronto (1994), Klaver and Baart (2011) and Hay (2019). As stated in Chapter Three, attentiveness is a multifaceted concept, the various dimensions of which are expressed in the work of practitioners in several different ways. I begin this discussion by considering the importance of attentiveness in alleviating the practical challenges faced by informal carers at times of care home admission. I then move on to exploring the significance of attentiveness in the provision of emotional or psychosocial care.

### **1. Attentiveness and the Practical Needs of Informal Carers**

It is important to appreciate that at the outset of her care home admission ‘journey’, Ruth was no less anxious than many other informal carers. Ruth was clear that she lacked all knowledge of care homes:

*The first time that I heard ‘nursing home’ I thought: ‘My goodness me, I don’t know any nursing homes! Where are they? I’d had no contact with anything to do with that side of things because I’d always looked after my mother.*

**(Interview with Ruth – IC10)**

She described herself as completely unaware of the care home admission process and expressed high levels of uncertainty concerning the actions she should take:

*Because I’d had no connection with this system at all, I was thinking ‘Oh, what do I do about this; what do I do about that; where have I got to go about this?’*

**(Interview with Ruth – IC10)**

Ruth, like many informal carers engaged in this study, needed practical assistance to navigate the care home admission process. Nevertheless, the ways within which Chloe (the social worker) worked with Ruth appeared to make a significant difference to Ruth's overall admission experience. In the following excerpt, Ruth describes Chloe's approach to providing her with information throughout the care home admission process:

*When she explained about the system for payment, that I found a great relief, because I thought: 'What do we do about paying? How much is it going to cost? Are we going to be able to?' ... the social worker just sort of went onto that next, and when she... you know... explained that... because I said 'I was really worried about payment' and she said 'Oh, no-no, don't be; this is the system, this is what will happen; it will be done with [Local Authority] and she gave me the... it was called the – (name of the department) and their phone number, and said that they would contact me and that this was the system for payment. So that I found very useful, because I'd had no idea how the system would work. So when she explained all that to me, that was a great relief... I found that very useful.*

**(Interview with Ruth – IC10)**

As stated in Chapter Three, care-givers may undertake their caregiving roles and responsibilities *with attentiveness*. Here, Ruth discusses the way that Chloe explained and guided her through the system of payment related to care home admission, in an attentive and “diligent” (Klaver and Baart 2011, p. 688) way. Chloe breaks down the information into a series of manageable steps (“*this is the system, this is what will happen*”). Furthermore, Chloe remains in contact with, and continues to provide Ruth with information and advice *throughout* the care home admission process.

The impacts of Chloe's attentive approach in working with Ruth are very clear. Ruth was clearly worried about how she and her mother would pay for the admission (*'What do we do about paying? How much is it going to cost? Are we going to be able to?'*). However, Ruth's anxieties were alleviated by Chloe's “care full” (Barnes

2012, p. 9) approach towards information-provision, and to her explaining the system of payment:

*I found the whole process very straightforward, and very clear; everything was explained, you know 'Once this is done, this is what will happen next; and when that is done, that's what will happen next'. So I knew... I was sort of 'kept in the loop' all the way through.*

**(Interview with Ruth – IC10)**

Through taking a focused, “diligent” (Klaver and Baart 2011, p. 688) “care full” (Barnes 2012, p. 9) approach to her work, Chloe appears determined to *simplify the system* and to alleviate Ruth’s anxieties and stresses, to the greatest possible degree.

Chloe’s attentive approach to information provision and to guiding Ruth through the system, contrasted sharply with that of Jackie’s social worker:

**Jackie:** *To get hold of the social worker was unbelievably difficult.*

**AC:** *Ok.*

**Jackie:** *Really, really difficult, even by email, by phone, it would take days to actually get an answer from him...you hit your head against a brick wall, basically, to find out what's going on...it's like sometimes you're just left hanging in the air. And it's like... 'We need to sort something; what can we do; how do we go about it?' Because being in this tunnel, now, with care home situation, it's like... well, we don't know what needs to happen.*

**AC:** *Right.*

**Jackie:** *We're not told. We're just like... well... you know... 'What can we do here; we need this, we need that' and it's like... you know... trying to sort out everything; even the bills, ... it's... it's just like a minefield! it would be so much easier if we had, like someone to talk to – to actually like guide us through the steps – it would be so much easier.*

**(Interview with Jackie – IC05)**

Here, Jackie describes the social worker as *inattentive*. It appears that the social worker was inaccessible (hard to “*get hold of*”) and ‘*care less*’ in his approach to information provision. Thus the social worker is described for example, as leaving many questions unanswered and as leaving things “*hanging in the air*”. Whilst it seems that Ruth felt well “*cared for*” (Gray 2010, p.1801) within the care home admission, Jackie clearly perceived a lack of care within her situation. Critically, this lack of care compounds Jackie’s already very challenging experience and contributes to her levels of anxiety, stress and frustration.

As stated in Chapter Three, Tronto (1994) conceptualises attentiveness in terms of “*noticing*” (p. 127). Attentive social workers are those who are observant, astute and pick up on the detail of the situation of others. When practitioners take the time to be attentive and to notice what might otherwise be overlooked, they show that they are concerned for and “*care about*” (Tronto 1994, p. 106) the overall outcomes of the care home admission process. During the research, I observed Chloe’s interactions with Ruth and I was struck by the ways that Chloe had seemingly paid close attention to the personality and possible preferences of the older person. Chloe had noticed for example, that the older person seemed to enjoy “*people watching*” (she discussed noticing this, when she had visited the older person in the hospital). As a result of her observations, Chloe made the following comment:

*“I’ll see how you feel about this but I had thought to ask for a room in a (busier) area – not one tucked away at the end of a corridor”. The daughter smiles and nods at this (in agreement).*

**(Observation - Six)**

Chloe makes a conscious effort to ensure that the nursing home accommodates the older person’s personality and preferences and suggests therefore, that she is given a “*room in a busier area – not one tucked away at the end of a corridor*”. In so doing, Chloe’s actions promote and attend to the older person’s emotional well-being within the care home environment, and arguably contribute to the likelihood of the admission working well. Chloe’s attention to detail was clearly pleasing to Ruth (thus Ruth *smiles and nods at (Chloe’s suggestion) in agreement*).

The “attentiveness” (Tronto 1994, p. 127) of practitioners, is also of course, fundamental to meeting the emotional needs of *informal carers* at times of care home entry. It is to the impacts of attentiveness on the emotional well-being of informal carers that I now turn.

## **2. Attentiveness and the Emotional Needs of Informal Carers**

Attentiveness or noticing is particularly important in respect of psychosocial need because emotional needs may not be immediately visible (Hall 1990). As stated in Chapter Three, some informal carers find it difficult to verbalise their feelings and emotions with the result that such needs could easily be overlooked. When Tronto (1994) writes of attentiveness, she refers to the need for care-givers to push aside all other concerns and distractions, so as to notice, observe and pay attention, to the full impacts of the care-receiver’s situation. The positive impacts of practitioners paying attention to the emotional needs of informal carers, are illustrated in the following excerpt from my interview with Ruth:

***Ruth:** The social worker often asked, you know, if I was coping all right, and if I was all right, and was there anything that... you know... help that I wanted with anything, and I thought that was good.... Yes.... I was asked on several occasions if... you know... I was all right; if there was any information that I wanted...and of course, I was asked if I wanted to join the Carer’s Group.*

***AC:** When the social worker was asking you were you ok, was that... how did you feel about things?*

***Ruth:** Well, I thought that was very nice, that somebody was asking how I was.*

**(Interview with Ruth – IC10)**

Noticing the potential emotional impacts of the admission, means that Chloe can then take action to try and meet Ruth’s emotional needs (she suggests a possible referral to the “*Carer’s Group*” for instance). More than that, however, the very act of *noticing*, of Chloe recognising the ways within which Ruth might be affected by the care home admission experience, was also, in and of itself, an important means of attending to

Ruth's psychosocial needs. Ruth interprets Chloe's attentiveness to the emotional impacts of her situation as an expression of kindness, concern and care ("*I thought that was very nice, that somebody was asking how I was.*").

Such expressions of care have a positive, psychosocial effect because they communicate that care-givers *understand* the challenges facing the other person. As discussed in Chapter Three, understanding is critical to meeting emotional need (Peacock and Nolan 2000; Halpern 2001). As stated by Benner and Wrubel (1989), when individuals *feel* understood they in turn, feel less alone and isolated, with the result that their feelings of emotional distress are reduced.

Informal carers, like Maggie, attached great importance to behaviours that showed practitioner understanding:

*(He) understood how I was feeling and - here we go – [IC begins to cry at this point] - and how (the son) was feeling as well and (he was) so reassuring that – you know – she'll be safe and – she's nearer to me you know, I can go and see her more often: she's only up the road...and... it did, you know, it still frightened me. But I know she's safe [cries].*

**(Interview with Maggie – IC01)**

Maggie describes being comforted by her social worker who tells her that the older person will "*be safe*" and that she, as an informal carer, will now be in a position to visit more often: "*she's nearer to me you know, I can go and see her more often: she's only up the road*". Maggie makes explicit that she interprets the social worker's comments of assurance as an expression of understanding, stating "*(He) understood how I was feeling*". Maggie's appreciation at feeling "*understood*" is very obvious within the extract (she describes the social worker as "*so reassuring*").

Hay (2019) argues that practitioners show attentiveness and "caring about" (p. 106) those with whom they work, when they "go the extra mile" (p. 365) within their practise and engage in "small acts of kindness" (p. 365) that express sympathy and understanding. The *effects* of these expressions of sympathy and understanding on the experiences of informal carers are highlighted within the following excerpts. The first is taken from my interview with social worker, Sarah:

*She was... distraught obviously, coming to terms with what had happened... So we just spoke... weekly... I met her two weeks after the admission (and) she still felt the same. But when we came then to the four-week review, she really felt more comfortable, and she could see that she'd made the right decision for her Mum. And it was then that she was thanking me for all the support and being able to speak to somebody, she said, was the most... most important thing. And she'd sent me a card, then, explaining that although people had given her information, it was just somebody to speak to. And I thought that was so... it seemed so simple, but that's how I helped her adjust to the horrible situation.*

**(Interview with Sarah – SW03)**

The second excerpt is taken from my interview with Team Manager, Ross:

*There's one example which I worked on whereby I asked the carer to complete a... a sort of little 'life history book' really, which would accompany her Mum into the care home, so the care home had a better understanding of the Mum. I think... I remember that person in particular has always stuck with me, because she thanked me for suggesting that, and it was a very sort of therapeutic way for her to have... the carer come to terms with the fact that Mum was moving into a care home, and she felt involved in it.*

**(Interview with Ross – TM03)**

Sarah expresses kindness towards, and shows understanding of the circumstances of an informal carer, through providing her with continued opportunities to talk through her feelings of anxiety and distress. Ross meanwhile, describes involving the informal carer in the completion of the “*life history book*”. Ross’s intervention shows his appreciation of the challenges experienced by informal carers, when relinquishing their caregiving roles and responsibilities and his commitment to alleviating these challenges to the greatest degree possible (he is concerned that the informal carer should feel “*involved*” in the care home admission). The value that these informal carers attach to the understanding actions of these practitioners is shown in that they are both “*thanked*” for their input.

Attentiveness is a critical dimension of what I will from now on refer to as *care-embedded social work*. The other elements of care-embedded social work are discussed in the remaining analysis chapters of this thesis.

## **Summary**

In this chapter I have explored the emotional and practical challenges experienced by a group of informal carers in relation to care home admission. I have also explored the value and importance of “attentiveness” (Tronto 1994, p.127) to practitioners meeting the practical and emotional needs of informal carers at such times. It has been argued, that attentiveness is critical to practitioners showing *understanding* of the needs and circumstances of individuals and families at times of transition and that understanding in turn, helps alleviate feelings of anxiety and distress. In order to *show* understanding, practitioners must of course, *have* understanding. As will be seen within Chapter Six, understanding is dependent upon practitioners developing certain types of relationships with those with whom they work. Critically, I consider the importance of “competence” (Tronto 1994, p.133) and “responsibility” (Tronto 1994, p. 131) (as outcomes of practitioner understanding) in enhancing levels of care within social work practice. It is to Chapter Six that I now turn.

## Chapter Six: Developing a “Care Full”<sup>24</sup> Approach to Social Work Decision-Making

### Introduction

To reiterate, care ethicists perceive care as provided in and through relationships (Sevenhuijsen 1998; Tronto 1994). Within this chapter, I explore the ways within which relationships facilitate *care-embedded social work* practice, through promoting “competence” (Tronto 1994, p. 133) and “responsibility” (Tronto 1994, p. 131) in the work of social workers.

Critically, however, it will be seen that not all relationships are what I call *care-facilitative* and within this chapter I argue that some relationships are in fact, *counter-caring*. The discussion draws upon the work of Buber (1970) whose distinction between “I-thou” and “I-it” modes of interaction is a useful way of understanding the different types of relationships that co-exist within contemporary social work. I-thou and I-it relationships differ significantly both in terms of their linguistic characteristics and their levels of intersubjective presence. As will be seen in the following sections, it is the linguistic characteristics of I-thou relationships and the levels of presence with which they are imbued, that makes such relationships *care-facilitative* within the day-to-day work of practitioners.

I begin the discussion by exploring the importance of I-thou relationships, in promoting *competent* practitioner decision-making within contexts of care home admission. I then move on to highlight the value of I-thou relationships in increasing levels of practitioner *responsibility*. It will be seen that responsibility is critical to increasing the extent to which practitioners actively care for older people and informal carers during care home admission processes.

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<sup>24</sup> The concept of “care full” social work is borrowed from the work of Barnes (2012, p. 9)

## Exploring Competent Practitioner Decision-Making in Contexts of Care Home Admission

Within Chapter Five I discussed the challenges faced by many informal carers when making decisions in respect of care home admission. The findings of previous research show that many informal carers find the experience of making decisions in respect of care home so emotionally demanding, that they simply do not want to make these decisions alone (see Courts et al. 2001; Pearson et al. 2004; Fitzpatrick and Grace 2019). My discussions with informal carers likewise showed that they wanted the input of practitioners when making decisions related to care home admission. Informal carer Rose describes, for example, wanting a social worker to go “*with*” her, when she chooses a care home on behalf of her mother:

*It'd be a lot better if like a social worker or someone could come with you or somebody in the profession could take you around. Help you. Not make the decision for me but to be there. You know, someone to be there.*

**(Interview with Rose – IC02)**

Similarly, when I asked informal carer Jean what had helped her in making her decision in favour of care home entry, she told me that she valued the fact that the decision-making process had been shared; that she, her wider family members and the social worker, had “*all made*” the decision together. Such extracts illustrate the value that informal carers place on shared and collaborative decision-making. In the following sections I argue, however, that the extent to which practitioners are enabled to facilitate decision-making processes, is dependent upon the quality of their relationships with older people and informal carers.

My discussions with practitioners suggested that they sometimes found it difficult to facilitate decision-making processes in meaningful ways. Decisions surrounding care home entry were often complex and posed substantial challenges not just for informal carers but also for those practitioners working with older people and their families (Brannelly 2006). For many practitioners determining *whether* an older person should be admitted to a long-term care setting constituted a significant ethical dilemma. During interview, social worker Aled made the point that whilst care home admission

can result in certain “*benefits*” for older people, there are also important “*costs*” to be “*considered*”:

*Clearly, the whole point of the exercise is to bring some benefit to the life of the (older person) and /or the carer, depending on the circumstances. But I’m conscious that with that benefit there are often a series of costs that need to be considered.*

**(Interview with Aled - SW05)**

Within the following quote, Josie (Social Worker) elaborates upon the perceived nature of these “*costs*” and “*benefits*”:

*Her (son) is very much for (his) mother going into a care home because he sees her struggle ... But again, I don’t know if he’s thinking of the emotional impact... that (it might be) better for her to really struggle at home... than to actually be ‘waited on’, if you like? [Laughs] ... in a care home, but actually it’s not her... it’s not her place – it’s not her home*

**(Interview with Josie - SW04)**

Josie acknowledges the potential “*benefits*” of entry into a care home setting and she makes reference to the older person’s “*struggle*” within her own home environment. Josie suggests that this “*struggle*” might perhaps, be eased in an environment where there are others to provide care and “*to wait on*” the older person. Josie also highlights, however, the potential “*emotional impact*” of an admission by making the point that in entering a care home environment, the older person will face the challenge of leaving behind “*her place...her home*”. The impacts of losing a home were explored within Chapter Five.

Critically, in resolving this dilemma, Josie informed me of her intention to adopt a *care-approach* to decision-making. As stated in Chapter Three, decisions made with care are relationship-dependent in a number of important ways. Significantly, “care full” (Barnes 2012, p. 9) decisions are seen as facilitated through what Dewar and Nolan (2013) call “caring conversations” (p. 1247), which enable practitioners to develop “particularistic” (Moore 1999, p.1) understandings of individual needs and circumstances. Josie makes the point that it is impossible to make standardised

decisions in respect of care home admission for older people. Instead and consistent with a care perspective, such decisions must be made in accordance with the “*individual*” circumstances of older people and informal carers:

*There’s not any set kind of ‘list’... people ask me ... ‘Oh, what’s the criteria for someone going into a care home? ... It’s quite hard to say when you reach the threshold of someone needing to go into a care home in the first place, because it is such an individual thing.*

**(Interview with Josie - SW04)**

Thus, Josie is clear regarding her intention to undertake *caring conversations* with the older person and her family:

*My plan (is) to go and talk to her... and obviously talk to her family as well. Because this lady has capacity... I’m going to be guided by her... So I think they’re the conversations I’m going to need to have in the next few weeks, with all the family, really...*

**(Interview with Josie - SW04)**

The work of Buber (1970) is important in illustrating the precise nature of these caring conversations. Within the following sections, I explore the ways within which the characteristics of I-thou relationships facilitate practitioner understandings and hence promote *competent* social work decision-making.

## **The Linguistic Characteristics of I-thou Relationships**

As discussed in Chapter Three, I-thou and I-it relationships differ significantly in terms of both their linguistic characteristics and levels of presence. I will begin by exploring the linguistic qualities of the two types of relationships and in so doing I make reference to the following two extracts, both of which are taken from my observations of care home reviews. Within the first extract, the practitioner relates to an informal carer in an I-it linguistic mode:

*(The Care Manager) says that she has a “few questions to ask for the review and says that she has a form to complete; she says it is an: “old style document” but a form that she “like(s) to use.” (The Care Manager)*

*firstly asks the daughter about 'privacy'; she asks if the staff at the care home knock before they enter the older person's room. The daughter says that she is unable to answer this question as she is not always with her father in the care home. The daughter says, however, that if staff "knocked and then waited for an answer," that they would be waiting all day."*

*The daughter says that she is: "perfectly happy with what the staff do" and with how "arrangements are managed." The daughter says that her father is: "not so good today"; she says that her father has: "good days and bad days." The care manager asks: "what about choices?" and then asks the daughter if her father is given choices: "for example, choices of meals?" ... The nursing manager responds to this question saying that the older person is generally "quite consistent" in what he chooses to eat. The practitioner asks if the older person will make choices as to his clothing for each day. The daughter says that her father: "won't mind" what he wears.*

**(Observation - Ten)**

I-it relationships exist for instrumental purposes; they are a means to some other end. Since such relationships have a predominantly instrumental function, the dialogue within these relationships tends to be limited to the purpose of *achieving* that instrumental function (in this case, the completion of a care home review). Within the extract, we therefore see that the dialogue is exclusively "task-centred" (Westerhof et al. 2013, p. 358). Since the aim of the interaction is to complete the review undoubtedly with maximum efficiency, the practitioner retains control of the dialogue. The dialogue is "one sided" or "unidirectional" (Westerhof et al. 2013, p. 356), with the practitioner asking a series of functional questions which are then duly answered by the informal carer. The conversation does not extend beyond the confines of the review document.

Within the second extract, the practitioner interacts with the informal carer in a characteristic I-thou mode:

*The social worker says that she feels that the older person has: “much more stimulation” within the care home. The Daughter says that her ... mother is: “much better here.” The social worker talks about the conversations that she has had with the older person since her admission to the care home; she says: “it is nice to hear her talking pleasantly and to enjoy retelling her story.” She (i.e. the social worker) says that in the past, the older person had become “fed up quickly” during conversation and would “ask (her) to leave.” The daughter (agrees) saying that she feels that her mother: ‘enjoys longer conversations now...’.*

#### **(Observation - Eight)**

The difference in the modes of relating within the two extracts is arguably subtle, but nevertheless important. Whilst the practitioner still appears to guide the conversation within the second extract, there is, however, a greater degree of two-sided exchange. There is also more apparent ease and *flow* within the interaction. Zerwech (1997) coins the phrase “genuine dialogue” (p. 260) to characterise conversation marked by high levels of reciprocity and “feedback based communication” (p. 260). Feedback based communication is that where both participants are receptive to and respond accordingly, to the comments made by the other. We see, for example, that when the informal carer speaks of seeing an improvement in her mother’s well-being on account of the admission (*the Daughter says that her ... mother is: “much better here”*) that there are high levels of *spontaneity* within the social worker’s response (she talks of how the older person’s levels of social engagement appear to have increased ‘*it is nice to hear her talking pleasantly and to enjoy retelling her story*’).

Dewar and Nolan (2013) view “caring conversations” (p. 1247) as critical to practitioner understanding. Due to there being more apparent openness and reciprocal interaction within these conversations, it is argued that there is greater potential for practitioners to develop the kinds of personalised knowledge critical to “competent” (Tronto 1994, p. 133) decision-making processes.

### **I-thou Relationships and Presence**

Buber (1970) also draws attention to the importance of the levels of presence within I-thou relationships. From a practitioner perspective being present (being physically

present and ‘there’ over time) is no doubt important to understanding. Several practitioners highlighted the ways within which relationships maintained over time allowed for the sorts of on going caring conversations that enabled them to develop genuine, contextualised understandings of the needs and circumstances of those with whom they worked:

*I walk out from the hospital with Lindsay (the practitioner) and ask her whether she feels differently about undertaking an assessment where she knows the older person and informal carer very well ... Lindsay reiterates that she knows the couple very well and says that this is not just a matter of the length of time; she tells me that Hilda (the informal carer) contacts her to speak with her every day. Lindsay says that undertaking an assessment where she knows the older person and informal carer so well is “definitely different.” She says that she can then “contribute more” and explains, for example, that in this case, she knows that the wife is very particular about the cleanliness / neatness of the home and so she would find it extremely difficult to care for her husband’s particular needs within the home environment.*

**(Observation – Seven)**

The extract is important for a number of reasons. Firstly, it affirms the importance of what Dewar and Nolan (2003) call “relational knowledge” (p. 1247) in decision-making processes. Critically, relational knowledge or what Murphy and Skillen (2015) refer to as “situated and personal knowledge” (p. 637) or “soft knowledge” (p. 637), holds much weight in terms of shaping appropriate decisional outcomes. Lindsay draws attention to possessing such knowledge when she talks about knowing that the informal carer likes her home environment to be especially “*clean*” and “*neat*”. As such, Lindsay states that she “*would find it extremely difficult to care for her husband’s particular needs within the home environment.*”

Secondly, we learn that whilst this kind of knowledge might not be immediately available to practitioners (Murphy and Skillen 2015), it is nevertheless possible for practitioners to acquire personalised knowledge and understanding through retaining a level of “physical proximity” (Malone 2003, p. 2318) with older people and informal

carers, over time. Malone (2003) argues that “physical proximity” (p. 2318) leads in turn, to “narrative proximity” (p. 2318); in other words, being ‘present’ (physically ‘there’ over time) opens up the kinds of discussion and dialogue through which practitioners “come to know” (p. 2318) the needs and circumstances of those with whom they work. Lindsay refers to feeling that she *‘knows the couple very well’* and makes a point of discussing (a) the *length of time* over which she has maintained contact with Hilda and Tom, and (b) the frequency of their continued contact (Lindsay refers to Hilda contacting her *‘to speak... every day’*).

Critically, Lindsay refers to her feeling that decision-making is *“definitely different”* when knowing the needs of individuals and families very well. Lindsay highlights the risk of practitioners making *“assumptions”* in the absence of relational knowledge and understanding:

*Lindsay says that ...workers will “inevitably make assumptions” if they do not know service users and carers well. Lindsay says that this shouldn’t be the case but: “we all do it.”*

**(Observation – Seven)**

As stated in Chapter Three, assumption runs counter to the provision of effective caregiving since it presupposes that the “way” (Buber 1970, p. 124) of others is similar to our own.

Other practitioners too, described feeling more confident in “competent” (Tronto 1994, p. 133) decision-making when having established relationships with those with whom they worked. As stated by social worker, Adrian:

*The better you know them, the better the quality of the decision you make.*

**(Interview with Adrian – SW01)**

Within the following extract, social worker Sarah talks of the benefits of an established relationship in helping to support an older person in making a choice of care home setting:

*Sarah: I mean I can think of a case that I worked with for – on and off – for about 2 years in the community, and then they needed a placement...*

*Yeah, and... and getting to know the person well, and like stuff as well, and...*

*AC: And how did that help, do you think?*

*Sarah: I think because you can really understand what their life was like before and what they needed from the care home, to move in and feel comfortable and to feel like it was an environment that was right for them.*

**(Interview with Sarah – SW03)**

Sarah makes the point that she feels better able to contribute towards the decision-making process (to help determine an environment that is ‘*right for*’ the older person), within the context of an established relationship. From Sarah’s perspective, knowing the person for a period of “2 years” and getting to ‘*know the person well*’ through continued conversation, enables her to facilitate (to guide and shape) the decision-making process in more productive ways.

It is important to recognise that knowing and understanding is not necessarily only the outcome of two-way, dyadic relationships. In order for practitioners to develop contextualised and holistic understandings of the needs of older people, it is often important for them to undertake discussion with the family unit as a *whole*, particularly where older people have dementia and may not, therefore, be in a position to directly provide practitioners with personalised and “relational knowledge” (Dewar and Nolan 2013, p. 1247). In the absence of such discussions the knowledge and understanding of practitioners will inevitably be limited, with the result that the anxieties and stresses of informal carers are then increased. As stated by informal carer Jackie:

*Jackie: We... we really didn’t have any dealings with the social worker at all. It was... he was there – he was interviewing my Mum – he was there on the day; he said a couple of sentences to us; ‘Hello’ ‘How are you?’ and that was it! There was no... sit down; ‘Hi’ you know ‘Can you tell me what your Mum was like?’*

*AC: Right, ok.*

*Jackie: You know ‘...before all of this happened?’ and... you know... ‘Are you a close-knit family; are you this, are you that; what do you do?’ There was no ‘sit down and get together’ with the social worker as a family, as a whole. And then even with my Mum sitting down with us, as a family as a whole. So the social worker didn’t even know anything about us, as a family.*

**(Interview Jackie – IC05)**

Within the excerpt, Jackie is explicit in highlighting the families’ absence of relationship with the social worker. Thus, she states “*we really didn’t have any dealings with the social worker at all*”. Jackie says that there was very little conversation with the practitioner and states “*there was no... sit down; ‘Hi’ you know ‘Can you tell me what your Mum was like?’*”, which she then sees as contributing towards the social worker’s perceived lack of understanding. “*So the social worker didn’t even know anything about us, as a family*”. Jackie’s comments convey her feelings of stress and frustration at feeling that the practitioner does not fully understand her mother’s needs and circumstances. I move on to explore the importance of multifaceted relationships in promoting understanding and hence “authentic caring” (Holstein et al. 2011, p. 128) in more detail in Chapter Seven of this thesis.

From a care perspective, knowing and understanding is not only a matter of dialogue and discussion, it is also a matter of ‘*feeling*’. Relationships of presence, “I-thou” (Buber 1970) relationships, are critical to practitioners *feeling* something of the situations and circumstances of others. Osterman and Schwartz-Barcott (1996) have developed a framework for analysing levels of presence within the work of professionals (see Chapter Three). From the perspectives of these theorists, ‘presence’ is seen less in terms of practitioners ‘*being there*’ (that is, physically present) and more in terms of them ‘*being with*’ individuals and families in their situations and circumstances. When practitioners are ‘*with*’ those with whom they work, they are emotionally available to them; they open themselves up to experiencing the situations of others and to feeling the emotions connected with their circumstances.

Osterman and Schwartz-Barcott (1996) see care-givers as operating at differing levels of presence within their work. Some practitioners are simply 'present' (physically there) but refrain from psychological engagement. Others are seen as "fully present" (p. 25) (both physically and psychologically). Full presence is considered to have potentially "transformative" (p. 25) effects. As an example of fully present social work practice, I refer to the following extract taken from my observation:

*The informal carer (Lois) and I walk into the meeting room and take two seats around a large table. We are joined soon afterwards by the social worker (Chloe) who sits on the opposite side of the table. Chloe asks for an update - i.e. "How are things?" at which Lois becomes very tearful. Chloe waits quietly and then (seemingly relating the daughter's upset to her caring situation), says: "it can be so hard, caring for someone." Lois agrees and says: "it really is difficult." Chloe says to Lois: "You gave up everything" [inwardly, I agree with this statement - reflecting back upon the consent visit]. Lois says: "It's awful. I feel so lost."*

**(Observation - Seventeen)**

Osterman and Schwartz-Barcott (1996) argue that practitioners *show* psychological presence when they are "present orientated" (p. 25), that is, when they are present *in the moment*. Practitioners like Chloe show presence in the moment through demonstrating that they are fully focused upon the person sat before them. At the time of this interaction, Chloe showed willingness to push aside all other concerns and potential distractions to focus solely upon Lois's situation. Full presence is embedded with high levels of "attentive, listening behaviour" (p.25) and as seen within Chapter Five, it is through "attentiveness" (Tronto 1994, p. 127) that practitioners show that they "care about" (p. 106) those with whom they work. Critically, as Chloe shows care towards Lois, so Lois begins to 'open up' and to express her feelings and emotional concerns (*Lois says: "It's awful. I feel so lost."*).

As informal carers articulate their feelings and emotions, it becomes possible for practitioners to empathise with those feelings and emotions. As stated in Chapter Three, the term "empathy" describes a practitioner's ability to experience something of the feelings and emotions of others within the context of their work. In the words

of Trevithick (2014) empathy is: “an ability to look beyond an individual’s overt or external behaviour and to ‘feel’ another person’s emotions – the inner world of sensations” (p. 294).

As observed by Team Manager Ella, it is not always easy for older people and informal carers to talk about how they feel. According to Ella, increasing levels of intersubjective presence within relationships and decreasing levels of psychological distance, is critical to facilitating the expression of feeling and emotion:

*And the thing is... I don't suppose that... distress and damage that's caused to carers and to people is ever picked up, because it's almost 'silent', isn't it? You know, you wouldn't... unless you approached carers, you wouldn't know ... how they felt.*

**(Interview with Ella –TM02)**

The importance of close, trusting relationships in freeing others to express their feelings and emotional concerns is, of course, a fundamental element of relationship-based social work (Trevithick 2014).

It is also the case, however, that not all practitioners seek presence within the course of their social work interactions. Indeed, some practitioners appear to intentionally maintain a degree of psychological distance. The potential for psychological distance to thwart an informal carer’s attempts to discuss emotions and anxieties, is highlighted in the following extract:

*The Practitioner tells the wife (the informal carer) that it is now time to go through the “nursing needs assessment.” The Practitioner has a blank copy of the ‘nursing needs assessment’ in front of her and says to the wife: “you go through it with me and I can point it out to you.” The wife (referring again to her feeling that care home admission is needed) says: “He can't stand; he can't move off the chair even. I can't; I can't. I've noticed this week with myself; I'm getting very weak. I walk very slowly. I think I need a tonic; I'm getting very tired.” The wife goes on to talk about her daily visits to the hospital and that this is difficult for her... The practitioner and (Health Care Professional) acknowledge this...*

*The Practitioner (and Health Care Professional) move on to discuss the various elements of the 'nursing needs assessment'.... I observe the discussion that takes place between (them)... in reaching a decision as to the (older person's) level of need... I notice that the informal carer does not readily contribute to the discussion at this point.*

**(Observation - Seven)**

Whilst maintaining psychological distance arguably enables practitioners to remain 'on task' and to avoid being drawn into deliberating issues of wider concern, it is also clear that relational distance potentially closes down important areas of conversation. The informal carer within the extract seemingly moves from a position of *wanting* to talk about the way she feels in relation to the admission (to perhaps justify her reasons for care home entry and to receive affirmation from the social worker), to being relatively silenced regarding her thoughts and feelings. It is possible that the informal carer feels that she has little to contribute to the technical conversation undertaken between the '*practitioner*' and the '*health care professional*' in the meeting. Since the practitioner does not readily facilitate the informal carer's attempts to discuss her experience on her own terms, then the opportunity for "caring conversation" (Dewar and Nolan 2013, p. 1247) is brought to an end.

It is of course, not only hearing and listening to the emotional expressions of others that facilitates understanding. If practitioners are to genuinely understand the situations of older people and informal carers, they must also engage and connect with those emotions. Buber (1970) conceptualises presence as a psychological and intersubjective phenomena, whereby one individual develops "mutual contact" and a deep, inner "connection" (Itzhaky and Hertzanu-Laty 1999, p. 19) with the 'being' of another. It is within this context of connection that feelings flow and that emotions are then shared. The nature of what Buber (1970) calls "encounter" (p. 66) is arguably captured within the following quotation, taken from my observation with social worker, Sarah:

*'We've been through a lot together, haven't we?'*

**(Observation - Eight)**

The observation was of a ‘closure visit’ where the practitioner was ending her involvement in working with an older person and informal carer after several years of sustained relationship. Sarah’s comments are suggestive of a relationship with fluid “borders” (Buber 1970, p. 55) where she had shared in and was affected by the informal carer’s transition journey. In being affected in such ways, so too her levels of understanding are increased (she had likewise “*been through*” elements of the transition experience).

Klaver and Baart (2011) make reference within their work to “practitioners of presence” (p. 687). Practitioners of presence are willing to open themselves up and to feel something of the emotions of those with whom they work. Within her interview, social worker Sarah identified herself as one such practitioner of presence; she described a recent visit within which she felt and was affected by the emotional impacts of the situation of an informal carer:

*I’ve actually been on a visit this morning to a nursing home where I’ve been working with a family where the daughter holds lasting power of attorney for health and also finances as well; so she’s made all of the decisions around her Mum’s care. And this morning, she explained to me that she’s made a huge decision health-wise for her Mum; and I mean she was in absolute tears – she’s very, very distraught and upset about the whole situation – and she just wanted to... to talk about it, and go through their reasoning, really, and how it feels for her and also her Dad as well... It was... I’m feeling the effects of it myself! [laughingly]*

**(Interview with Sarah – SW03)**

When Sarah describes ‘*feeling the effects*’ of the informal carer’s situation, she is describing the essence of “empathy”. From both an ethic of care perspective and from the perspectives of proponents of “relationship-based social work”, empathy is considered critical to genuine practitioner understanding (Todres 2008). As such, it is considered fundamental to effective assessment outcomes. Empathy requires the highest levels of relational presence; it demands that practitioners ‘stand with’ another in their time of need and distress (Fredriksson 1999).

The benefits of empathy are significant. Hingley-Jones and Ruch (2016) argue that because empathy increases levels of practitioner understanding, it likewise enables practitioners to “think outside the box” (p. 236) and generates creative thinking:

*Adopting a stance that allows and encourages practitioners to ‘look beneath the surface’ in order to understand – to feel – the affective, irrational and unconscious aspects of practice and to simultaneously ‘think outside the box’. (p. 236)*

Due to its potential to promote creative thinking, empathy helps improve the caregiving interventions of practitioners. By way of illustration, I refer to the following excerpt taken from my interview with Care Manager, Carole:

**Carole:** *This lady had had a diagnosis of a dementia... (She had) quite severe behavioural problems and (the family) couldn’t manage her anymore at home... (She and her husband) had been married for 70 years... and there were no (dementia) nursing placements in their local area, so she had to move quite far from where (they were) living. It wasn’t accessible by bus, (the husband) had to wait (until) his daughter was available to be able to go and visit. So he’d gone from being with his wife every day to seeing her once a fortnight... And it was... its heart breaking, you know...*

**AC:** *Yeah.*

**Carole:** *So I was explaining this to the manager... I said ‘Oh, it must be... it’s like grieving. It’s a grieving process.’ And in all fairness – it was only once a month – but they said ‘What if we arrange for a carer ... to take Mrs. So-and-so down to visit him, and just to have a cup of coffee and ...they started doing that... So... it’s only once a month but you know, that just little bit of quality time for the husband, and just to be in his environment, as well... (It) was probably life-changing for him.*

**(Interview with Carole - CM02)**

From an ethic of care perspective, care cannot be adequately delivered *without* feeling (Vonk 1999). Thus, for example, Graham in Finch and Groves (1983) refers to care as

a combination of “labour and love” (p. 13). The importance of feeling the experience of others in heightening practitioner understanding is made explicit within the excerpt. Carole allows herself to feel and to be *affected* by the situation of the informal carer; she imagines the kinds of losses that he has experienced on account of his wife moving into a residential home (she makes reference to a feeling of grief or “*grieving*”) and refers to his situation as “*heart breaking*”. Critically, Carole then *uses* these feelings to generate a creative solution in alleviating the informal carer’s feelings of isolation and loneliness. In this case, Carole arranges for the older person to be taken to ‘*visit*’ her husband within her own home “*once a month*”. Whilst Carole acknowledges that these visits were infrequent, she nonetheless draws attention to their potential impact from the perspective of the informal carer: “*(It) was probably life-changing for him*”.

In some ways, it could be argued that Carole “goes the extra mile” (Hay 2019, p. 365) in trying to attend to this informal carer’s losses and to meet his emotional needs. Carole relays this scenario as an example of a situation where she feels she has worked particularly well in a care home admission context; suggesting perhaps, that this type of practice is not typical of the responses of social workers and care managers. There is no-doubt that Carole goes over and above in seeking to care for this informal carer, precisely because of her levels of empathy for his challenging situation. It is critical to understand that intersubjective relationships are fundamental not only to increasing practitioner “competence” (Tronto 1994, p. 133) in decision-making, but also to increasing levels of social work “responsibility” (Tronto 1994, p. 131) in overall caregiving. As stated within Chapter Three, *responsibility* has to do with the extent to which practitioners involve themselves in the circumstances of another and hold themselves *responsible* for meeting that person’s needs. The importance of responsibility to care is discussed in the following section.

## **Relationships and Responsibility**

Due to their potential for increasing the depths of practitioner understanding, relationships of empathy are associated with *increasing* caring outcomes. As observed by Nortvedt (2001) and Nortvedt et al. (2011), relationships with the highest levels of intersubjective engagement are critical to *drawing* practitioners to care. As practitioners are drawn to care, so too, they increase their levels of care-giving

*involvement*. To illustrate this point, Noddings (2003) argues that *genuine care* (care that is neither “perfunctory nor grudging” (p. 9)) is given where one individual “feel(s) a stir or desire or inclination towards” (p.9) the other.

The difference that relationships potentially make to levels of caregiving involvement, was highlighted during interview by care home manager, Rob:

*I think there have been cases where people have had a lot of involvement yes.... usually those are quite complex cases and people have sort of held it for a while ...so again, I think time and familiarity and meeting on a number of occasions and I think particularly where the behaviour has been quite challenging ...and I think some people have found the involvement that they've had quite useful ...cause there has been I suppose the practical but also the emotional support ...and I suppose that if you just meet someone a few times that bit of support....the relationship just by the nature of it, it can't be there.*

**(Interview with Rob – CHM01)**

Rob makes clear that both the “*emotional support*” and the “*practical*” interventions offered by practitioners are shaped by the quality of their relationships with older people and their families. Similarly, care home manager Michael stated that the input of practitioners was “*totally different*” within the context of meaningful relationships:

*AC: And have you had experiences of that sort of admission and the other sort of admission where somebody isn't known at all?*

*Michael: Yeah...*

*AC: And does that present itself differently do you think?*

*Michael Oh yeah...totally different.... yeah because the attitude...the word attitude is wrong because I was going to say the attitude of the social worker but the ....way the social worker interacts with you is totally different.... and the information that the social worker gives someone to ...and the support the social worker gives someone to come into care.*

**(Interview Michael – CHM02)**

Here, Michael clearly draws attention to the correlation between the presence of care and the presence of a relationship. Michael makes explicit that in the absence of relationship (“*where somebody isn’t known at all*”), both the level of the practical support given by practitioners (for instance: “*the information that the social worker gives someone*”) and their mode of “*interaction*” (the ways they interact with older people and their families) are liable to suffer.

To illustrate the ways within which *feeling* the experience of others potentially increases levels of practitioner “responsibility” (Tronto, 1994, p. 131), I refer to the following extract:

*I’ve recently worked with a granddaughter – there weren’t any other family involved – there was some family conflict, and the granddaughter was the person acting in best interest, because the person had a dementia... and I just remember thinking – she was a bit younger than me, as well – and just thinking how hard it was for her. So I tried to give her as much information as I could, and to try and give her some experiences as well; so I gave her a few examples of people that I’d worked with – obviously, confidential – but saying how they felt about the different homes and experiences.*

**(Interview with Sarah – SW03)**

Within the excerpt, Sarah describes the ways within which she identifies with the emotional pain of the informal carer (she describes the informal carer as being a “*bit younger*” than her and reflects upon “*how hard*” it must have been for the granddaughter to choose a care home setting on behalf of her grandmother). Sarah’s feelings of empathy within the scenario appear to drive her to *increase* her levels of caregiving. Thus, in appreciating the practical and emotional challenges facing the granddaughter in choosing a care home setting, Sarah describes intentionally doing all that she could to facilitate the choice-making process. On the basis of “*thinking how hard it was for her*”, Sarah describes giving “*as much information as (she) could*” to assist the granddaughter in making her decision and outlines (anonymously), the experiences of other informal carers in different care home settings.

The informal carer described in the above scenario appears to have had a significant amount of input in enabling her to make the best possible decisional outcomes. Other informal carers, however, described very minimal support when making a choice of care home setting. By way of example, I refer to my conversation with informal carer Phillip:

*Phillip: No-one actually came out to visit – to see what was going on or anything – so...*

*AC: Do you know why that was?*

*Phillip: I don't know. I find that rather strange and bizarre, because... it's... funny that the person who I actually spoke to, he gave me a list of homes, which he thought were suitable... but I've never met him.*

**(Interview with Phillip – IC09)**

Phillip describes having nothing more than a “*list of homes*” on which to base his choice of care home setting and is clearly disappointed with the lack of practitioner input, which he describes as “*bizarre*”. Importantly, Phillip describes a total lack of relationship with the social worker, stating that he “*never met him*”. Within the following excerpt, he goes on to say that all of his contact with the social worker has been by “*phone*”:

*If you look at families, families have been through a lot. And when a loved one is being taken into care... there, would be... a bit of advice, you know? Turn round to people and say ‘This is what we’re going to do; this is what we’ve got to offer, and this is what we’re going to do.’ It’s putting a plan in place, which would make it easier for people to say ‘Yeah, ... they’re going away, but they’re still going to be fine’... It gives you a point of contact; face to face is a damned sight easier than on the phone.*

**(Interview with Phillip – IC09)**

Phillip draws attention to the need for practitioners to be *present* with those individuals and families with whom they work. Phillip recognises the importance of relationships of physical presence (he says that “*face to face is a damned sight easier*

*than on the phone*”) and highlights the need for practitioners to be psychologically present to those with whom they work (to recognise that “*families have been through a lot*”). Phillip is explicit that from his perspective, both the practical care made available by social workers (“*this is what we’re going to do; this is what we’ve got to offer*”) and the emotional care offered (“*they’re going away, but they’re still going to be fine*”) are influenced by levels of deep, empathic understanding. Insightfully, Phillip makes explicit the importance of the “*face to face*” in eliciting feelings of empathy and in therefore promoting higher quality caregiving. Phillip’s comments are reminiscent of those made by Levinas (1998) who argues that from an ethical perspective “all (persons) are (theoretically) responsible for one another” (p. 107). However, it is in the “face” of the other that our sense of moral responsibility is awakened.

There are several possible reasons for the differences in the quality of social work relationships described in this chapter. The possible psychological risks associated with such relationships, were highlighted within Chapter Three, for example. It is also possible that within the context of contemporary social work practice, where “I-it” (Buber 1970) relationships are favoured, that practitioners feel slightly uncomfortable about engaging in warm, close, empathic relationships with others (Alexander and Charles 2009; Muzicant and Peled 2018). Some practitioners demonstrated having an *awareness* of the need to maintain a so-called professional degree of “formality and distance” (Meagher and Parton 2004, p. 13) within their interactions with others. By way of example, I refer to the following extract taken from my observation with social worker, Sarah:

*The social worker stands up to leave the meeting; the daughter stands up and hugs the social worker. The social worker then leaves the room.*

*I note that as the informal carer hugs the social worker, that the social worker looks slightly embarrassed and a little awkward. I wonder if this is due to my being present within the meeting and whether the social worker worries that I may judge this as perhaps unprofessional on her part? I wonder if the social worker assumes that in being professional, a certain distance must be maintained?*

Within contexts where distanced, business-like relationships are prioritised, there is a risk that physical expressions of care (such as “hugs”) are deemed *unprofessional* (Muzicant and Peled 2018). Sarah’s looks of “*embarrassment*” and “*awkwardness*” suggest that she somehow feels she has transgressed so-called professional boundaries within her interaction. Such excerpts highlight that for many practitioners, forging and sustaining genuine relationships within the current context of contemporary social work practice, is a complex and challenging task. Expectations related to perceived professional behaviour, are by no means the only barrier to *care-facilitative relationships* within social work practice, however. In Chapter Eight, I explore the barrier of time to practitioners developing such relationships in social work practice.

## Summary

In this chapter, I have explored the importance of particular types of relationships to practitioners engaging with *care-embedded social work*; undertaking their roles and responsibilities with *care*. I have argued that relationships of “I-thou” (Buber 1970) type characteristics enable practitioners to develop greater understandings of the “particularistic” (Moore 1999, p. 1) needs and circumstances of older people and informal carers, thus promoting “competent” (Tronto 1994, p. 133) social work decision-making. I also argued that such relationships are fundamental to increasing levels of caring “responsibility” (Tronto 1994, p. 131). It was seen that the level of feeling and emotion often generated within such relationships, has the effect of motivating and drawing practitioners towards higher levels of involvement in caregiving, with the outcome that informal carers then feel more “cared for” (Gray 2010, p.1801) within care home admission processes.

I have also considered something of the temporal qualities of *care-facilitative relationships*, arguing that the competence of practitioners is facilitated when they develop relationships with older people and informal carers, over a period of *time*. In Chapter Seven, I extend this discussion by showing that *care-facilitative relationships* (those relationships between practitioners, older people and informal carers) also need to continue in the time *beyond* care home admission.

## Chapter Seven: Care as the Work of Many Hands <sup>25</sup>

### Introduction

As stated in Chapter Six, *care-facilitative relationships* are not necessarily dyadic in nature. This chapter explores the network of relationships fundamental to the well-being of older people with dementia in care home settings. Firstly, it examines the importance of informal carers and care home providers “working together” (Davies and Nolan 2003, p. 436) to promote good quality care to older people with dementia. Drawing on the work of Kitwood (1997a) and colleagues (Brooker 2003; 2007), it will be seen that good care for older people with dementia is individualised and *person-centred*. The discussion focuses on the roles of informal carers in the provision of person-centred care and it will be seen that care becomes individualised and person-centred, through the “relational knowledge” (Dewar and Nolan 2013, p. 1247) provided by informal carers.

Practitioners who engage with *care-embedded social work* pay attention to the quality of their own relationships with informal carers (see Chapter Six). In addition, they are mindful of the need to promote and maintain the quality of the network of wider relationships that positively impact the care of older people with dementia. It will be seen that the process of informal carers and care home providers *working together* within care home settings, is not easily achieved and is very much dependent on the quality of informal carer – care home provider relationships and interactions. I examine the roles played by social workers in facilitating productive, collaborative, informal carer – care home provider relationships, in the best interests of older people with dementia.

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<sup>25</sup> Mol (2008) states that care is a “matter of various hands working together (over time) towards a result” (p. 21)

## **The Significance of Working Together: Exploring the Information-Provision Roles of Informal Carers in Long-Term Care Settings**

The findings of this study provide good evidence for the importance of collaborative caring; for informal carers and care home providers *working together* to improve the quality of care for older people with dementia. As stated in Chapter Two, informal carers undertake many different types of caregiving roles and responsibilities within care home settings (see Rowles and High, 1996). Within this discussion, however, I will focus on the roles of informal carers as providers of “biographical” (Clarke et al. 2003, p. 697) knowledge, “relational knowledge” (Dewar and Nolan 2013, p. 1247) or what Harvath et al. (1994) call “local knowledge” (p. 29), which has the potential to individualise care for older people with dementia.

As stated in Chapter Two, Harvath et al. (1994) argue that *good* care is dependent upon the integration of “cosmopolitan” and “local” (p. 29) knowledge. The local knowledge of informal carers could be seen to benefit processes of caregiving, in a number of important ways. By way of illustration, I refer to the following extract taken from an interview with informal carer, Lynne. Within the extract, Lynne uses her intimate, personal knowledge to help maintain standards of physical caregiving for her mother:

*Lynne: She's got problems with her legs and she's got a wound on her leg; I want to see it. I know I've got power of attorney over everything, right... but I'd say to [the care home manager] 'How are her legs?' 'Oh, I'm re-dressing it' 'Oh right; I'll come and have a look then'...*

*You know, I want to keep an eye on her legs, I did that on Monday, and they were all wet, you know, because of the heart problem; and that's what's causing this... this wound on her leg... and if they... call a doctor, I want to know. I would like to be there, because I've always been there.*

**(Interview with Lynne - IC06)**

Since many informal carers provide care for significant lengths of time ahead of residential or nursing home admission (see Chapter Two), they develop a level of perceived expertise in understanding and meeting the needs of their older loved ones

(Nolan et al. 1996a). Lynne clearly considers herself to have such a level of expertise and therefore feels that she has a heightened understanding of her mother's physical care needs; she states that having "*always been there*" she "*knows*" the reason for the problem with her mother's legs. Lynne says "*they were all wet, you know, because of the heart problem; and that's what's causing this... this wound on her leg*". According to Rowles and High (1996) the potential of the personalised knowledge of informal carers should not be underestimated. These authors argue that such knowledge can promote standards of caregiving through enabling informal carers to "reveal concerns to staff, before they (might otherwise) become apparent" (p. 20).

It must be recognised, of course, that good care pays attention to both the physical *and* psychosocial needs of older people with dementia. From Kitwood's (1997a) perspective, it is psychosocial care that significantly promotes the emotional well-being of such older people and as discussed in Chapter Two, he identified five interrelated domains of psychosocial need. In the following sections, I explore the importance of the "relational knowledge" (Dewar and Nolan 2013, p. 1247) of informal carers, in ensuring that care home providers meet these psychosocial needs in "personally significant" (Kitwood 1997a, p. 83) ways.

On account of the length and strength of their relationships, many informal carers have a sound understanding of what might work in meeting the psychosocial needs of older people with dementia. One of the domains of psychosocial need to which Kitwood (1997a) refers within his work was that of "comfort" (p. 81). Those with dementia characteristically experience symptoms that give rise to feelings of stress, anxiety and fear (Hoffmann and Platt 2000) with the result that a need for comfort is increased (Kitwood 1997a). Within the following excerpt, Lynne uses her relational knowledge to provide comfort to her mother, Mary:

*Mary (the older person) asks her daughter (Lynne) if she can go to bed (Mary seems a little unsettled at this point). Lynne tries to encourage Mary to stay up and seated in the chair – she says: "you've only just got up." Lynne asks Mary if she would like something to drink – Mary is offered a cup of tea or a glass of mulled wine (Lynne told me that her mother has always drunk mulled wine – "all year round" and that she still brings her a few bottles each week now that she is in the care home.)*

*Mary's face seems to brighten at this point, she asks for the wine and Lynne pours her a glass. Lynne says: "We'll put a nice film on now Mam: she tells me that they always watch a film on a Wednesday afternoon and says that her mother likes: "crime films."*

**(Observation - Eight)**

When I first entered the nursing home, Mary had seemed "*unsettled*" (perhaps agitated and distressed); she consistently asked Lynne if she could "*go to bed*" (despite having "*just got up*"). Lynne had cared for her Mary for many years before Mary had moved into the nursing home, thus she is able to interpret her mother's behaviour (her need for comfort). Kaufmann and Engel (2016) state that older people with dementia "find comfort in the small pleasures of life (that provide) relaxation" (p. 780) and Lynne is seen to provide her with much-needed comfort through offering Mary something to drink and through suggesting that they spend time together, watching a "*nice film*".

Person-centred theorists see "persons (as) existing in relationship" (Kitwood and Brendin 1992, p. 284). Thus, individuals are seen as deriving comfort: ("the calming of anxiety, the feeling of security" (Kitwood 1997a, p. 81)), from connection and "being close to another" (p. 81). Relational knowledge is critical to comfort because it allows care-givers to *connect with* and to meet the needs of care-receivers in ways that are meaningful to them (Kitwood 1997a). Lynne is able to comfort her mother because she is able to connect with her on a very personal level (she knows Mary's personality and preferences and is aware of what is likely to help in alleviating her agitation and distress). Lynne tells me that her mother especially likes "*crime films*" and says that she and Mary have routinely watched a film together on a "*Wednesday afternoon*". Lynne also tells me that her mother has "*always drunk mulled wine – all year around*".

Lynne's actions (which are grounded in the history of their relationship) are seemingly successful in helping Mary to feel "secure" (Kitwood 1997a, p. 81) and "close to" (p.81) her daughter; they appear to instil in Mary, feelings of trust and psychological safety and thus assuage her feelings of anxiety. It is important to appreciate that even those with the most advanced dementia (Mary lived within a

specialist, dementia nursing home) can respond to and affirm the effectiveness of the care given when provided with the opportunity to do so. It was noticeable that when Mary is offered the “mulled wine”, “*her face seems to brighten*” and she appears more contented. It is easy to imagine how Mary’s vulnerabilities might have been increased, had she been faced with a care-giver who lacked the insight to recognise and to respond to her psychosocial need for comfort, in meaningful ways.

Care homes have often been criticised for focusing on the physical and instrumental care needs of older people with dementia, at the expense of their psychosocial needs (Thompson and Thompson 2001). During interview, social worker Aled made the following comment:

*So if this person’s obsessed with 3 meals a day, and is happy talking to a total stranger that washes him in the morning, and he likes a comfortable bed, then ... Bob’s your uncle! He’s got everything he needs in life! But people don’t come in those easily packaged shapes, do they? [Laughs ironically]*

**(Interview with Aled – SW05)**

Aled ironically suggests that if all a person needs is “*3 meals a day, and is happy talking to a total stranger that washes him in the morning, and he likes a comfortable bed*”, then his needs will be well-accommodated within many care home settings. Later within the interview, Aled offered suggestions as to why the caregiving within many institutional settings is so potentially limited in its focus:

*Aled: I think we don’t think about people’s emotional needs enough. I mean ... a way of illustrating that is, when someone goes into a care home, their care service is all-encompassing. So in other words, whatever that person’s needs are, it’s met under that roof. So, for example, I’m a [a city’s football team] season ticket holder. So if I went into a care home, I would reasonably expect to go and see [that football team] every other Saturday. Now you wouldn’t write that on [documentation for care home], because the home would say: ‘We haven’t got the staff for that! Who would pay for the staff’s ticket?’ ... There are the time considerations and monetary considerations that would make that situation untenable.*

*Ok, we look to the family. Well, there's only his wife; she doesn't like football, and she's 83! Well he can't go then, can he?*

**AC:** *Mm.*

**Aled:** *So, we're not looking at... we're looking at care... if you reach a certain age, we assume that all those needs... because, You won't want to go and see football, you won't want to go to the pub; all you want is 3 meals a day, to be warm and to have a chat with a carer a couple of times a day; so therefore the care home can look after you... So there's a 'glass ceiling' of expectation and aspiration there, that can't be met unless your son or daughter, or grandchildren, can come and take you to the football!*

**(Interview with Aled – SW05)**

Aled reflects on the limited attention often paid to the “*emotional needs*” of older people with dementia. Aled discusses this in terms of his own situation, explaining that he enjoys going to watch the football “*every other Saturday*” and describes how this would be largely impossible within the context of a care home environment unless there were family members “*a son or daughter, or grandchildren*” to pick up on this task. From Aled’s perspective, there are several reasons as to why it would be unlikely he would be taken to watch the football on a routine basis. Aled highlights, for example, the issue of resources (“*time considerations*” and “*monetary considerations*”) and states “*the home would say: ‘We haven’t got the staff for that!’*”. Significantly, Aled also draws attention to the low-level expectations often inherent within the provision of care for older people (he refers to a “*glass ceiling of aspiration*”). The low level aspirations often embedded in caring for older people, are very much highlighted in the ‘critical gerontological social work literature’ (see Chapter Three).

The impacts of this “*glass ceiling of aspiration*” on the lives of older people with dementia cannot be underestimated. In highlighting the “social nature of human life” (Kitwood 1997a, p. 83), Kitwood argues that the quality of social interaction experienced by older people with dementia is fundamental to their well-being. Conversely, a lack of positive social interaction is seen to lead to an “ever-deepening ill being” (Kitwood and Brendin 1992, p. 278) amongst those with dementia. In a

similar vein, Sweeting and Gilhooly (1997) make reference to the phenomenon of “social death” (p. 93). Social death is seen to occur when those who are biologically living are treated as if dead, through the lack of attention paid to their social needs. It is critical to understand that social death arises not because older people with dementia are *incapable* of social participation and interaction; rather, it is a consequence of the kinds of ‘low-level’ expectations to which Aled refers in his comments. As stated by Brannelly (2011), older people with dementia are often considered “unworthy of social participation” (p. 662) and little effort is therefore made to engage them in social interaction.

Some informal carers remarked upon the ways within which older people with dementia were excluded from social interaction within care home settings. The following citation is taken from an interview with informal carer, Maggie:

*I'll be honest, the first time I went there, I cried when I saw Alzheimer's in it's full...not very nice. Like the girls there said: (whispers) 'walking corpses.'*

**(Interview with Maggie – IC01)**

Maggie's comment that the older people within this care home setting were like “*walking corpses*” is reminiscent of Sweeting and Gilhooly's (1997) concept of “social death” (p. 93). Insightfully, Maggie sees these older people as facing social death because of their limited opportunities for participation in “occupation” (Kitwood 1997a, p. 83) and social interaction (she refers to the residents as not even having “*a T.V*” to pass the time of day):

*And you went in through the hall and they were all sat in the chair – not even a T.V.*

**(Interview with Maggie – IC01)**

Whilst these residents are described as “*all sat in the chair*”; presumably in the same room, she does not describe them engaging in any sort of conversation. Informal carer Lois makes the point that many older people resident within care home settings not only lack interaction with their peers, but are also provided with very limited opportunities for interaction with care home providers:

*I have to say, I'm not completely satisfied with the care home; I don't think that they do a great deal with clients. I know the staff are in the same room with them; but from what I've seen, there isn't a huge amount of interaction.*

**(Interview with Lois – IC08)**

Some informal carers were very concerned about the perceived lack of focus on the quality of social interaction within some care home settings. Informal carer Phillip described his mother (once a very socially engaged person) as now socially withdrawn. During interview, Phillip said:

*That she (his mother) "loved cooking and gardening" and (that she) was the "leader of the pack" and as "the one everyone looked to". Phillip stated that Connie (his mother) "she was strong." He said that to "see Connie now... is very hard". Phillip told me that his mother is: "half the woman she was".*

**(Observation - Eleven)**

Later, Phillip told me that his mother has now reached a point where "*she won't say too much to anyone*". Phillip clearly had a sense of the importance of social interaction to Connie's well-being; thus he states that the quality of social interaction has implications for the ways that older people with dementia feel about themselves (their "self-esteem" (Kitwood and Brendin 1992, p. 283)) and that older people "*in a care home... need to talk to people; they need to be made to feel that they're still useful*". Phillip stated:

*Somebody said 'She's not talking' I said: 'Ask a question she's got to answer!' 'What do you mean?' 'Open questions; make – her – talk – to you!' 'I can't do that!' I said 'Well how do you think I communicate with Mum?' I said 'That's what you've got to do!'... People have got to realise... although they're in a care home and in long-term care, they need to talk to people; they need to be made to feel that they're still useful.*

**(Interview with Phillip – IC09)**

Within the extract Phillip urges the care workers within the care home setting to engage his mother in conversation. Significantly, he provides them with the tools (the “relational knowledge” (Dewar and Nolan 2013, p. 1247)), to facilitate conversation and social interaction.

Phillip thus suggests, for example, that the care workers address his mother using her “middle name”:

*Phillip says that... (the staff) were calling his mother by her first name - he states that his mother likes to be known by a ‘middle name’*

**(Observation - Eleven)**

Phillip also advises that Connie is encouraged to tell the “stories” of her past during those times where she is more conversational:

*Phillip then says to Elizabeth “If she’s talking (that is, if Connie is talking), ask her about her foot”. Phillip explains that Connie had “caught” her foot in a door (resulting in injury). Phillip says that Connie used to [undertake a certain role] “in the war.” He says “she’s got some stories to tell!”*

**(Observation - Eleven)**

The implication within Phillips’s comments is that if care-givers focus upon talking to Connie about *her* unique life history (her experiences and the things that she has gone through) then she is more likely to ‘open up’ and to begin to engage within meaningful conversation. As stated in Chapter Two, Kitwood did not see “ill-being” (Kitwood and Brendin 1992, p. 278) as a symptom of dementia per se; rather, he viewed it as a consequence of the limited social interaction experienced by those with dementia. From such a perspective, Phillip’s efforts in promoting meaningful social interaction between his mother and her care-givers is of the utmost importance; it provides opportunities for what Kitwood and Brendin (1992) describe as “stabilisation” (p. 280). Stabilisation refers to a situation within which the progress of the path of dementia is slowed down or even reversed, through environments that foster “activity and cooperation” (p. 280).

As an example of the stabilisation potentially achieved through environments that encourage activities and relationships, I make reference to the following extract taken from my observation involving informal carer, Kate. Within her interview, Kate told me that her grandmother (Lorna) had “*flowered*” since entering the care home setting; she said that Lorna’s memory loss was far “*less noticeable*” than it had been when she was at home. Kate attributed this apparent improvement in her grandmother’s condition to her level of engagement in social activity within the care home environment:

*Kate (the informal carer) discusses Lorna (her grandmother’s) involvement in social activities within the care home; she says that Lorna has been involved in an activity to make “Easter bonnets” and that she has also “made cards.”... Kate refers to Lorna taking part in a “Mexican Night”; she says “At home, she was just sitting in a corner doing nothing. She had no quality of life.”*

*Reflecting on Lorna’s life before her illness, Kate says that Lorna was “always a busy woman; she was always doing things for everyone else. She would be up town – doing the shopping.”*

**(Observation - Thirteen)**

Whilst some care home environments have been criticised for their dearth of occupational provision (Perrin 1997), Kate discusses this particular care home as offering high levels of social activity (Lorna is described as having the opportunity to make: “*Easter bonnets*” (and) “*cards*” and to take part in a “*Mexican Night*”). The impacts of this social participation upon Lorna’s well-being are very clear. Kate describes her grandmother as becoming very socially withdrawn within the home environment; she states that Lorna was “*was just sitting in a corner doing nothing. She had no quality of life*”. Lorna is described as having always been a “*busy woman*” someone who was out and about in “*town - doing the shopping*”. Since her admission to the care home, however, Kate sees Lorna as much “*more like herself*” (as more like the person she used to be).

It can be difficult for care home providers to ensure the “individualisation” (Brooker 2003, p. 44) of care for older people with dementia. As stated by care home manager

Rob, those with dementia are not always in a position to provide “biographical” (Clarke et al. 2003, p. 697) knowledge to care home providers:

*So you’re kind of getting someone coming in and obviously with the dementia, they can’t explain terribly well verbally and you’re having to kind of guess at things.*

**(Interview with Rob – CHM01)**

As such, Rob makes the point that from a care home provider perspective, it is often the “*personal history*” of older people that is most “*lacking*”:

*AC: And what about personal history?*

*Rob: That can often be quite lacking ...it’s the thing that we can struggle with most.*

**(Interview with Rob - CHM01)**

Efforts towards working collaboratively with the informal carers of older people with dementia, are hugely important in overcoming this issue. When care home providers sought “relational knowledge” (Dewar and Nolan 2013, p. 1247) from informal carers, it was often far easier for them to meet the psychosocial needs of older people with dementia in meaningful ways. Within the following excerpts, two care home providers describe the impacts of working collaboratively with informal carers to meet the “occupational” (Kitwood 1997a, p. 83) needs of older people with dementia:

*Dawn: It’s getting that information from the families; and we get them to fill in life-story books, and bring in pictures, and... that the staff can relate to...*

*AC: And what sort of impact do you think that has for them?*

*Dawn: Oh, really good. I’ve got an excellent maintenance man, and... you know... we’ve got a resident in our dementia unit who used to be an electrician, so he’s made him a board with sort of plugs and things on there – that won’t harm him, obviously – it’s not connected to anything –*

*that he can... you know... so it's going back to what he's familiar with, you know, so... yeah.*

**(Interview with Dawn – CHM04)**

Dawn discusses the importance of care home providers seeking “biographical” (Clarke et al. 2003, p. 697) information from “families” to develop meaningful occupational activities. Dawn describes how (through the provision of such information), the home’s “*excellent maintenance man*” had produced “*a board with sort of plugs and things*” for one older person who had previously worked as an “*electrician*”.

Care home manager Rob, similarly described how an informal carer’s personalised knowledge enabled the care home to meet another resident’s “occupational” (Kitwood 1997a, p. 83) need:

**Rob:** *So you've got a gent upstairs who takes things apart and fiddles with things and initially, it was quite a problem where as now we realise...whereas we didn't know it at first that yes...he was a 'fitter' and he'd done engineering ...so what he's doing and what he's fiddling with and pulling things apart, makes sense to him and if you know that...you can interpret it and get him involved in doing other things.*

**AC:** *I guess you can facilitate it a bit...and make it a worthwhile occupation almost.?*

**Rob:** *Yes...yes...I mean it still can still cause problems but at least we understand why he's doing it ...and to him it's meaningful.*

**(Interview with Rob – CHM01)**

The personalised knowledge provided in this situation is critical for two reasons. Firstly, it helps the care home providers to meet the older person’s need for “occupation” (Kitwood 1997a, p. 83) in ways that matter (Rob recognises that as the older person “*was a fitter*” and had “*done engineering*”, that it was important to get him “*involved in doing other (related) things*”). Secondly, such knowledge helps to promote levels of tolerance amongst the staff within the care home setting, because it

helps them to understand the *meaning* behind the older person's behaviour. Thus, whilst Rob refers to the older person "*pulling things apart*" as "*still (potentially causing) problems*" within the care home environment, he is also explicit that *understanding* this behaviour and its association with the older person's past employment, shapes the reactions of care home providers in more positive and affirmative ways. As stated by Kitwood and Brendin (1992), older people with dementia need positive, affirmative relationships; such relationships are critical to their sense of "personal worth" (p. 283) and ultimately, to their feelings of "self esteem" (p. 283).

Thus far, I have provided positive examples of informal carers and care home providers working in collaborative ways so as to promote effective caregiving for older people with dementia. It must be recognised, however, that the "interweaving" (Bulmer 2015, p.172) of informal and formal care is not always easily achieved. Indeed, that there are many barriers to collaborative caring within long-term care settings (see Chapter Two). The barriers to collaborative caregiving are discussed in the following sections.

### **Factors Influencing the Involvement of Informal Carers in Care Home Settings**

There are many factors that shape levels of informal carer involvement in care home settings. These factors included for example, the quality of past relationships. As stated by Care Home Manager Dawn, some informal carers simply do not *want* to be involved in caring for an older person beyond institutionalisation because there have been past tensions in their relationships with that older person:

*It can be where people have had disagreements in the past, and haven't had a close family network around them, and... you know... they don't have visitors or whatever.*

(Interview with Dawn - CHM04)

Such findings illustrate that whilst collaborative caregiving is important, informal carers must also be given *choice* regarding their continued caregiving roles and responsibilities. Unresolved feelings of guilt and distress could also be a major barrier

to informal carers continuing caregiving within care home environments. As highlighted within the following observational field note:

*Kate talked about how she and (another family member) had both visited Lorna in the care home on 'Mother's Day'. Kate explained that the visit had been very short ("less than five minutes") as (the other family member) had been too upset to stay at the care home.*

**(Observation - Thirteen)**

Such comments show that the emotions experienced by informal carers at times of admission are not easily resolved and highlight the importance of the roles of practitioners in providing care to meet these emotional needs (see Chapter Five).

A significant barrier to the continued caregiving involvement of informal carers was also the potential *location* of the care home setting. It is important to recognise that many of the continued caregiving roles and responsibilities of informal carers were undertaken within the context of care home visits. As such, care homes need to be geographically accessible if informal carers are to remain involved in caregiving beyond the time of care home admission. My discussions with participants highlighted that there were significant limitations in the availability of certain types of care home provision. This meant that when some older people needed these care homes they were often located at a considerable distance from family and friends, which limited the extent of informal carer visits. As stated by Social Worker, Alice:

*We don't have many (dementia) nursing homes... They never have availability... So you can say it could be years before someone is placed there. And 2 of those homes are all the way up the top of [a particular locale] and for people that are living down in [a more distant locale] it's a long way! Especially for an elderly spouse to visit.*

**(Interview with Alice – SW06)**

Alice makes the point that there were particular limitations on the availability of dementia nursing homes in the Local Authority. This meant that many older people needing this type of care provision had to move outside of the Local Authority area.

Levels of informal carer visiting (and hence continued caregiving) were then significantly curtailed.

The findings of this study show, however, that the most influential factor in determining levels of continued informal involvement in caregiving, was the quality of their relationships with care home providers. Such a finding is consistent with the earlier literature in this area (Bowers 1988; Hasselkus 1988; Chen et al. 2007). Informal carers were clear that the perceived quality of their relationships with care home providers was critical to their confidence in relaying “relational knowledge” (Dewar and Nolan 2013, p. 1247) on behalf of the older person. As stated by informal carer Lynne, relationship or “*rapport*” was fundamental to her feeling able to inform and direct the caregiving efforts of care home providers:

*But I've now built up a bit of a rapport with the staff. I tell them what my Mum likes and doesn't like.*

**(Interview with Lynne- IC06)**

Without relationships, informal carers can be reluctant to influence the quality of caregiving. As stated by Care Manager Janet, when informal carers lack confidence in their relationships with care home providers, they often worry about: “*rocking the boat*”. When Janet spoke of “*rocking the boat*”, she was referring to informal carers’ anxieties about offending care home providers. Many informal carers worry that there will be negative consequences for the older person if they upset or offend the staff within a care home setting.

I learnt much about the importance of informal carer – care home provider relationships in shaping the knowledge provision roles of informal carers during my conversation with Phillip. (I introduced Phillip earlier in this chapter when discussing the roles of informal carers in promoting social interaction with care home providers.) At the time of my involvement with Phillip, his mother (Connie) had lived within the nursing home for a period of “*around thirteen months*”. At that time, the social worker was about to undertake a review of Connie’s care within the nursing home. During the review, I observed Phillip provide personal knowledge to help a care worker engage Connie in meaningful social interaction. I recall feeling surprised that it had taken Phillip so long to provide this sort of knowledge; he was clearly very

frustrated at the apparent lack of social interaction with his mother. I wondered why Phillip had not seemingly made previous attempts to provide such knowledge.

I was gifted a moment of insight when within a later interview, Phillip described having only very limited relationships with the staff within the nursing home setting. Prior to entering the nursing home, Connie had lived within another residential home (she had ‘transferred’ to nursing home care when her health deteriorated). Phillip compared his present relationships with the staff in the nursing home setting with his relationships with the care workers in the previous residential home. In the residential home, Phillip stated that the staff were “*absolutely fantastic!*” and described being on “*first-name*” terms with them. In comparison, Phillip describes not really knowing the staff within his mother’s current nursing home:

*I knew 90% of the carers ... there by first name; I only know a couple of people up (here) by first name.*

**(Interview with Phillip – IC09)**

The fact that Phillip had provided the care worker with this knowledge within the context of a Review Meeting<sup>26</sup> seemed important. It appeared that in the absence of productive relationships, the Review Meeting (where there was a social worker present) gave Phillip the confidence to say *what* he wanted and to provide the sorts of information to help meet his mother’s psychosocial needs.

Practitioner Janet made the point that it can take a long time for informal carers to develop relationships with care workers in care home settings:

*They have to build up – relationships with the staff that work there, and it takes a long time for someone to feel comfortable.*

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<sup>26</sup> Older people who require Local Authority funding to enter long-term residential care will generally have an allocated social worker or care manager. This social worker or care manager usually undertakes a review (four to six weeks after admission) to evaluate the impacts of the care home admission. Thereafter, members of the ‘Care Home Review Team’ undertake reviews on an annual basis.

(Interview with Janet- CM01)

In the meantime, Janet states that informal carers can be very reluctant to raise their concerns with care home staff:

*Janet: Even though they might have a little concern or an issue, they don't like to mention it to the staff.*

*AC: Mm. Why wouldn't they mention it, do you think; is there a reason for that, or...?*

*Janet: I think sometimes they think 'Oh...' something little, 'We won't mention it – they're doing their best', you know? It could be something really small, like... the lady – or the gentleman – the resident – have always slept with the bedroom door open, and they're keeping the door closed, it could be something that simple, you know. But I think families sometimes don't like to 'rock the boat' kind of thing. Not that there'd be any implications, but they just don't always feel comfortable mentioning their concerns. It takes a long time, I think, for carers to build up a relationship with staff and managers in care homes.*

(Interview with Janet – CM01)

Janet made explicit the impacts of a lack of informal carer – care home provider relationship when she told me elsewhere, that some informal carers wait “*all year*” (that is, for the annual review) “*to mention complaints and issues*”.

Such comments caused me to reflect upon the important roles and responsibilities of social workers in long-term care settings, particularly in enabling productive informal carer – care home provider relationships. Thus, I see social workers as fundamental to a network of relationships within care home settings. In the final sections of this chapter, I explore the roles of social workers in facilitating positive informal carer – care home provider relationships, with a view to collaborative caregiving.

## Exploring the Roles of Social Workers in Facilitating Collaborative Informal Carer – Care Home Provider Relationships

Throughout this chapter, I have argued that collaborative informal carer – care home provider relationships, have the power to transform the quality of caregiving to older people with dementia. Drawing on theories of “person-centred care” (Kitwood 1997a) it has been argued that the “relational knowledge” (Dewar and Nolan 2013, p. 1247), provided within the context of these relationships, is critical to meeting the psychosocial needs of older people with dementia and to challenge possible low-levels of caring. To reiterate, however, collaborative relationships between informal carers and care home providers are not always easily achieved, particularly when informal carers distrust the quality of care in institutional settings (see Chapter Five). Care home managers like Elizabeth, very much understood and accepted that trust took time to develop:

*They've always got to have a settling-in period; nobody's going to trust you with a family member immediately; they've got to suss you out, really; get to know you, make sure their relative is being looked after properly. They usually relax a little bit then.*

(Interview with Elizabeth – CHM05)

Until the point of developing “trust”, some informal carers might remain wary of the quality of care provided within care home settings with the result that relationships might well be strained. It seemed that social workers had critical roles to play in easing the anxieties of informal carers at such times; providing them with the kinds of reassurance that helped them to learn to trust the quality of care. By way of example, I refer to the following extract, taken from an interview with social worker, Sarah:

*Sarah: What I did, I... after that first 4-week review, I met with them again 2 weeks later. We spoke about... there were 3 different issues; one to do with medication – the time of medication – so it was about looking at those individual issues. So I'd say then 'Right, ok, if we've addressed those, are there any other concerns?' and there was, at first, but I think it was about her 'letting go' a little bit. And as we got, then, to the 3-month*

*review, I'd done 2 other informal visits, and she'd said... well, we didn't do a... it was to do with the medication, again, and the carer explained the situation. And because she'd built a relationship with them, she learned to trust the care and learnt to trust that things were being done properly...*

*AC: It sounded like she valued you being involved until she developed that confidence?*

**Sarah:** *Yeah, she had that confidence and trust, and to be able to – if there were issues – that she could take them to the manager. Because I think, at first certainly, she was feeling so stressed about the whole situation, it was like... she was going to explode, because of her anxieties. And yeah, so I think it just took that bit of time for her to have someone else that she could go through; so almost like a third-party, really, to work on their relationship – the home's and the carer's.*

**(Interview with Sarah – SW03)**

Sarah described her method used in working with an informal carer to help her to learn to trust the quality of care provided for her husband. Sarah discusses remaining involved in working with the older person and informal carer in the time beyond care home admission and describes how, through her continued involvement, the informal carer learns “*to trust that things were being done properly...*”. Critically, as the informal carer became convinced that “*things were being done properly*”, so too, she “*built a relationship*” with the staff within the care home setting. Sarah is explicit that it is within the context of this “*relationship*” that the informal carer develops the “*confidence*” to take her concerns directly to the care home providers. In the meantime, Sarah’s mediating or “*third-party*” role within this situation, was critical to offsetting the informal carer’s “*anxieties*” and helped allay her feelings of distress until she gained a greater level of assurance in the quality of caregiving.

Sarah is clearly very understanding that “*anxieties*” experienced by informal carers within such situations are often related to their difficulties in accepting the need for a care home admission. Within such situations, it is not uncommon for informal carers

to project their feelings of anxiety and guilt on to care home providers; with the result that their expectations for caregiving can seem on times, unrealistic:

***Sarah:** There are loved-ones who've done everything up to the point of admission, so when the placement first starts, I think it starts off very traumatic. I can think of a certain case where the wife would be on the phone to me almost daily, saying 'This has happened, this has happened' and...it was about sort of looking at those scenarios; they couldn't do everything that she did for her husband. They feasibly couldn't, because her life completely revolved around him and I think it took her a lot, then, to take a little step back from what she was doing, and...*

***AC:** Yeah.*

***Sarah:** ...when we got to the 4-week review then, things weren't perfect by any means, and we still had things to work through, but we did another review then, 3 months later, and things were going really, really well. So... because she'd gained more of a relationship with the carers at the home, and the manager, she could see that they were delivering the best care they could.*

**(Interview with Sarah – SW03)**

Again, Sarah emphasises the importance of informal carers developing trust, through developing a “*relationship with the carers at the home*”. In facilitating that relationship, Sarah provides on going reassurance and support (she makes reference to an initial and subsequent “*review*”). As a part of her role, Sarah mediates between the informal carer and care home provider (she describes “*working through*” the “*issues*” and “*scenarios*” highlighted by the informal carer) until the informal carer developed confidence in the care provided (“*she could see that they were delivering the best care they could*”).

Some care home providers have what Sandberg et al. (2002) call “*empathic awareness*” (p. 507) of the challenges of care home admission from an informal carer perspective. In other situations, however, care home providers appear far less aware of the impacts of the care home admission experience, and how these might ‘play out’

in the actions and interactions of informal carers. Within such situations, social workers have significant roles to play in raising an awareness amongst care home providers of the emotional gravity of care home admission and helping them to understand and to appreciate why informal carers might present as perhaps ‘demanding’ in their behaviours. By way of example, I refer to the following extract taken from an interview with Team Manager, Ross:

*I'm thinking of a case that I worked on – it's going back to starting as a social worker... I was talking about those anxieties, and it was a son that had cared for his Mum, and he was sort of like on the phone every 10 minutes, and he wanted to sort of be there all the time, check up on what they were doing. And in this situation, the care home had a very, very negative view of the son, and was at the point where they were trying to serve notice because of the son.*

*I think, when we did work with that carer he was absolutely fine...and we were able to resolve it, but I think that is just... I suppose ... for care homes to try and have more of an understanding of how hard it is for sons and daughters obviously, when somebody goes into a care home.*

**(Interview with Ross – TM03)**

During his interview, Ross demonstrated a depth of understanding of the potential impacts of care home admission on informal carers. He recognised, for example, the issues experienced by informal carers in losing their caregiving “*identities*” and the importance of providing support to promote their continued involvement. Within the above extract, Ross is seen to use his own understanding to facilitate the empathic understandings of these care home providers; he wants them to recognise “*how hard it is for sons and daughters obviously, when somebody goes into a care home*”. For Ross, it is clearly important that these care home providers are able to interpret the actions and behaviours of informal carers in light of the very real “*anxieties*” often experienced at the onset of care home admission. Ross is clear that in working within this situation, the difficulties were eventually “*resolved*”. The risks of failing to “*resolve*” such situations are, however, very real (Ross states that the care home were *trying to serve notice because of the son*). Clearly multiple moves (and hence

transitions) are far from in the best interests of older people with dementia and such extracts highlight the critical importance of practitioners intervening within such situations, in a timely and proactive way.

From Ross's perspective, it is easy for informal carers to misunderstand the kinds of care offered within care home settings and to therefore have false expectations of care home providers:

*I think it's... can be really hard to... as a family – as a carer – to understand, sort of, the different care homes and the type of care that's provided; the day-to-day activities, what the routines are and what their life... what type of care... quite often it's seen, I suppose, that if somebody needs to go into a care home to have 24-hour care, but often the reality is that that is that it's not that 24-hour care which people sometimes expect they're going to be getting.*

**(Interview with Ross – TM03)**

He also states that some informal carers are unsure of the sorts of roles and responsibilities within which they can feasibly engage within long-term care settings:

*It's frustrating for the carers as well, is in terms of what level of involvement they can still have once the person has moved into care, because it's... I think... [it can be] too easily ... seen that you're a carer for x-number of years, for your Mum or your Dad; your Dad or Mum goes into a care home, and then from that day your care role has stopped.*

**(Interview with Ross – TM03)**

Together, unrealistic expectations and a lack of clarity around respective roles and responsibilities, can easily give rise to significant tensions in relationships (Shuttlesworth et al. 1982). In resolving some of these tensions, Ross describes a potential solution by drawing up a “contract of expectations” between informal carers and care workers:

*I've sat down with carers, with members of staff in the care home, to try to detail what the expectations are upon the care home, what the*

*expectations are upon the family, and try and sort of get some balance, really, in terms of that level of 24-hour care – of what does that look like*

(Interview with Ross – TM03)

Ross's comments suggest that in detailing "*expectations*" (both the expectations that informal carers might reasonably have of care workers and care workers' expectations on the "*family*"), it is possible for practitioners to help the respective parties reach a level of agreement. This agreement is critical in helping to preserve longer-term relationships.

Having outlined the types of important roles that might be undertaken by practitioners in facilitating collaborative relationships and in therefore promoting effective caregiving, it is important to appreciate, however, that many social workers had only very limited contact with older people and informal carers in the time beyond care home admission. As will be seen in Chapter Eight, the pressures of time within social work practice mean that many practitioners *cut short* the duration of their involvement in working with older people and informal carers, following care home entry. The problem of time and its adverse impacts upon *care-facilitative relationships*, are explored in Chapter Eight.

## **Summary**

This chapter explored the importance of multifaceted relationships in promoting effective caregiving to older people with dementia. The discussion began with an exploration of the importance of informal carers and care home providers "working together" (Davies and Nolan 2003, p. 436) to meet the needs of residents within care home settings. Particular focus was placed on the knowledge provision roles of informal carers and the ways within which the "relational knowledge" (Dewar and Nolan 2013, p. 1247) of informal carers, assisted care home providers in meeting the psychosocial needs of older people with dementia.

It was argued that the extent to which informal carers felt able to influence caregiving within care home settings, was dependent upon the quality of their relationships with care home providers. When these relationships were inadequate, informal carers were not in a position to shape and to direct care. Practitioners who engage with *care-*

*embedded social work* are mindful of the importance of informal carers and care home providers working together to care for older people with dementia. These practitioners are also aware of the challenges of collaborative caring and take action to address these challenges. The chapter explored the importance of practitioners remaining involved in working within care home settings, so as to facilitate the development of productive, collaborative informal carer – care home provider relationships. I provided examples of the types of roles and responsibilities undertaken by practitioners in alleviating relational tensions and in preserving longer-term relationships.

I ended this chapter by stating that despite the important roles of practitioners in care home settings, these roles are often curtailed. Many practitioners have minimal involvement with older people and informal carers following care home admission because of pressures on time. Chapter Eight moves on to explore the problem of time in social work practice and to consider its implications for *care-embedded social work*.

## **Chapter Eight: Time to Care in Social Work**

### **Introduction**

The findings of this study have strongly evidenced the importance of certain kinds of relationships, to *care-embedded social work*. In this chapter, I explore the importance of time to these relationships. I consider the ways within which constrained time in social work practice potentially undermines the development of *care-facilitative relationships* and hence diminishes the caring endeavours of practitioners.

In beginning this chapter, I draw upon the work of Adam (1990; 1995; 2004) to explore the ways within which time is “commodified” (equated with money) within contemporary social work. I consider the effects of time commodification on social work and examine the ways within which the pressures of time potentially diminish the extent to which practitioners might incorporate caring ethics and values into their work, thus decreasing the quality of their relationships.

Significantly, the discussion explores the potential harms of inadequate caring from the perspectives of both informal carers in transition and practising social workers. It will be seen that *care-embedded social work* was of the utmost significance to the practitioners engaged in this study; it resulted in them feeling satisfied with their work and gave a sense of having performed social work, *well*. On the other hand, feeling *unable* to care gave rise to feelings of dissatisfaction, demoralisation and what Fenton (2015; 2020) calls, “ethical stress”. The actions needed in addressing the limitations on *care-embedded social work*, are picked up in Chapter Nine of this thesis.

### **The Commodification of Time within Social Work**

During interview, practitioners were asked to identify their perceived barriers to working well within situations of long-term care entry. The barrier most often discussed as undermining the efficacy of admission-related practice, was that of time. As stated by social worker, Chloe:

*We all want to provide the support the carers deserve; but I think if we're honest, we don't always provide as much support as we'd like to because of the time constraints.*

**(Interview with Chloe – SW02)**

Adam (1990; 1995; 2004) refers to the “commodification” of time with the emergence of industrial capitalism. As I argued within Chapter Two, when time is commodified, it is given a financial value (Lovgren et al. 2010) and when finances are constrained, there is a heightened need to use time with maximum efficiency. The equation of time with money and the focus upon *saving time* is made explicit within the following extracts (taken from observations of social care ‘panel meetings’<sup>27</sup>):

**Extract One:**

*TM01 states that she feels that if the call is purely for pressure relief, then this may need to be provided by community nursing staff. TM02 then says that she will “seek clarification” from the social worker who has made the request for increased support.*

*TM02 returns to the room a few minutes later and says that the social worker will explore the need for calls at the level identified (i.e. the amount of time requested), in further detail. TM02 said that the social worker had stated that a reduction in the time of the calls “was not fair”.*

**(Observation - Four)**

**Extract Two:**

*TM02 then introduces the second case for discussion. Again, TM02 details the service user’s physical care needs and (reading from the panel form) outlines the role of the family member (“carer”) in providing assistance to the service user. TM02 states that the social worker making the request “has negotiated” – she says that the care manager has discussed a decrease in the amount of support provided with laundry*

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<sup>27</sup> Panel Meetings: Within social care panels, team managers were seen to discuss the assessments of practitioners and to scrutinise their requests for allocations of care provision.

*tasks in order to “make room” for the extra care provision. The request for support is approved.*

**(Observation - Four)**

When time is given a monetary or economic value, there is significant pressure for practitioners to *save* time wherever possible. The extracts highlight the need for practitioners to be mindful of cost (and hence time) when making arrangements for the provision of care. Within Extract One the request for additional care provision is refused (at least temporarily) until the social worker has gathered more information. It seems that the social worker is regarded as giving insufficient consideration to time/cost saving strategies when making his request (in this case, the Team Managers question whether the cost of the increased service could be absorbed by another agency). Within Extract Two, however, the request is considered legitimate. Here the giving of time on the one hand, is negated (cost wise) through taking away time on the other (the decreased amount of time for *laundry tasks*).

### **Time-Saving Strategies**

My discussions with participants suggested that two fundamental strategies were used in saving time within the organisation. The first is consistent with what Adam (1990; 1995; 2004) calls “compression” and has to do with increasing the pace of work, so as to reduce the “money time... tied up in the process” (2004, p. 128). Many practitioners spoke of the accelerated pace of their workloads and discussed feeling the need to ‘squeeze’ more work into less time. As stated by social worker, Sue:

*Sue: Then they (that is, the informal carers) come to the meeting, and then... it's usually the DST<sup>28</sup> ... then they're looking... if the person doesn't have capacity, you've got to go through the capacity assessment and the best interest assessment, so you're doing three big decisions in one afternoon.*

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<sup>28</sup> ‘DST’= ‘Decision Support Tool’ – used in assessing a person’s eligibility for ‘Continuing Health Care’ funding.

*AC: Yeah.*

*Sue: And I understand that you've got the Hospital Discharge Process to work through because you've got to get people in and out of hospital as quickly as possible, but where else in life would you make 3 major decisions in one afternoon? ... I can't think of any other examples where you would do that.*

**(Interview with Sue – SW08)**

Sue's comments suggest that she finds the pace of her work extremely intense; she refers to having to make "*three major decisions in one afternoon*" and implies that the time allocated for these "*major decisions*", is simply inadequate (thus she states she "*can't think of any other examples*" where such important and consequential decisions are made in equally, time-limited ways).

The second time-saving strategy highlighted by participants was the *standardisation* of time. Practitioners were *kept to time* through the implementation of policies and procedures, which set stringent 'time-scales' for the completion of social work activities. Many social workers discussed, for example, the need to arrange care home admission from an acute hospital setting within a period of "*twenty-eight days*". The standardisation of time is an example of what Adam (1990; 1995; 2004) calls the "colonisation" of time. The colonisation of time in social work is seen in the prioritisation of *clock-time* over other, subjective times. As stated within Chapter Three, "lived time" (Stone 2012, p. 1) is subjective, unique and differs from person to person. Policies that standardise time, set time-scales with reference to clocks and calendars ("*twenty-eight days*" for hospital discharge) and *fail* to acknowledge the need for temporal flexibility.

### **The Impacts of Time-Saving Strategies on Social Work Care**

Within the following sections I explore the impacts of these time-saving strategies on the quality of social work relationships. In beginning this discussion, I draw again upon the work of Tronto (1994) and Klaver and Baart (2011), to explore the importance of expressions of attentiveness in building *care-facilitative relationships*. As discussed in Chapters Three and Five, "attentiveness" (Tronto 1994, p. 127) is a

way of practitioners showing that they care about those with whom they work. As practitioners show “caring about” (p. 106) or “caring orientation” (Reid et al. 2015, p. 905), so relationships are developed and maintained.

Critically, levels of attentiveness are very much shaped by time. As will be seen in the following excerpt, practitioners *use time* to show attentiveness. Time is a critical means of expressing that practitioners care about the needs and experiences of individuals and families:

*We've got one lady here who doesn't have visitors, and her social worker – if she's visiting anybody else in the building – will come and say hello.... Might bring her a box of chocolates... you know, it doesn't really matter, it's the fact that she's shown up. She might bring in the paper for the day; but it's not about the things, it's the fact that she shows up without having to be there. And I know that's unusual, but it makes so much difference to that lady, to have a visitor.*

**(Interview with Elizabeth – CHM05)**

Klaver and Baart (2011) describe “beneficent attentiveness” (Klaver and Baart 2011, p. 689) as “attentiveness for the sake of attentiveness” (p. 690). It is attentiveness shown simply to communicate *care* and to make visible, a practitioner’s affective feelings for the situations of those with whom they work. The practitioner described within the extract, recognises that this older person does not have visitors and so gives of her time freely and generously, to show the older person that she is “cared for” (Gray 2010, p. 1801) and valued. Care home manager, Elizabeth, makes the point that the “*social worker (within this scenario)... shows up without having to be there*”. Elizabeth clearly interprets the practitioner’s actions as an expression of kindness (a “gift of care” - Bolton 2000; Brinkman 2008); she describes the perceived impacts of this ‘gifted time’ on the older person (*it makes so much difference to that lady, to have a visitor*).

The ways that practitioners use time, says much about their priorities and values. When practitioners use their time to focus solely upon the completion of instrumental tasks and when they avoid social interaction, they express value for the task and not

for the person sat before them. By way of illustration, I refer to the following extract, taken from an interview with care home manager, Michael.

*I can see the person sitting there.... and it was 'oh well, this is it.... I'm glad we've found a place for your nearest and dearest; that's fine, lovely, can you sign here please' and the process is over.... very sharp.... not sharp but very matter-of-fact.... people don't want matter-of-fact.... not sharpness, that's the wrong word, but it's matter of fact 'oh well, here we are, we're done...everything sorted"... yeah.... a hardened approach to it...*

**(Interview with Michael – CHM02)**

Here the practitioner's interaction is described as distanced and formulaic; he or she is focused on using the time available for the completion of the task at hand. It is the task (and not the older person) that warrants the practitioner's attention. Such modes of interaction are characteristic of "I-it" (Buber (1970) relationships) (see Chapter Six). Critically, Michael is also clear that when such practitioners interact with older people and informal carers in such ways, they fail to express empathy, understanding and *care*. Michael's perceptions of the social worker as *uncaring* are clear when he describes the practitioner as "*hardened*" in his or her approach.

"Caring efficacy" (Reid et al. 2015, p. 905) may be defined as: "the ability of a person to convey a caring orientation and build up caring relationships" (p. 905). The previous examples show that *how* practitioners use time, has a fundamental impact upon the quality of social work relationships. To elaborate on this point further, it can be seen that when practitioners took their time and particularly when they used time in accordance with the specific temporal needs of informal carers, they clearly showed "attentiveness" (Tronto 1994, p. 127) within their work.

By way of example, the time needed for decision-making in respect of care home admission is subjective; it is unique and differs from person-to-person. Cipriani (2013) refers to the concept of "kairos time" (p. 10). "Kairos time" has nothing to do with the times of clocks or calendars but refers to an individual's intuitive sense of the right time for an "action to be accomplished" (p. 9). The following excerpt shows that

some informal carers intuitively felt that there is a ‘right’ time for care home admission to take place:

*I feel that the time has come where my mother would be better off in a place where she has 24-hour support. I am really worried about making this decision as I want her to stay at home really, but I know that things are changing and she needs more help.*

**(Data from Documents related to Observation Eight)**

Many informal carers “worry” about making a decision in favour of care home admission (see Chapter Five). Nevertheless, this decision is arguably eased when informal carers recognise the need for “*more help*” and when they are intuitively convinced that the “*time has come*” to make alternative caregiving arrangements.

Klaver and Baart (2011) highlight the importance of practitioners attuning to the temporal subjectivities of those with whom they work. In so doing, it is argued that practitioners express “attentiveness” (Tronto 1994, p. 127) and show caring in ways that then enable the development of *care-facilitative relationships*:

*She gently persuaded me ‘Have I thought of Mum going into a home?’ I said ‘Yes, I’ve thought; but I don’t want her to.’ As this lovely social worker could see my Mum getting worse, you know; and she didn’t push me, she didn’t say ‘You’ve got to do this’; she just said ‘Do you think now is the time?’ and she was very gentle in her approach, and took her time; talking me round.*

**(Interview with Lynne – IC06)**

Lynne described her social worker, Sarah as “*taking her time*” when working with her within the decision-making process. Lynne’s appreciation of Sarah’s “*gentle*” manner and the impact of Sarah’s refusal to “*push*” Lynne beyond her own temporal pace, is clearly interpreted as an expression of care and assisted the development of their subsequent relationship. Sarah’s expressions of care are clearly beneficial to her relationship with Lynne, thus Lynne describes Sarah as a “*lovely social worker*”.

On the other hand, relationships were frustrated when there was a lack of attentiveness to the temporal needs of individuals and families. Lynne told me that she had “*eight*” different social workers during the time that she had cared for her mother and that not all of these social workers had been sensitive to and respectful of her need for time in making her decision around care home admission:

*Oh yes, I'd thought about it for a long time; ... and ... everybody told me, and I kept thinking 'Oh, shut up!' I will make the decision – nobody else. 'Oh, you must do it; you must do this, you must...' 'No; I will make the decision when I'm ready'.*

**(Interview with Lynne – IC06)**

Here, Lynne highlights the potential for tension and frustration to arise within relationships, when practitioners fail to acknowledge and to respect the subjective temporalities of informal carers within decision-making (“*I kept thinking 'Oh, shut up!' I will make the decision – nobody else*”). Such extracts affirm the importance of practitioners using time in what Davies (1994) calls “process time” (p. 277) ways, if they are to build meaningful relationships with those with whom they work. When used in accordance with the principles of process time, time is used flexibly, takes account of the subjective needs of care-receivers and allows practitioners to express caring as they undertake their social work roles and responsibilities.

Policies which standardised time were seen to detract from expressions of care and to therefore undermine social work relationships:

*They are told they need to find somewhere within 28 days from Hospital and you're thinking 'well that's a pretty big decision to put kind of a very set time scale on'. I understand we've got our time-scales of course because you can't have people in hospital indefinitely...but at the same time, from their point of view, it's not going to be about time-frames for them, it's going to be about finding the best place. If that takes 5 weeks or 6 weeks not 4 weeks, then does it matter? ... You know, I think but we are then the ones pushing 'no, no you've got to find somewhere, they've got to have a vacancy, so it doesn't matter if you think its the best one, if they've got a vacancy then you might have to go for that one' ... I think from the*

*family's point of view, then I think they would feel very pressured... it would be very uncaring... from their point of view I think.*

**(Interview with Adrian – SW01)**

Adrian is clear that in adhering to the requirements of time-stringent policies (working determinedly towards a discharge within “*twenty-eight days*”, irrespective of individual circumstances), there is a risk that practitioners will be seen as “*very uncaring*” within their work. From the perspective of Reid et al. (2015), such practitioners would be seen as lacking “*caring orientation*” (p. 905) with the result that the potential for relationship building is then limited.

The ways within which social workers use time within their work is, of course, influenced by ‘*the time*’ (context) of social work practice. According to team manager Ella, there was a time where practitioners had far greater temporal discretion in undertaking their roles and responsibilities and where time itself, was far less constrained:

*Well, I just think because there wasn't the pace there... a bit... I think we spent more time, 'back in the day'... with admissions, and... you know... monitoring people and seeing they were all right when they... go in. In recent years, we've admitted people – they're safe – we don't go back till the review unless we get something. Years ago, going back when we practised, we'd call – even weekly – we'd call, and make sure they were all right. We'd stay in touch with the family and we would sort all the teething problems out and it was a much smoother transition into care.*

**(Interview with Ella – TM02)**

In Chapter Three, I discussed the ways within which the usage of time within social work is shaped by political context. There, it was argued that following the implementation of the National Health Service and Community Care Act 1990, managerial practises (Harris 2003) absorbed the time of social workers through requiring them to engage with increasingly bureaucratic processes and more administrative tasks (Yuill and Mueller-Hirth 2019). Within interview, social worker Sarah described the impacts of being more involved in administrative roles and

responsibilities. As a result of spending “*time at the desk*”, Sarah is clear that she has less time to spend in “*direct work*” with older people and informal carers:

*Sarah: I mean we spend far too much time at the desk, and I just think that, as much as I try and spend quality time with service users and carers, I think we don't do enough of it. And you feel pulled in different directions; maybe you've got meetings to attend, which can be very lengthy and you haven't spent the time doing enough on the assessment or the care plan, or different interventions?*

*AC: Mm... And by 'interventions'?*

*Sarah: I mean the direct work with people.*

**(Interview with Sarah – SW03)**

Care home manager Rob, described feeling that increased amounts of administration had an adverse effect upon the quality of social work care:

*I think it's got to be the workload, it's got to be the pressure of work...and I think care managers are no different to anyone else, I think the amount of paperwork has gone up dramatically over a long period of time ...and obviously, that then takes time.... so you can't be sitting and listening and sympathetic and supportive of people while also filling out large amounts of paperwork.*

**(Interview with Rob - CHM01)**

Rob states that it is impossible for social workers to spend time “*sitting and listening and [being] sympathetic and supportive of people while also filling out large amounts of paperwork*”. Implicit within Rob's comments is that the nature of the social work relationship is altered when practitioners are preoccupied with the completion of “*paperwork*”. The impacts of administration on the quality of social work relationships are well documented within the social work literature (Postle 2002; Harlow 2003; Carey 2003; Weinberg et al. 2003; Munro 2011).

Throughout this thesis, I have argued that when meaningful social work relationships are compromised, a practitioner's desire, motivation and sense of “responsibility”

(Tronto 1994, p. 131) to care, will be decreased (see Chapter Six). It is also the case that practitioners are likely to lack the *ability* to care well, in the absence of relationship. Without relationship, a practitioner's levels of understanding and hence "competence" (Tronto 1994, p. 133) to care, will inevitably be impaired.

Whilst there were times when social workers had longer-standing, pre-existing relationships with older people and their informal carers, this was by-no-means typical. As stated by social worker, Chloe:

*Like some hospital discharge cases that we get; that could be the first time we're meeting the older person and the family.*

**(Interview with Chloe – SW02)**

In the absence of prior relationship, practitioners needed to gather a lot of information very quickly. Within such situations, the pace of the assessment process left some informal carers feeling that practitioners lacked understanding of the specific needs and circumstances of their older loved-ones. As stated by informal carer, Jackie:

*Jackie: And the ... social worker – ok, ...he sat down, he was talking to her. It must be very difficult for them, because they don't know... they don't know of that person – they only can see what they see, and go from there, and make notes – it's not as if they've spoken to her... you know... or met her before – before all of this happened – and...*

*AC: So, was this... I mean I think that's an important point, that you're making; was this Mum's first contact with a social worker of any sort, or...?*

*Jackie: Yes!*

*AC: Ok.*

*Jackie: Yeah, yeah. And, you know, it must be very difficult for social workers, because they come in, and they only see the person which they are then – when they're ill, or whatever – they don't actually see the person before that... So they have... they don't have an idea of what they were like, or their personality – their character – because that is all being*

*taken, stripped away from them, really, to a point – depending on how ill they are... And it might have only been like an hour, or something like that, but I mean... it's not very long, is it, to form an opinion of someone, and to know their care needs?*

**(Interview with Jackie – IC05)**

Here Jackie is explicit, that the pressure of time (the social worker is described as “*only (having) an hour*” to spend with her mother) significantly undermines his ability to genuinely understand her mother’s needs. Jackie states that whilst the practitioner might have been “*sitting and talking*” to her mother, it was impossible for him to know her mother’s “*personality (and) character*” on the basis of an “*hour*”-long conversation.

Significantly, the findings of this study showed that it was not only the caregiving “*competence*” (Tronto 1994, p. 133) of social workers, but also of care home workers, which was adversely affected by the constraints on time. Thus far, I have not discussed the importance of respite care in this thesis. However, a number of participants highlighted the importance of respite<sup>29</sup> care in facilitating the development of collaborative relationships between older people, informal carers and care home workers. Respite was seen as critical to enabling these care workers to develop deeper understandings of the needs and circumstances of older people.

When respite was undertaken over a sustained period of time, it also enabled informal carers to develop trust and confidence in the care home and therefore helped offset, the feelings of stress and anxiety that could otherwise create tensions in subsequent relationships (see Chapter Seven). To illustrate the potential benefits of respite, I draw on the example of ninety-year-old Winnie who had undertaken respite in the same, Local Authority residential home for several years, prior to moving in to the home on

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<sup>29</sup> Residential respite entails an older person spending a temporary period of time within a residential (or nursing home) setting (Willoughby 2017) and is often seen as a means of providing informal carers with a ‘break’ from their caregiving roles and responsibilities (Neville and Bryne 2007).

a permanent basis. During observation, Mandy and Ray (Winnie's informal carers) described the difference that planned respite had made to their overall admission experience. They spoke of having developed very good relationships with the care home staff (telling me that the manager of the home is: "lovely") and commented on how well these care workers knew and understood Winnie's needs:

*Ray states: "They are so used to her, they know" (i.e. the staff are so familiar with his Mother, that they are familiar with her preferences).*

**(Observation - Two)**

For Mandy and Ray, the process of care home admission had very much eased, by these on going opportunities for respite:

*Ray says: "Fortunately she had been coming to the home for respite twice a year and so she ... just 'slipped in.'"*

**(Observation - Two)**

However, as highlighted by care home manager Rob, levels of respite care were seen to have significantly decreased over recent years:

*I think several years ago, I would have noticed more people that had had day care somewhere or that maybe had had some respite. They had kind of tried it out a few times before looking at permanent.*

**(Interview with Rob - CHM01)**

The "commodification" (Adam 1990; 1995; 2004) of time has resulted in a situation where the focus of care home providers, is upon maximising the number of their residents. Within such a context, avoiding 'empty time' (that is, times where beds are vacant), is critical to increasing profit and avoiding financial loss. From such a perspective, respite care is often not regarded as financially viable. As stated by care manager, Lindsay, "*private agencies don't keep respite beds*" because in so doing, they would potentially need to decline permanent residents who would offer them greater financial security. Lindsay stated:

*Private agencies don't keep respite beds, because they're running a business; so they want their beds occupied 24/7, so there is no bed available for respite unless by chance they're waiting for somebody to come in the week after.*

**(Interview with Lindsay – CM03)**

It was not only the commodification of time but also the standardisation of time that was seen to complicate informal carer – care home provider relationships. The requirement to meet pre-specified hospital discharge time scales (meaning that older people have to leave hospital for admission to a care home within a 28-day period) is seen to have resulted in some older people and informal carers *having* to accept their second choice of care home setting:

*The daughter (Beverley) informed me that her mother had been living within the care home for a period of almost a year; she explained that her mother had been admitted to the care home from hospital and said that the care home had been one of five visited. Beverley said that the older person's current care home was not really the care home 'of choice' (she said that at the time of looking, her mother's name had been placed on the waiting list for another local care home but that there had not been a vacancy within this care home)...Beverley said that her mother had moved to the present care home because (her words): "we had to get her out of hospital." Beverley talked about the move being made quickly: "within days."*

**(Observation - Fourteen)**

Feeling obliged to accept a vacancy out of necessity rather than choice, has the potential to cause feelings of resentment and to significantly impact the quality of subsequent relationships:

*Beverley and William (son-in-law) talked about how they felt that the older person was not happy within the care home – they said that they felt that they might have to move her from the existing care home. Beverley and William described not being satisfied with the care given to the older*

*person by the staff at the care home (they described it as having been: “a year of complaints with staff”).*

**(Observation - Fourteen)**

Beverley and William had been very open about the continued tensions within their relationships with the care home providers from the very start of our meeting. Importantly, the observation was taken from a meeting within which the social worker was discussing alleged ‘safeguarding concerns’ related to the quality of care within the care home setting. Whilst the legitimacy of these allegations remained unclear (the social worker’s recording referred to continued “*vexatious complaints*”), the extent to which a lack of perceived choice had caused hostility and relational tensions was nevertheless, very clear. The observed meeting was one of several undertaken by the social worker who had remained involved in working with the family for an extended period of time because of the on going issues. It seemed that within this situation the actions to save time (by promoting a speedy hospital discharge), had actually been a ‘false economy of time’; they had significantly increased the length of time needed for subsequent social work intervention.

Typically, practitioners remained involved in working with older people and informal carers beyond care home admission for very *limited* periods of time. The pace of work meant that many practitioners were anxious to “*close*” cases as quickly as possible, in order to free up time for “*other work*”. As stated by social worker, Chloe:

*I’m always... because of the fast-paced way in which we work, PIs [Performance Indicators] ...and demanding caseloads, I’m almost looking to close when I can... to prioritise other work...*

**(Interview with Chloe – SW02)**

This meant that practitioners were not always available to facilitate the kinds of informal carer – care home provider relationships that enabled them to work collaboratively (see Chapter Seven). In some cases, the involvement of social workers was so short-lived, that initial reviews did not take place. Care home manager Chris, referred to social work reviews as a “*bone of contention*”. During interview, Chris

told me that there were many occasions where initial reviews were completely overlooked:

*Chris: The reviews, yeah... they should be planning them when they come in. I can diary them, because at the end of the day, I also am looking to see if this person is going to fit in; if we can meet their needs. And I could tell you, I've had loads of people in that haven't had a first review yet.*

*AC: Ok. The 28-day review?*

*Chris: Yeah, the 28-day review hasn't been done.*

*AC: And do they get missed totally?*

*Chris: They get missed, yeah.*

**(Interview with Chris - CHM03)**

In situations of time-pressure, some practitioners felt that reviews were given “*less priority*” than other areas of work. There was a perception that older people living in care homes were comparatively “*safe*” when compared with others who, for example, were “*living alone within the community*”. As stated by care manager, Janet:

*Janet told me that placement reviews are given less priority. She explained that it may be assumed that a person is “safe” within a care home setting, compared to for example, an older person living alone within the community where there are escalating risks.*

**(Observation - One)**

It is important to recognise, however, that a practitioner’s failure to engage with continued “*caring conversations*” (Dewar and Nolan 2013, p. 1247) within review, has serious consequences for the provision of *care-embedded social work*. Tronto (1994) highlights the ethical principle of “*responsiveness*” (p. 134) as a fundamental component of integral care. It is argued that the authenticity of care is maintained when practitioners take the time to understand the *impacts* of care from the *perspectives of care-receivers*. As stated by Scourfield (2007), the review process is an important means of practitioners engaging with these sorts of evaluative

conversations. They also provide opportunities for practitioners to adjust or “tinker” (Molterer et al. 2019, p. 95) with the care provided, to help maximise its effectiveness in meeting the needs of an older person. The “integrity” (Tronto 1994, p. 136) of care is undermined when practitioners fail to engage with the review process and where opportunities for determining the “responsiveness” (p. 134) of care are then lost.

There was also a feeling, however, that even when reviews were undertaken, they were often undertaken too soon in time. As stated by social worker, Josie:

*Josie informs me that an initial review of the care home placement is needed; she explains the review is slightly late (within the Local Authority, the review would normally be undertaken at a point of 28 days); however, she states that she thinks that sometimes this is better – since it gives people: “more of a chance to settle.”*

**(Observation - Fifteen)**

The implication within Josie’s comments is that older people and informal carers need opportunities to genuinely *experience* the care on offer, in order to comment on that care. It is impossible for older people and informal carers to constructively evaluate the care provided before being given a “*chance to settle*”. It is also important to recognise that older people “*settle*” within care home settings at variable rates of time and that informal carers adjust to the transition of care home admission in temporally distinctive ways (Selder 1989). As stated by care home manager, Michael:

*It depends from family to family...it never goes away for some families.*

**(Interview with Michael – CHM02)**

From such a perspective, the standardisation of time for reviews (twenty-eight days post admission), which took no account of the variability of ‘transition time’ (Selder 1989), was unhelpful in determining the “responsiveness” (Tronto 1994, p. 134) of caregiving.

Following the review, it was usual for practitioners to ‘transfer’ older people and their informal carers to a separate team (where subsequent reviews would then be undertaken on an annual basis)<sup>30</sup>. Some social workers sought to mitigate the impacts of ending their involvement at this time, by stating that the informal carer could contact the Care Home Review Team to discuss any future issues or concerns:

*Chloe (the social worker) says that the admission will now be: “permanent” and that she will “transfer the admission to (a new team) who will come out in: “six months or a year to review”. Chloe says to Harriet (the informal carer): “They will contact you beforehand”, to which Harriet responds: “So if I’ve got any issues can I ring you?”*

*Chloe says that she will remain involved until further notice: (“It will be me until you hear from me”), but that she will give Harriet the telephone number of the new team, to raise any further issues. Chloe says: “sometimes families can feel awkward in speaking to the care home directly if issues arise. Let us know – we can say it is from us rather than from the family.” Harriet says that the staff within the care home: “are approachable” but she says: “you always worry a little bit”.*

**(Observation - Nine)**

Harriet’s comments show, however, that she is very apprehensive about the prospect of losing contact with the social worker. Harriet is not seemingly at the point where she has developed an established relationship of trust with the care workers within the care home setting; she therefore says whilst the care workers are “*approachable*”, she would still “*worry*” about raising concerns on her Mother’s behalf. Harriet will not of course, have relationships with those practitioners within the “*new team*” and so may not feel confident in raising her concerns with an unknown person.

As stated by care manager Janet, it can be difficult for informal carers to raise concerns without relationships with practitioners:

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<sup>30</sup> For the purposes of this discussion I will call this separate team, the “Care Home Review Team”

*If you don't know someone, people are not always going to tell you if there's a problem ...you're not always going to feel comfortable bringing it up to a stranger.*

**(Interview with Janet – CM01)**

Janet also makes the point that when subsequent yearly reviews are undertaken, these are often undertaken by any one of a number of practitioners within the Care Home Review Team. In other words, she told me that the consistency of practitioners is not necessarily maintained on a year-to-year basis:

***Janet:** And I think the carers... feel more comfortable, again, if you were the person that did the last review, you know? It's continuity for them, because otherwise they could be thinking 'Well, we've got a different person coming in to do the review every year; what's the point of that? They don't know who my mother is – or my father – or whatever'.*

***AC:** Yeah. Do you know why it's managed in that way?*

***Janet:** No, I don't know.*

***AC:** Ok, ok.*

***Janet:** Because, you know, I could go into a review, and someone's been in a home for 10 years, and they could say: 'Well every year, we've had a different person doing the review'.*

***AC:** Mm. Do you think... do they give the impression that's difficult for them, or...?*

***Janet:** Yeah, some of them, because they all ask, you know, 'Well where's So-and-so today? She did the review last year, and she was really good; she sorted out this for me, she sorted out... whatever?' you know.*

**(Interview with Janet – CM01)**

Janet makes clear that because of the discontinuity in practitioners undertaking care home admission reviews, it is often far more difficult for informal carers to raise issues of concern.

During interview, care home manager Chris also raised concerns about the fact that those undertaking reviews, did not always have prior relationships with older people and informal carers:

*Chris: Now the common-sense thing to me, you see, you know... would be to maintain that [pause] that partnership then, yeah? And then you've got someone coming in and doing a review, who has no idea about this person at all; is just reading from bits of paper...*

*AC: Do you mean at the annual review?*

*Chris: Yeah, at the annual review; and it's like all 'Why is this; why is that; why does this...?' and I'm thinking 'You don't even know the man!'*

**(Interview with Chris – CHM03)**

Chris makes the point that practitioners who routinely undertake “annual reviews” simply have no knowledge or understanding of the needs of the older people and informal carers they are reviewing. As such, she questions whether these practitioners are “competent” (Tronto 1994, p. 133) to determine the “responsiveness” (Tronto 1994, p. 126) of care. Elsewhere in her interview, Chris tells me that “continuity” within relationships is critical to shaping the effectiveness of long-term care admissions.

The practise of ‘off listing’ cases to a separate team, is an example of the ways within which social work practice has been organised in accordance with principles of managerialism (see Chapter Three). When organised in such ways, different workers, often placed within different teams, undertake discrete social work tasks. The findings of the study show, however, that the organisation of social work in such ways creates high levels of discontinuity in practice relationships and has the potential to adversely impact the overall effectiveness of care.

In the preceding sections, I have argued that pressures on time adversely impact social work relationships and, by implication, *demoralise* practises of care within social work. Much of this thesis has been concerned with the ways in which this demoralisation of care, adversely impacts the care home admission experiences of informal carers. In the final sections of this chapter, I now explore the effects of the time-related limitations on caring, from a social work perspective. This is important because, as stated by Yuill and Mueller-Hirth (2019), the existing literature rarely attends to the impacts of the challenges of balancing “often competing and contradictory temporalities” (p. 1534) on practising social workers.

### **The Impacts of Time-Constraints upon the Lifeworlds<sup>31</sup> of Social Workers**

There was no doubt that *care-embedded social work* mattered from a social work perspective. Consistent with the perspectives of other social work theorists, many practitioners saw care as a core social work ethic or value (Parton 2003; Gray 2010; Clouston et al. 2018; Hay 2019). As such, doing social work *with care* was seen as synonymous with doing social work *well*, and in accordance with the core principles and values of the profession. As stated by Adrian:

*They (the informal carers) might be saying: “Well look we found one but it's not available quite yet, there are a couple of people on the waiting list”. The hospital are saying: “Well put them somewhere else in the meantime”, which is another move before they go to the place they want to be going to...and sometimes you know...on balance the hospital then isn't the best place for them to be in terms of infection, risks and all those things going on for them, but ultimately if there's no, if those things aren't present then, like I said, I would rather take that on the chin from my manager from hospitals, I'd rather take that than go home and be unhappy that I'd done something that I don't think is ethical.*

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<sup>31</sup> “Lifeworlds” (Yuill and Mueller-Hirth 2019, p. 1532)

**(Interview with Adrian – SW01)**

Here, Adrian is explicit that from his perspective, the requirement for an interim, temporary admission is *non-caring*. It is inattentive to the potential harms caused to an older person with dementia when moving multiple times before finally settling into their chosen long-term care setting. Critically, Adrian states that should he comply with the requirements of such policies, he would be taking action that he considered to be not only uncaring, but also *unethical*. Adrian makes the comment that he would “*rather take (it) on the chin from (his) manager (and) from hospitals... than go home and be unhappy that (he’d) done something (he didn’t feel was) ethical*”.

As stated by Weinberg and Banks (2019) it is challenging for practitioners to practise ethically in present times. It should be understood, however, that despite the time constraints on caring in social work, many practitioners still found ways to prioritise the time for care within their work. Practitioners with a “caring orientation” (Reid et al. 2015, p. 905) recognised the importance of sustaining relationships in promoting the longer-term emotional well-being of older people and informal carers (Nortvedt 2001; Nortvedt et al. 2011). According to Tronto (1994), care is a site of potential conflict. Practitioners who worked in *care-embedded* ways, sought to diffuse conflict and to reconcile relationships wherever possible. As stated by social worker, Sue:

*Because you’ve got to be very... mindful, haven’t you, that ... those family members are going to pick it over, aren’t they? Who said what, who did what, what their facial expressions were like! [Laughs]... So you’ve got to... you’ve got to think about mending bridges so that there is no comeback on any individual within that family... because they’ve all got to live together thereafter.*

**(Interview with Sue - SW08)**

In the interests of relationships, practitioners like Sue described extending the typical time-scales for meetings in respect of hospital discharge so as to help resolve situations of conflict:

*Well, because... you can’t... you can’t make progress if there are clear disagreements within a family. And if family are getting very emotional,*

*they're not going to make a decision – they're not going to listen – so you have to challenge, and... you know... say to Health, 'Well actually, we'll have to abandon this meeting. We've done half of the meeting... We've done half of the DST, but we'll need to reconvene in a couple of days to complete it, because I need to do some more work with the family'.*

**(Interview with Sue - SW08)**

Other practitioners sought to preserve the relationships between older people and informal carers through challenging the requirement for an interim or temporary admission (interim admissions were often required within those situations where a chosen care home did not have a vacancy and where awaiting a vacancy, would require an older person to remain in hospital beyond the twenty eight day time scale). To reiterate, social workers that approached their work with care, were alert to the adverse impacts of multiple moves (and hence transitions) on the lives of older people with dementia. As stated By Josie:

*I've have had disputes with hospitals, where they're saying... because there's a lack of placements, that they're saying 'Well this lady will have to go to an interim placement' and that's not always in someone's best interest, to have so many changes, you know? They're already not going to be able to go back home, they've been in hospital for a long time, let's just try and make one smooth move to one chosen placement, rather than to go somewhere that might be where relatives can't visit, or something like that, because it's too far away; and then put them back. It doesn't happen very often, but there sometimes are those discussions to be had.*

**(Interview with Josie – SW04)**

Josie also recognises the risks to relationships when an older person moves out of their immediate locality and when, for example, “*relatives can't visit... because it's too far away*”. Josie is therefore willing to challenge the requirements of time-stringent timescales even though this potentially brings risks to her wider professional relationships (thus she refers to the “*disputes (she has had) with hospitals*”).

As stated within Chapter Three, the work of political care ethicists places issues of justice at the heart of caring. The principle of “solidarity” (Tronto 2015, p. 36) demands that those who care, “care enough *about* care to start caring *for* care” (p. 38). It is clear that in working in *care-embedded* ways, practitioners are required to engage with issues of social justice. As shown in the previous extracts, such practitioners “resisted” (Weinberg and Banks 2019, p. 361) and challenged the time constraints on caring within their work and advocated for *more time*, so as to preserve and protect the important relationships of older people and informal carers.

Given that engaging with issues of social justice has traditionally been seen as central to social work (Ray et al. 2009; Drakeford 2014; Ray et al. 2015; Hyslop 2018), it is arguably unsurprising that many practitioners were proud of those situations where they had challenged time, to care well for those with whom they worked. On the other hand, it should also be understood that levels of care were not necessarily consistent amongst those social workers engaged within this study. There were times where all of these practitioners cared well for those with whom they worked. There were also times, however, where these same practitioners felt they simply had not cared in the way that they would have liked. By way of example, I refer to the following extract, taken from an interview with social worker, Chloe:

*If I'm honest – if I'm totally honest... some carers that I've worked with for many years, I put a lot more time into carer support and providing emotional support... I might be going to see that carer on their own rather than (with the older person)...maybe (the older person) is at a day centre, and I'm doing a lot of visits to the carer directly. Whereas when it's a last-minute crisis, or hospital discharge, I don't really know the family that well, I don't provide as much support as the ones that I work longer with.*

**(Interview with Chloe – SW02)**

In contexts of time constraint, many social workers sometimes had to make ‘tough’ choices as to how they should allocate their finite time in their day-to-day work. Critically, when they are unable to care for everyone, there is some evidence that practitioners were more likely to care for those with whom they have established

relationships. Thus, Chloe states that when she has “*worked with (individuals and families) for many years*”, that she puts: “*a lot more time into carer support and providing emotional support...*”

Chloe’s comments both affirm the importance of relationships in promoting and increasing caring “responsibility” (Tronto 1994, p. 133) and also illustrate the very real potential for “parochialism” (Tronto 1994; 2010) in care, in contexts of resource-constraint. As stated in Chapter Three, parochialism arises in situations where caregivers give better care to those with whom they have stronger relationships; critically, it increases levels of caring inequality. Chloe’s feelings of “ethical stress” (Fenton 2015; 2020) at this perceived inequality, were evidenced in her comment:

*It’s such a drastic... divide, between the type of care and support that I give, depending on the situation. I question myself: ‘Is that right, really?’*

**(Interview with Chloe – SW02)**

During interview, social worker Aled stated:

*Aled: And I think this is the problem. When we have jobs that are so complex and so laden with bureaucracy, we are trying to keep our heads above water. And what I’ve noticed is that sometimes, just being able to do the job to the satisfaction of the Local Authority appears to us good enough. So, therefore, we’re not dealing with the humanistic issues. If we’re sending out letters in time and we’re getting signatures and we’ve given lists of care homes, we’re unconsciously patting ourselves on the back, saying ‘We did a good job there’ and our managers are saying ‘Well done! You processed that care home admission very well!’*

*AC: Yes. That’s a good point, I think.*

*Aled: Are we? You know what I mean? Yeah, from a robotic perspective, we are! ... From the humanistic perspective, we’re failing badly!*

**(Interview with Aled – SW05)**

Aled is clear that because of the bureaucratic nature of social work practice, there are times when practitioners seem to take the ‘path of least resistance’ and work in

“robotic” ways, so as to ensure their tasks are completed as quickly as possible. Whilst Aled suggests these modes of practise enable social workers to keep their “heads above water”, he is not reconciled to such practise. Hence, Aled draws attention to the failure of practitioners to “deal with the humanistic issues” when functioning in a speed-focussed “bureaucratic” manner.

As stated within Chapter Three, distinctions are made between a “duty of care” (Moss et al. 2015, p. 277) and ethical caring (practises of care incorporating caring ethics and values). Aled’s comments suggest that he sees current social work practice as sometimes operating at the level of the former. People are “made safe” but are not necessarily well cared for during social work intervention:

*I think we’ve slightly lost our moral compass, in an unconscious way... I don’t think anyone has seriously gone out of their way to make our service faceless and hurtful but I think we are flirting with it – I think we really are... becoming almost – I won’t say ‘counterproductive’ because at the end of the day, people are being made safe – but we’re doing it in a way which is a million miles away from our social work training...*

**(Interview with Aled – SW05)**

Like Chloe, Aled makes clear his feelings of dissatisfaction, disillusionment and “ethical stress”<sup>32</sup>(Fenton 2015, p. 1415) when practising within such ways.

As I stated in Chapter Three of this thesis, the timing of my period of data collection, meant that it was impossible for me to evaluate the impacts of the then new Social Services and Well-being (Wales) Act 2014 (Welsh Government 2014). Nevertheless, my interviews with social workers afforded me the opportunity to ask them whether they expected their practise to change in light of the amended legislation. It was noticeable that whilst a number of practitioners perceived the Act as having certain

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<sup>32</sup> Fenton (2015) refers to the “ethical stress” (p. 1415) experienced by practitioners when feeling unable to practise in ways consistent with the core values of the social work profession.

positive elements (for example, the opportunity for more “*person-centred*” work through “*What Matters?*” conversations) there was a general feeling that this sort of work might potentially take “*more time*”. Without “*more time*” and increased “*resources*” there were concerns that little would change in terms of the challenges facing social work practice.

Feelings of “ethical stress” (Fenton 2015; 2020), dissatisfaction and demoralisation amongst practitioners are clearly unhelpful; particularly at a time where there is such concern about recruitment and retention issues within adult social care (Pollock 2021). The actions needed in levelling some of these inconsistencies are a part of what will be discussed within Chapter Nine of this thesis.

## **Summary**

Within this chapter, I have highlighted the ways in which the time pressures faced by social workers are often a significant barrier to them undertaking their roles and responsibilities with *care*. I have explored the ways in which the quality of social work relationships is diminished within contexts of time constraint. As a result, older people and informal carers feel less well “cared for” (Gray 2010, p. 1801) in processes of care home admission. Consistent with earlier work (Meagher and Parton 2004; Hay 2019; Weinberg and Banks 2019), the findings of this study show that the context of contemporary social work is antithetical to *care-embedded social work*.

There were, however, occasions where practitioners challenged the constraints on time to *care well* for older people and informal carers. In so doing, there were clear benefits to older people, to informal carers and to practitioners themselves, who were very proud of working in “caring ways” (Engster 2005, p. 54). With this in mind, I move on to explore some of the strategies needed to increase the consistency of *care embedded social work* practice.

## **Chapter Nine: Summary, Discussion and Recommendations**

### **Introduction**

This study has analysed the care home admission experiences of informal carers, the importance of social workers engaging in *care-embedded social work* at such times, and the possible barriers to care within social work practice. In this final chapter, I reflect upon the implications of the study findings from a policy and practice perspective and highlight their contribution to the existing field of knowledge. I also explore the limitations of the study and consider areas for possible, future research. I begin the discussion with a brief summary of the preceding chapters of the thesis.

### **Chapter Summaries**

In Chapter One, I discussed my rationale for undertaking this research. I explained that my interest in informal carers' experiences of care home admission and of social work care at that time, had arisen as a result of my own practice experience. The primacy of the roles of social workers in respect of residential and nursing home admission were outlined and I discussed the terminology used within this study.

In Chapter Two, I explored the existing literature related to informal carers' experiences of care home admission. This literature shows that for many informal carers, care home admission is an experience characterised by high levels of anxiety and stress. I explored the possible reasons for these anxieties and stresses and discussed the concepts and theories used in this thesis, to heighten understanding of the emotional gravity of care home entry. I also considered what is currently known of the effectiveness of the roles and tasks of social workers in respect of residential and nursing home admission.

Chapter Three explored elements of the vast, theoretical literature related to care. My aim within this chapter was to think about what care *is* and *does*; to explore its characteristics and attributes; and to consider its potential importance to informal carers at times of care home admission. The chapter drew upon the ethic of care literature to understand the qualities and characteristics of caring. It also discussed the work of Buber (1970) as a means of highlighting the attributes of *care-facilitative*

*relationships*; examined the importance of time to care; and considered the impacts of the current social policy context on levels of social work caring.

Chapter Four discussed the methodology used within the study. Here, I justified my ontological and epistemological approach in undertaking the research. I argued that a constructivist research methodology is consistent with ways of knowing and understanding within social work practice, and with the undertaking of “care full” (Barnes 2012, p. 9) social science research (Herron and Skinner 2013).

In the first findings chapter (see Chapter Five), I examined the challenges experienced by informal carers when making decisions in favour of care home admission. These challenges were explored through the conceptual lens of transition. The findings evidenced the intense feelings of distress, guilt and fear experienced by many informal carers as they engaged in care home admission processes. Within the second part of Chapter Five, I considered the importance of care as a specific approach to social work practice with informal carers at such times. My focus within this chapter was on the value of *attentiveness* to social work practice. The chapter examined the impacts of different elements of attentiveness on the care home admission experiences of informal carers and helped affirm the importance of caring social work, in alleviating admission-related anxieties and stresses.

Attentiveness was the first dimension of what I then introduced as *care-embedded social work*. Chapter Six explored the importance of two other elements of care-embedded social work in the work of practitioners: those of “competence” (Tronto 1994, p. 133) and “responsibility” (Tronto 1994, p. 131). With reference to the work of Buber (1970), the chapter examined the kinds of *care-facilitative relationships* critical to the enactment of these dimensions of caring. It was seen that practitioners who undertook their work in *care-embedded* ways, used their relationships to develop deep, contextualised understandings of the specific needs and circumstances of older people and informal carers. These understandings in turn, enhanced their abilities to contribute to competent, effective decision-making outcomes. Chapter Six also explored the importance of *feeling* and *affect* to understanding. It was seen that as practitioners *felt* something of the challenges experienced by informal carers, their levels of insight were increased and their desire or motivation to care was heightened. As practitioners were *moved* to care, they undertook their caregiving roles and

responsibilities with greater levels of commitment and in ways that significantly eased the challenges faced by informal carers.

Within Chapter Seven I turned my attention to considering the caregiving roles of care home providers. I argued that in order to care *well*, care home providers must develop productive relationships with informal carers so as to provide opportunities for the transfer of “relational knowledge” (Dewar and Nolan 2013, p. 1247). My aim within this chapter was to highlight the important roles and responsibilities undertaken by social workers in the time following care home admission. I particularly drew attention to the ways that practitioners might facilitate collaborative informal carer – care home provider relationships in the best interests of older people with dementia. As made clear towards the end of Chapter Seven, however, many social workers have only minimal levels of contact with older people and informal carers in the time following long-term care admission and are not therefore, consistently able to fulfil these relationship-enhancing roles and responsibilities.

Chapter Eight explored the barrier of time to *care-embedded social work*. It examined the impacts of ‘time-commodification’ (the equation of time with money) on the quality of social work relationships and hence, on levels of social work caring. In this chapter, I considered the impacts of diminished caring on older people, informal carers and upon social workers themselves, highlighting the feelings of “ethical stress” (Fenton 2015, p. 1415) experienced by practitioners when unable to perform their roles in “caring ways” (Engster 2005, p. 54).

## **Discussion**

In the following sections, I discuss the findings of the study in answer to the research questions and explore the contributions of the study to the existing field of knowledge. I also consider the implications of the study findings, from a policy and practice perspective.

One of the aims of this study was to add to and update the existing research on informal carers’ experiences of care home admissions. The findings of the study affirm the outcomes of much of the earlier research in this area (for example, Dellagesa and Mastrian 1995; Dellagesa and Nolan 1997; Ryan and Scullion 2000;

Cheek and Ballantyne 2001). They show that many informal carers experience feelings of great turmoil and overwhelming anxiety when making decisions in respect of care home admission.

The concept of transition provided a valuable conceptual lens through which to understand the challenges of the decision-making process. As stated in Chapter Two, this study is not unique in exploring care home admission from the perspective of transition (see Zizzo et al. 2020). Nevertheless, I intentionally chose transition theorists whose work does not appear to have been previously used in the analysis of informal carers' experiences of care home admission (for example, Murray-Parkes 1971). Through conceptualising transition as a "life-space" (p. 103) change, the work of Murray-Parkes (1971) provides insight into the emotional gravity of the losses experienced by informal carers at such times. Critically, it also adds depth to the work of existing theorists such as Lloyd and Sterling (2011) who highlight the potential for a loss of caregiving roles to adversely impact upon the identities and selfhoods of informal carers.

Consistent with the outcomes of earlier studies in this area (see Bowers 1988; Rowles and High 1996; Tilse 1997; Seddon et al. 2002), the findings of this study show that many informal carers both want and need to engage with continued caregiving roles and responsibilities in the time following care home admission. To add to this earlier literature, this thesis uniquely combines the work of Murray-Parkes (1971) with insights from the work of Atchley (1989), Selzer (1989) and Morgan (1996; 2011), to highlight the critical ways within which the selfhoods of informal carers are promoted through their on going caregiving roles and responsibilities. Atchley (1989) illustrated the ways within which individuals construct their selfhood with reference to societal norms and cultural expectations. Families are expected to care within contemporary British society; caring is what Morgan (1996; 2011) terms a normalised "family practice". In relinquishing their caregiving roles, many informal carers perceive that they have deviated from social norms and expectations, with the result that they experience feelings of guilt, failure and shame. Performing continued caregiving roles beyond institutionalisation is critical to such informal carers reengaging with 'normalised' family type behaviours (Selzer 1989) and to therefore offsetting feelings of guilt, failure and shame (see Chapter Five).

Whilst there are several areas of consistency in the findings of this study and those of earlier research, it is important to state that this study differs from the majority of the earlier research in two significant ways. Firstly, it has explored the admission-related experiences of informal carers living in Wales. As stated in Chapter Two, there has been very little research exploring the care home admission experiences of informal carers within an explicitly Welsh context. I have argued in this thesis that informal carers' experiences of care home entry are strongly shaped by social constructions of care and by socioeconomic and political contexts. Wales has its own distinctive socioeconomic and political character (Williams 2011) and as such, it cannot be assumed that the findings of studies undertaken internationally or even elsewhere within the UK are necessarily appropriate to the Welsh context.

Secondly, this study focuses on the practises of *social workers* working with informal carers in respect of care home admission. As I stated in Chapter Two, there has been very little research undertaken on the admission-related practice of social workers with informal carers, especially within a UK context. The paucity of research in this area is concerning. Social workers undertake a primary role in assessing for and arranging admissions to long-term care settings, yet little is known of the effectiveness of the social work interventions offered to informal carers at such times. This study has generated findings to help address this important gap within the current research literature.

Based on the findings of this study, I argue that social work *can* make a positive difference to the care home admission experiences of informal carers, provided that practitioners undertake their roles and responsibilities in “caring ways” (Engster 2005, p. 54). The fact that this study has explored *performances* of care within social work (that is, it has looked at the ways within which care and caring are *enacted* in the work of practitioners) is significant. Hay (2019) makes the point that whilst it is generally assumed that caring social work is *good* social work, there have in fact been few attempts to examine “concrete” (Hay 2019, p. 365) practises of care within social work.

Through amalgamating the work of different care ethicists and relationship-based theorists, this study has developed a model of *care-embedded social work*. As stated in Chapter One, care is an ambiguous and nebulous concept (Morse et al. 1990;

Phillips 2007). Whilst many individuals no-doubt have an innate sense of what care is or might look like, the elusive nature of care means that it is difficult to articulate its various dimensions, which therefore complicates its analysis in practise (Engen et al. 2021).

The model I have proposed draws out and makes *visible* the various dimensions of care. Through highlighting the dimensions of care, the concept of *care-embedded social work* makes it possible to determine *the presence of care* in the work of practitioners. Knowing whether and when practitioners are working in “caring ways” (Engster 2005, p. 54), is fundamental in turn, to appreciating the *impacts* of care (the potential difference that caring social work makes from the perspectives of individuals and families). The development of a practical model, which illuminates the multifaceted nature and benefits of care, is critical to social work practice. It provides an important teaching tool for social work educators for example; a means of highlighting the qualities, characteristics and significance of care to social work. It also enables practitioners to reflect upon and to appreciate the potential impacts of their interactions and interventions with individuals and families.

In developing this model, I have drawn upon theoretical work which, to the best of my knowledge, has not previously been used in the analysis of social work care. By way of example, the model of *care-embedded social work* draws upon the work of Klaver and Baart (2011), which disaggregates the ethical concept of attentiveness. As stated in Chapter Three, attentiveness is a critical component of “authentic caring” (Holstein et al. 2011, p. 128). It provides a way of practitioners expressing their caring feelings towards those with whom they work and therefore ensures that individuals and families feel “cared about” (Tronto 1994, p. 106) during social work intervention.

I have explored the importance of expressions of attentiveness in several of the empirical chapters of this thesis. For example, in Chapter Five, I argued that social workers can undertake their roles and responsibilities *attentively*; they can be diligent and focused in the ways they provide information. In Chapter Six, I showed how attentiveness (the pushing aside of all other potential distractions when in interaction) constitutes an expression of care from the perspectives of informal carers. Such attentiveness was seen to open up deep conversations, allowing practitioners access to

the feelings and emotions of those providing informal care and heightening their understandings of the gravity of care home admission experiences.

A care approach places a great deal of emphasis on practitioner understanding. As stated in Chapter Six, however, only certain sorts of relationships have the potential to enhance the understandings of practitioners. Ferguson et al. (2022) recently made the point that there have been too few studies exploring the qualities and characteristics of meaningful relationships within social work practice. This thesis adds to the limited literature in this area, exploring the quality and characteristics of *care-facilitative relationships* with reference to the work of Buber (1970). With the exception of one other study, which explored supervisory relationships through the work of Buber (Itzhaky and Hertzanu-Laty 1999), I do not believe that Buber has been used elsewhere in the analysis of social work relationships. As such, this study makes an important and unique theoretical contribution to the existing field of knowledge in this area.

In Chapter Six, I tested out the importance and impacts of “I-thou” (Buber 1970) relationships in the work of practitioners. As stated in Chapter Three, such relationships embody certain linguistic characteristics and are also high in levels of presence. It could be seen that I-thou relationships significantly increased the understandings of practitioners. Due to these increased understandings, practitioners were then better able to perform their roles and responsibilities *with care* (to engage in “competent” (Tronto, 1994, p. 133) decision-making, for example). I-thou relationships contrast sharply with “I-it” (Buber 1970) relationships, which are seen as instrumental, perfunctory, cool and distanced. Such relationships are limited in levels of reciprocal conversation and intersubjective presence; they minimise practitioner understandings and diminish competent decision-making outcomes.

The concept of *presence* has been an important analytical device in this study. Like attentiveness, presence is a multifaceted concept (Osterman and Schwartz-Barcott 1996). In Chapter Six I argued that the understanding of practitioners was dependent upon them being physically and psychologically present with those with whom they worked. Significantly, however, the presence of practitioners in the lives of individuals and families has been curtailed in recent times, due to the covid-19 pandemic.

Incidentally, the findings of this study arguably make an important contribution to the emerging body of literature, exploring the impacts of covid-19 on levels of care and caring (Byrne et al. 2021; Nielson et al. 2021). Peek et al. (2020) draw attention to the ways in which direct relationships have been significantly diminished throughout the pandemic with some forms of care even being provided through digital means. In highlighting the importance of face-to-face, intersubjective relationships in the provision of care, this study makes explicit the potential risks associated with the ‘digitalisation’ of care. Todres (2008) makes the point that practitioners acquire understanding through far more than just verbal means. Here, reference is made to the importance of “embodied relational understanding” (p. 1566), which illustrates the importance of practitioners using all of their senses and emotions in the process of information gathering. Muzicant and Peled (2018) describe, for example, how practitioners acquire information even through the use of their sense of smell during home visits. Clearly, it is impossible for practitioners to acquire such sensory information, in the absence of face-to-face, physical contact.

Some commentators have also explored the particular risks faced by older people living in care homes throughout the pandemic (Oliver 2020; Older People’s Commissioner for Wales (2020a; 2020b; 2020c); Anand et al. 2021; Bows and Herring 2022). Visits from regulatory bodies were suspended meaning that there were fewer opportunities for monitoring the quality of care provided to older residents (Anand et al. 2021). It is also the case that many informal carers were unable to visit their older loved-ones within care homes for significant periods of time (Anand et al. 2021), thus reducing the potential for them to contribute to the provision of care. In Chapter Seven, I discussed the important roles of informal carers in contributing to the quality of care to older people with dementia through providing “relational knowledge” (Dewar and Nolan 2013, p. 1247) to care home providers. As a result of the restrictions on visiting, many opportunities for maximising the quality of care through collaborative discussions, were no doubt lost.

One of the aims of this thesis was to determine levels of caring in social work. Whilst acknowledging that the findings of this study are based on the work of a limited sample of practitioners, there is nonetheless strong evidence to suggest that levels of *care-embedded social work* are highly variable. The practitioners engaged within this

study certainly *cared about caring*. As such, they did their very best (often with success) to “transcend the barriers” (Hay 2019, p. 372) of time within their work (see Chapter Eight). There were also times, however, where these same practitioners spoke of compromising care in order to maintain the pace of their workloads.

According to Yuill and Meuller-Hirth (2019), there have been very few attempts to explore the impacts of time constraints on the “lifeworlds” (p. 1532) of social workers. The findings of this study show that care was of the utmost significance to the practitioners engaged within this study; they gleaned an enormous sense of satisfaction when feeling that they had cared well for those with whom they worked. On the other hand, feeling unable to care, led to practitioners experiencing what Fenton (2015) calls “ethical stress” (p. 1415). As argued by Evans and Huxley (2009), job satisfaction has significant implications for retention of staff. High levels of ethical stress no doubt negatively impact “workforce retention” (Chiller and Crisp 2012) within social work and social care.

Consistent with the findings of much of the existing academic social work literature, this study highlights the ways within which time constraints have become a critical barrier to levels of social work care, in contexts of neoliberalisation (see Postle 2001; 2002; Harlow 2003; Harris 2003; Dustin 2007). In contrast with the majority of this literature, however, this study adopts a conceptual analysis of time in exploring the problem of time within social work practice.

Specifically, the study examines the importance of practitioners paying attention to the subjectivities of time when seeking to build relationships with older people and informal carers. Through exploring the ways within which time is used in the development of care relationships, this study makes a further important theoretical contribution to knowledge. As stated by Habran and Battard (2019), despite the assumption that relationships are time-dependent, few studies have in fact, explored the importance of different modes of time utilisation in the development of meaningful, caring relationships.

In finalising this discussion, I argue that the findings of this study provide good evidence for the importance of care in transition and the importance of care in social work, *per se*. It is important to state that social work theorists and academics have

sometimes disagreed as to the importance and appropriateness of care to social work practice. Some commentators conceptualise care as an “ideal” (Meagher and Paton 2004, p. 10) in social work (see also Dustin 2007; Hay 2019). Others have been sceptical about the value of care to social work. Healy (2000) for example, highlights the potential for power-imbalances and paternalism in care (see Chapter Three). Oliver and Barnes (2012) argue that welfare professionals predominantly deliver care in accordance with “individual, medical models” (p. 136) where the focus is on ‘treating’ the individual, rather than challenging “negative assumptions and ideologies surrounding impairment” (p. 121).

From a critical social work perspective, it is not enough for social workers to “practise traditional casework” (Houston 2016, p. 4). Instead, it is argued that the practises of social work must understand the ways within which the situations and circumstances of individuals are shaped by “the broader socio-political sphere in which they live” (Barak 2019, p. 2130). The version of care advocated within this thesis, is the *politicised* version of the ethic of care, which seeks participatory, co-produced solutions to the problems facing individuals and families, and which challenges the adverse impacts of political, social and economic structures (see Tronto 1994; Barnes 2012). Insofar as the provision of such care is dependent on practitioners engaging with issues of social justice (see Chapter Eight), I argue that there is a fundamental ‘fit’ between *care-embedded social work* and the ethics and values of the social work profession.

I will shortly consider the actions needed to enable social work to become a more consistently care-embedded profession. Before moving on to explore these actions, however, I will briefly consider the methodological contributions of this study to the existing field of knowledge.

## **Methodological Contributions**

The existing research focused on informal carers’ experiences of care home admission, is largely undertaken using interview methods (see Chapter Two). The very limited UK research exploring the interventions of social workers at such times is primarily undertaken using discursive methodologies. This study differs methodologically from the existing studies in this area. It explores admission related

practice with informal carers through combining interview methods with the use of ethnographic *observation*.

The fact that this study used observational methods in examining practises of care in social work is also significant. Observation enabled me to directly explore *performances* of care within social work; it enabled me to produce findings that facilitate “concrete understandings” (Hay 2019, p. 365) of the ways that social workers *enact* care within their day-to-day encounters. As stated in Chapter Four, proponents of observational social work research argue that it increases understanding of the realities of ‘on the ground’ social work practice (Ferguson 2016). Through undertaking direct observations of social work encounters, I was able to witness first-hand, the impacts of practitioner caring upon the transition experiences of informal carers. The smiles and looks of relief on the faces of these informal carers said much about the importance of practitioners working in “caring ways” (Engster 2005, p. 54) at times of care home admission.

It is also important to state that observation provided a means of ensuring the inclusion of otherwise, marginalised groups in the research process. As stated by Ries et al. (2017) “research often excludes people with dementia” (p. 359) due to anxieties around mental capacity. Yet there is ample evidence to show that older people with dementia can effectively participate in research, provided that researchers make use of correct research methodologies (Dewing 2007; 2008; King et al. 2016). The importance of observation as a means of including older people in research has been highlighted elsewhere in the literature (see Hubbard et al. 2003). Through undertaking observational research, I was able to speak with the older people engaged within this study, in an informal, conversational and non-threatening way (see Chapter Four). Critically, such conversations ensured the inclusion of the voices and perspectives of older people with dementia in my analysis of the impacts of residential and nursing home admission.

Having discussed the findings of the study in answer to the research questions, and having explored the contributions of my work to the existing field of knowledge, I will now move on to considering the kinds of actions needed to alleviate the challenges of care home admission from an informal carer perspective.

## **Recommendations**

Based on the findings of the study, it is recommended that the following actions are taken to alleviate some of the challenges faced by informal carers at times of care home admission:

### **1. Actions to Make Care Home Entry a Positive Choice**

Throughout this thesis, I have argued that care home admission is a highly stigmatised transition. There is a need for action that reframes residential and nursing home care, as a *positive* choice in the lives of older people and informal carers.

#### **i. Policy action**

Policy makers must pay attention to the *impacts* of the messages they convey through social care policy and legislation. Social care policies are written in ways that emphasise the perceived value of independence and self-care. If care *is* needed, there is a clear expectation that preferably, it will be provided by the family or friends of older people and within their own homes. These discourses place an onus on informal carers to provide care irrespective of the challenges they may face in so doing; they heighten feelings of guilt and failure in situations where informal carers are unable to care.

Welsh Government has an important role to play in developing policy that avoids conceptualising institutional care as a final “last resort” amongst caregiving options. Social care policy needs to re-envision residential and nursing home care more positively; as a viable means of providing care to older people with dementia and as a legitimate part of a continuum of long-term caregiving options.

In addition, Welsh Government should channel funding to maximise the availability of respite care. As I argued in Chapter Eight, respite care in the same residential home, over time, helps care home providers develop greater understandings of the older person’s needs and circumstances. It also enables older people, informal carers and care home providers to build positive relationships well ahead of the time of permanent admission. This in turn, greatly alleviates the stress of the transition process. The recent Welsh Government pledge of £3m for respite care within the

Welsh Government's Strategy for Unpaid Carers (Welsh Government 2021a), provides a clear opportunity to enable action on this recommendation.

## **ii. Promoting positive attitudes**

If negative attitudes towards residential and nursing home care are to change, there is a need to highlight and celebrate *good* examples of residential and nursing home care. The media has an important role to play in shaping attitudes and as stated in Chapter Five, media coverage of life in institutional care has been predominantly negative (Manthorpe et al. 2016; Pedley and McDonald 2019). Recently, there have been positive portrayals of the experience of living in a care home and of the commitment and dedication of many care workers throughout covid-19 (see the BBC television programme, "*Rhod Gilbert's Work Experience: Care Worker*" and the C4, care home docudrama starring Jodie Comer and Stephen Graham: "*Help*"). Such publicity is critical to challenging negative attitudes around institutional care, framing it in more positive ways. As stated in Chapter Two, the "My Home Life" projects in the UK highlight and celebrate positive examples of life in a care home. There does not appear to be an equally well-established initiative in Wales. Developing a Welsh "My Home Life" initiative in Wales, would also offer an important means of raising the public profile of care home provision.

## **iii. Community integration**

In Chapter Five I highlighted the fact that care homes tend to exist on the edge of society. It is important that they become an integral part of the communities within which they are located, if negative attitudes are to be challenged and changed. The potential for integration to change negative perception was demonstrated through Age UK's initiative, '*Old People's Home for Four Year Olds*' broadcast on Channel 4 in 2017. In this intergenerational project, young children spent a period of six weeks interacting with older people in residential care. The programme illustrated many benefits to both parties including reductions in feelings of social isolation amongst the older people engaged in the project, and positive changes in attitude amongst the family members of the children. More projects of this kind should be encouraged via third sector organisations and perhaps promoted and financially supported by Welsh Government. This would fit with Welsh Government objectives to increase

intergenerational solidarity (Welsh Government 2021b) and to promote sustained community cohesion (Welsh Government 2015b). Other ways of opening up and demystifying care homes should be explored and might include, for example: using care homes as sites for community education; setting up a community café; using care homes for church services; or film showings; and developing a community garden/allotment initiative perhaps.

## **2. Facilitating Care-Embedded Social Work**

The study demonstrates the importance of relationships to practitioners working in *care-embedded* ways. It also shows, however, that the quality of social work relationships is dependent on the time available to practitioners. The recommendations that follow thus focus on ways of increasing the time available for practitioners to build relationships with those with whom they work, and hence to undertake their roles and responsibilities with *care*:

### **i. Action at policy and Local Authority level**

At Welsh Government level, there needs to be an emphasis on re-allocating and increasing existing funding to strengthen and expand the social care workforce. An increase in the numbers of practitioners will help reduce the volume of caseloads and allow more time for relationship building with individuals and families.

Within Local Authorities, there needs to be a conscious effort made to streamline bureaucratic processes, with a view to decreasing lower-value administrative tasks and freeing up and prioritising time for relationship building.

### **ii. Action at practitioner level**

Practitioners themselves have important roles to play in challenging the constraints on time within their work. As the study findings show, many social workers challenged expected working practises in order to carve out additional time to build and maintain relationships with older people and informal carers. Some challenged the constraints on time to preserve intra-familial relationships (for example, they sought to ensure that older people were admitted to care homes within a reasonable geographical distance from their informal carers, so as to allow for continued contact).

Whilst these actions were important, I argue that they are insufficient alone, in getting ‘to the root’ of the time problem in social work practice. Such actions, whilst laudable, will not promote sustainable change. What is needed is for social work to become a more *campaigning profession*, in ways advocated by critical gerontological social work theorists. My discussions with practitioners showed that they shared similar concerns. Practitioners need to strengthen their voices; they must raise their concerns around the impacts of inadequate time on social work practice in more collective ways.

Consequently, I strongly recommend that practitioners within the Local Authority are given time to routinely come together with managers in a form of discussion forum. Here, they would share their experiences and concerns and develop solutions that improve working practices. Through engaging with this process, practitioners will participate in a more collective form of advocacy. It is important for practitioners to challenge time-constraining policies at Local Authority level, but they should also seek to influence Welsh Government policy, which shapes time utilisation and therefore impacts on their social work roles and responsibilities. Through these discussions forums, practitioners could perhaps therefore, engage in preparing collective responses to proposed policy changes.

### **3. Promoting Informal Caregiving Within Care Home Settings**

#### **i. Social worker actions pre-admission**

The findings of the study highlight the importance of informal carers having opportunities to continue their caregiving roles beyond care home admission. This is critical to the selfhood of informal carers and to promoting the quality of care for older people with dementia (see Chapter Seven.) It is therefore vital that practitioners avoid simply assuming informal carers see care home admission as a relief from the burdens of caregiving. (See Chapters Two and Three.)

Before admission therefore, I strongly recommend that practitioners routinely discuss opportunities for continued caregiving with older people and informal carers; how informal carers would like to continue to care for their older loved-ones for example, and whether they would like to undertake wider influencing roles within the care home (such as sitting on a ‘residents’ board’ perhaps).

## **ii. Social worker actions post-admission**

The findings of the study highlight the critical importance of practitioners remaining involved in working with older people and informal carers within care home settings post admission, so as to promote the quality of relationships with care home providers. (As seen in Chapter Seven, these relationships influence the extent to which informal carers continue to provide care.) From such a perspective, it seems that there is much merit to the models adopted in countries like the USA and Canada, where social workers are permanently located in long-term care environments. It is perhaps unlikely that similar arrangements will be made in the UK at this present time; nevertheless, it still remains important for agencies and practitioners to find alternative ways for maintaining their involvement.

An alternative way of practitioners remaining involved with older people and informal carers post admission, would be for Local Authorities to develop *link worker systems* with care homes. Small groups of social workers could be aligned to a specific care home, increasing their physical presence and visibility, through spending a dedicated amount of time per week, within that care home setting.

It is possible for example, that as older people and their families became increasingly familiar with this small group of social workers, that they would then in turn feel more comfortable in raising issues and concerns. These practitioners could assist in addressing identified issues and concerns early and before they escalate into issues that heighten relational tensions. Being regularly on site, these practitioners may also better engage in more therapeutic type interventions helping to meet the emotional needs of informal carers. Such interventions might include for example, the setting up of groups where informal carers can then explore their feelings and emotions in a mutually supportive environment.

As these link workers spend time developing relationships with older people and their informal carers, it would also be beneficial for them to undertake responsibility for reviews within their allocated care home settings. Reviews as we have seen, are fundamental to the provision of effective care (see Chapter Three) although as highlighted in Chapter Eight, their impacts were often limited within the Local Authority. Practitioners generally undertook these reviews without prior relationships

with older people and their informal carers, meaning that they often lacked understandings of specific needs and circumstances. As a result of a lack of relationship, informal carers were also often reluctant to raise issues of concern. Since the *link worker system* would help ensure the development of relationships, it could help maximise the effectiveness of the review process.

#### **4. Education**

My final recommendation focuses on the importance of the roles of social work educators in preparing practitioners to engage in social work that promotes and upholds the rights of older people and informal carers. As stated in Chapter Three, critics have argued that there has been a reduction in practitioners engaging with issues of social justice, in the neoliberal era. Krumar-Nevo (2017) refers to the “depoliticisation” (p. 811) of social work, wherein it is argued that “social workers have abandoned their involvement in influencing macro level societal changes” (p. 811). As teachers of theory, social work educators play fundamental roles in shaping the ways that practitioners think about and conceive of practice problems and solutions (Deacon in Deacon and Macdonald 2017; McGregor 2019).

From a critical gerontological social work perspective, social work in the neoliberal era has arguably lost its ‘sting’; it has become more perfunctory and task oriented and has lost sight of its purpose in advocating for the rights and needs of older people. Educators who develop a curriculum that draws upon critical gerontological perspectives, will train practitioners who are better placed to appreciate the impacts of their practice on individuals and families. I argue that through engaging with critical research perspectives, these practitioners will be more able to challenge policies and procedures, which disadvantage older people and informal carers.

An effective and informed curriculum should also of course, draw upon the ethic of care literature and the literature on relationship-based social work. Practitioners well versed in such material will develop a stronger appreciation of what it means to undertake their roles and responsibilities *with care* and will be more aware of the potential risks of failing to engage in *care-embedded social work*, when in interaction with older people and their informal carers.

Practitioners maintaining their Continuing Professional Development should similarly be offered opportunity to attend training with focus in these areas.

### **Limitations of the study**

As I have stated previously, there are few studies of informal carers' experiences of care home admission undertaken in Wales. The fact that this study *has* been undertaken in Wales is therefore part of its unique contribution to knowledge. It is important to state, however, that the findings of this study cannot be considered as necessarily typical of care home admission experiences in Wales, *per se*. As stated by Williams (2011), "Wales is a small nation" but it is also "very diverse" (p. 6).

There are 22 Local Authorities in Wales and as highlighted earlier, these Local Authority areas differ significantly in terms of, for example, socioeconomic characteristics. The Local Authority site for this study had high levels of socioeconomic deprivation. It is important to recognise that socioeconomic inequalities across the lifespan, shape the health and well-being of individuals in subsequent older age and are likely to increase an individual's need for care and support (see Milne and Williams 2000; Phillips and Burholt 2007). These inequalities also have the potential for adverse impacts upon the transition experiences of informal carers. Choice is important in shaping positive perceptions of transition (Chentiz 1983) and perception matters because it influences transition outcomes (Nolan et al. 1996b). As discussed in Chapter Five, levels of choice are decreased in situations of socioeconomic disadvantage. Here, some informal carers had their options limited when choosing a care home setting due to the size of the 'third-party' payments requested by certain care homes. Had the study been undertaken in a more affluent area or one with a more diverse population, many informal carers might have had a greater choice of care home setting. In this case, care home admission experience might have been perceived and hence experienced, in more positive ways. It is also worth stating that there were relatively low levels of social mobility within the Local Authority area, meaning that many informal carers (adult children in particular) lived in close proximity to their older parents. These close living arrangements might have increased *expectations* to care, with the result that feelings of guilt and failure might then have been heightened when making decisions in favour of care home entry.

As observed by Williams (2011), “Wales is also a multicultural society” (p. 7). Due to the characteristics of the specific, Local Authority area, I was, however, unable to recruit informal carers from black or other ethnic minority groups to the study. Had I undertaken the study within Cardiff for instance, this situation might have been very different. I am very much aware that a lack of diversity within recruitment samples can be problematic and can limit the understandings of researchers (Greenwood et al. 2018). As stated by Mold et al. (2005), experiences of care home admission are often very different for those from within black and minority ethnic communities who, for example, face the additional challenge of services that fail to recognise their “language, cultural and religious” (p. 107) needs (see also Milne 2003; Winslow and Flaskerud 2009).

As argued within Chapter One, transitions are processes occurring over time (Meleis et al. 2000) and as such, the needs and experiences of informal carers inevitably differ at various points in time and in accordance with the phase reached by informal carers, on the transition trajectory. Nolan et al. (1996a) therefore suggest that studies of transition benefit from a longitudinal perspective. Given a limitation on time and resources, it was not possible for me to engage within a longitudinal study. It must be recognised therefore, that the findings of the study are inevitably shaped by the fact that care home admission was a relatively recent event in the lives of all of those informal carers participating in this research.

It could be, for example, that due to the fairly recent nature of the care home admission, many of these informal carers were at a stage where they were particularly active in their post-admission caregiving roles and responsibilities. It is important to recognise that the extent to which informal carers engage in continued caregiving beyond institutionalisation is not static. Engagement in caregiving, may well decrease over time and perhaps as informal carers become more confident in the quality of the care provided in care home environments (Hennings et al. 2013; Gladstone et al. 2006). Had I undertaken a longitudinal study (or had I recruited informal carers at later stages of the transition trajectory) there might well have been differences in informal carer perspectives on their continued caregiving roles and responsibilities.

Finally, I want to highlight a potential problem with the notion of *care-embedded social work* as I have conceptualised it within this thesis. Care, as it has been

envisioned within this work, is heavily reliant upon the input of informal carers. These informal carers undertake important decisional and other practical roles on behalf of older people with dementia and are critical to promoting and sustaining the quality of caregiving within institutional settings. Recent Welsh Government policy (Welsh Government 2021b) highlights changing patterns of family composition and an increase in “single person households” (p. 7). Many more older people are now unmarried, divorced or without children (Ray et al. 2015; Yeandle et al. 2017). A recent publication by the charity organisation Re-engage (2021) likewise states that older people from LGBTQ+ groups are “more likely to live alone, be single and less likely to have regular contact with their biological family”.

Since such older people will not necessarily have access to an informal carer, it is important to consider how their needs can also be met in *care-embedded* ways, within the context of care home admission. When reflecting upon the needs of these older people, I am minded of the importance of “Advanced Care Planning” processes. The Mental Capacity Act (2005) made provision for Advanced Care Planning, which offers people the “opportunity to plan their future care and support... while they have the capacity to do so” (National Institute of Social Care Excellence 2019). Advanced Care Plans are of critical importance if older people later lose the capacity to shape and influence processes of caregiving. They are arguably also of fundamental importance to those older people who do not have an informal carer to relay “relational knowledge” (Dewar and Nolan 2013, p. 1247) on their behalf. Tools such as the Alzheimer’s Society “This is Me”<sup>33</sup> document (2021), would also be important for older people without an informal carer, and would help facilitate the provision of ‘person-centred care’ within long-term care environments.

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<sup>33</sup> “‘This is me’ can be used to record details about a person who can't easily share information about themselves. For example, it can be used to record a person’s cultural and family background, important events, people and places from their life, their preferences and routines”. (Alzheimer’s Society 2021)

## **Avenues for Further Research**

In light of the comments made in the preceding section, I advocate for similar research in other Local Authority areas within Wales. This will help to identify differences in the transition experiences of informal carers based on geographical location, and will give a broader perspective on the care home admission experiences of informal carers across Wales. It would be important to understand, for example, care home experiences from the perspectives of informal carers from black and minority ethnic groups across Wales. There are also likely to be differences in informal carers' perceptions of the care home admission process depending on other characteristics of geographical locations (whether the Local Authority is primarily urban or rural, for example). Previous research undertaken by Ryan et al. (2012) suggests that processes of choice making are easier in rural areas where informal carers have a "strong sense of familiarity with the nursing homes" (p. 1) in their geographical location. Consideration of the impacts of these differing characteristics would be important in expanding the model of *care-embedded social work* that I have proposed within this thesis. It is critical that in undertaking their admission-related roles and responsibilities in "care full" (Barnes 2012, p. 9) ways, practitioners are *attentive* to the full range of characteristics shaping the care home admission experiences of informal carers.

Finally, it is important to reiterate that social work itself was at a point of transition when I undertook this study. As stated within previous sections, this research was undertaken at a time when the legislative context of social work practice was changing and at the point at which, the aims and objectives of the Social Services and Well-being (Wales) Act 2014 (Welsh Government 2014), were being implemented into the work of Local Authorities. Given the timing of my fieldwork, I have been explicit that it was neither possible for me to evaluate the impacts of the legislation upon the care home admission experiences of informal carers, nor to determine the ways within which the legislation might alter and shape subsequent social work practice. Further research will be needed to highlight differences in admission related outcomes based on the current legislation.

Future research should also consider the impacts of covid-19 on *care-embedded social work* and explore the extent to which the recently proposed funding increases<sup>34</sup> in social care in Wales, increase the consistency of *care* in social work practice.

## **Concluding Comments**

This thesis has explored the care home admission experiences of informal carers living within one, Welsh Local Authority. It has examined the roles undertaken by these informal carers at such times, considering the practical and emotional challenges they faced. Consistent with earlier research in this area, the findings of this study show that the experience of care home admission is characterised by high levels of anxiety and stress. These anxieties and stresses are not necessarily alleviated at the point of care home entry. Many informal carers struggled to establish relationships with care workers in a care home setting, which then compromised their ability to continue their caregiving responsibilities.

This study differs from most existing research in this area in that it specifically explores the input and intervention of *social workers*; examining the way they work with informal carers during admission processes. As stated in Chapter Two, very little research has focused on the roles and tasks of social workers, despite their primary responsibility for care home entry. If practice in this area is to be effective, practitioners must, at all times, bear in mind the challenges of the care home admission experience and its impact on the emotional wellbeing of older people and informal carers. The findings of the study demonstrate the importance of practitioners engaging with older people and informal carers with sensitivity, compassion and *care*.

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<sup>34</sup> At the time of writing, the UK government has announced its intentions to increase the levels of funding available to social care. These additional funds are to be secured firstly, through raising National Insurance contributions (2022) and then through the introduction of a Social Care Levy (2023). A part of the revenue produced via these mechanisms will be allocated to Welsh Government (Welsh Government 2021b, p. 23) although the exact amount of this increase remains unclear and as such, the adequacy of the funding allocated towards facilitating care-embedded social work, remains to be seen.

This study has specifically examined the importance of social workers adopting a *care* approach to their admission-related social work practice. It has drawn upon ethic of care theory to elucidate the qualities and characteristics of care and has examined the impacts of several of these characteristics, in the work of practitioners. The findings show that a care approach to social work or what I have termed *care-embedded social work* makes a critical difference to informal carers. The experience of care home admission is not necessarily painless in the presence of care; nonetheless, *care-embedded social work* goes a significant way towards alleviating the stresses and anxieties of informal carers at such times.

This study has explored the extent of care in the work of a small group of practitioners and has made explicit some of the barriers to caring in current social work practice. On the basis of these findings, it has then made a series of practical recommendations for increasing and sustaining *care-embedded social work*. These recommendations are made at the levels of both policy and social work practice.

The transition of care home admission has provided a valuable lens for examining the wider importance of *care* in social work practice. It is important to recognise that care home admission is just one type of transition experience and that in fact, social workers work with many individuals and families, engaged in many types of complex, transition situations (Petch 2009). I argue that the findings of this study will therefore have important implications for social work practice beyond gerontological social work, and will assist the development of wider models of effective, social work intervention for working with individuals at times of significant change.

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## **Appendices**

## Appendix A – Observations by Type

Observation Number	Detail	Location	Present
1.	Admission Review	Independent Residential Home	Care Manager; Care Home Provider; Older Person; Informal Carer
2.	Admission Review	Local Authority Residential Home	Care Manager; Care Home Provider; Older Person; Informal Carers (x2)
3.	Local Authority Panel Meeting	Local Authority Office	Team Managers (x2)
4.	Multi-disciplinary Meeting to discuss admission to a care home	Hospital Ward	Social Worker; Health Care Provider; Informal Carers (x2)
5.	Local Authority Panel Meeting	Local Authority Office	Team Managers (x 3)
6.	Meeting to discuss care home admission	Local Authority Office	Social Worker; Informal Carer
7.	Multi-disciplinary Meeting to discuss admission to a care home	Hospital Ward	Care Manager; Health Care Provider; informal Carer
8.	Monitoring Visit	Independent Nursing Home	Social Worker; Care Home Provider; Informal Carer
9.	Admission Review	Independent Residential Home	Social Worker; Care Home Provider; Older

		(Dementia Care)	Person; Informal Carer
10.	Admission Review	Independent Nursing Home	Care Manager; Care Home Provider; Older Person; Informal Carer
11.	Admission Review	Independent Nursing Home	Care Manager; Care Home Provider; Older Person; Informal Carer
12.	Admission Review	Independent Nursing Home	Care Manager; Care Home Provider; Informal Carer
13.	Admission Review	Local Authority Residential Home	Social Worker; Care Home Provider; Older Person; Informal Carer
14.	Safeguarding Meeting	Independent Nursing Home	Social Worker; Care Home Provider; older Person; Informal Carers (x3)
15.	Admission Review	Local Authority Residential Home	Social Worker; Older Person; Informal Carer
16.	Multi-disciplinary Meeting to discuss admission to a care home	Hospital Ward	Social Worker; Health Care Provider; Informal Carers (x2)
17.	Meeting to discuss support to Informal Carer / Potential Care Home Admission	Local Authority Office	Social Worker; Informal Carer
18.	Meeting to discuss care home admission	Older Person's Home	Social Worker; Informal Carers (x 2)

## **Appendix B – Interview Schedules**

- 1. Informal / Family Carer Interview**
- 2. Care Home Provider Interview Schedule**
- 3. Social Worker / Care Manager Interview Schedule**
- 4. Social Worker Interview Schedule (Hospital Discharge)**
- 5. Team Manager Interview Schedule**

## **1. Informal / Family Carer Interview**

### **Introduction:**

The purpose of this interview is to consider your own experience of being involved with a 'loved-one' entering a residential or nursing home. I would like you to tell me your 'story' of what happened in your own words. If you are able to, please tell me your 'story' from the beginning – from when you started caring for the older person - to the point of that person going into a residential or nursing home – to where you are now).

### **Prompts:**

#### **Pre-Admission:**

How long did they provide care and support for the person pre-admission to residential or nursing home?

What sorts of care and support were provided?

#### **Admission:**

What actually happened to result in the person going into a residential or nursing home?

Where was the older person at the time of deciding a care home admission was needed?

Who made the decision?

What was the involvement of the informal / family carer in the admission? What did they have to do? i.e. what was your role / part?

#### **Feelings and Emotions:**

How you felt / feel?

How would you describe the experience?

If the experience was hard, what was the 'hardest' part of the experience?

How long do these feelings last? / Are these feelings on-going now?

If the older person has been in residential / nursing care for some time – was there a point at which these feelings subsided? / A time where you might have felt better?

**Current Situation:**

What is the current situation?

What is your role now? (Visiting / Involvement etc.?)

How do you feel about the current situation?

**‘Help’ – (at time of admission) / the time of the person actually going in:**

If you could say that something would have really helped you at this time – what would it have been? What should ‘good help’ look like at this time?

Did you receive that help? Who provided it?

Most useful piece of help / advice you received?

**‘Help’ – (post admission) / the time after the person went in:**

Did you / do you need any help now that the person is living in residential / nursing care?

Do you receive that help? If so, who provides that help?

**‘Social work support’:**

When did they become involved?

What did the social worker do? (Did they do what you expected?)

Did the social worker provide you with any help? Was their involvement useful?

Could the social worker have done anything differently?

Do you still have contact with a social worker? If so, what do they do? If not, would that be helpful?

## **2. Care Home Provider Interview Schedule**

### **Introduction:**

The purpose of this interview is to give you an opportunity to consider the sorts of help provided by social workers / care managers to informal carers at a time of long-term care admission for older people. With your agreement, this interview is being voice recorded and will be transcribed (written up) for me to analyse. Please let me know if you would like a copy of this interview when it is written up.

1. What do you think might be the experience of many informal / family carers at a time of long-term care admission for older people?
2. What sort of help or support (in your experience), do you think might be needed by informal / family carers at this time?
3. What help do you provide in your own role (as a care home provider), to informal carers during times of care home admission. What do you need to do to support informal carers at this time?
4. In your role as a care home provider, what sorts of roles do you observe being undertaken by social workers / care managers in relation to care home admissions for older people? In particular – what (if anything) do you observe social workers / care managers doing, to help informal carers at this time (i.e. both a time of admission and following admission)?
5. Can you describe (anonymously) a case in which you feel a social worker / care manager has provided good / effective help to an informal / family carer? What particularly did that social worker / care manager do? What were the particular strengths of their role?
6. Can you describe (anonymously) a case in which you feel that a social worker / care manager did not / were unable to provide good / effective help to in an informal / family carer during long-term care admission? What was the context?
7. Overall, how effective is the current support provided by social workers / care managers to informal / family carers at a time of care home admission for older people?

8. What challenges do social workers / care managers face in providing good help and support to informal / family carers at a time of long-term care admission for older people?
9. What (if any) changes might be needed to provide more useful support to informal / family carers at a time of long-term care admission for older people?

### **3. Social Worker / Care Manager Interview Schedule**

#### **Introduction:**

The purpose of this interview is to consider the sorts of help provided by social workers / care managers to informal carers at a time of long-term care admission for older people. With your agreement, this interview is being voice recorded and will be transcribed (written up) for me to analyse. Please let me know if you would like a copy of this interview when it is written up.

1. What do you think might be the experience of many informal / family carers at a time of long-term care admission for older people?
2. What sort of help or support do you think might be needed by informal / family carers at this time?
3. What skills and knowledge do social workers / care managers have in potentially providing good help and support to informal / family carers at a time of long-term care admission for older people?
4. Tell me about the sorts of help you provide to informal / family carers at a time of long-term care admission for older people. i.e. what do you do in your role as a social worker / care manager/ what sorts of tasks do you complete?
5. Can you describe (anonymously) a case in which you provided what you would see as good / effective help to an informal / family carer? What particularly did you do? What were the particular strengths of your role?
6. Can you describe (anonymously) a case in which you feel that you did not / were unable to provide good / effective help to in an informal / family carer during long-term care admission? What was the context? What needed to be different to enable you to practice more effectively?
7. Overall, how effective is the current support provided by social workers / care managers to informal / family carers at a time of care home admission for older people? What are the challenges to providing good help and support to informal / family carers at a time of long-term care admission for older people?

8. What (if any) changes might be needed to provide more useful support to informal / family carers at a time of long-term care admission for older people?

#### **4. Social Worker Interview Schedule (Hospital Discharge)**

##### **Introduction:**

The purpose of this interview is to consider the sorts of help provided by social workers / care managers to informal carers at a time of long-term care admission for older people. With your agreement, this interview is being voice recorded and will be transcribed (written up) for me to analyse. Please let me know if you would like a copy of this interview when it is written up.

1. What do you think might be the experience of many informal / family carers at a time of long-term care admission for older people?
2. What sort of help or support do you think might be needed by informal / family carers at this time?
3. What skills and knowledge do social workers / care managers have in potentially providing good help and support to informal / family carers at a time of long-term care admission for older people?
4. Within your current role (i.e. focussed upon facilitating hospital discharges), please can you tell me about the sorts of help you provide to informal / family carers when older people are admitted to residential / nursing care? i.e. what do you do in your role as a social worker?/ what sorts of tasks do you complete?
5. In considering the work of 'care home admission', what (if any) are the particular strengths of the social work role?
6. Can you describe (anonymously) a case in which you provided what you would see as good / effective help to an informal / family carer? What particularly did you do?
7. Within your current role (and in considering care home admission work), can you describe the challenges of your role? What would need to change to support more effective social work practice with informal carers at times of care home admission?

## **5. Team Manager Interview Schedule**

### **Introduction:**

The purpose of this interview is to consider the sorts of help provided by social workers / care managers to informal carers at a time of long-term care admission for older people. With your agreement, this interview is being voice recorded and will be transcribed (written up) for me to analyse. Please let me know if you would like a copy of this interview when it is written up.

1. First of all, can I ask you to think about your own time in 'front-line' social work practice - what do you think might be the experience of many informal / family carers at a time of long-term care admission for older people?
2. Thinking upon your own experience as a social worker - what sort of help or support do you think might be needed by informal / family carers at this time?
3. What skills and knowledge do you think social workers / care managers need in potentially providing good help and support to informal / family carers at a time of long-term care admission for older people?
4. What sorts of things do you consider when allocating referrals for long-term care admission?
5. In your experience as a team manager, please can you talk about the ways in which social workers / care managers describe the needs of informal carers within assessments for long-term care? To what extent are the needs of informal carers considered and how are they discussed?
6. Can you talk to me about the process of authorising assessments for long-term care admission? What sorts of things do you consider when agreeing long-term care admissions? (i.e. what do you 'look for' in assessments when agreeing long-term care admission?)
7. What sorts of challenges do you think social workers face in providing good help and support to informal carers at times of care home admission? What (if any) changes might be needed to provide more useful support to informal / family carers at a time of long-term care admission for older people?

8. To what extent do you feel the new legislation (i.e. the Social Services and Well-being Wales Act) might change the practice of social workers / care managers in relation to care home admissions for older people?

## Appendix C - Types of Documents Analysed

<b>Details of Document</b>	<b>Number</b>
<b>'Contract' for Care Home</b>	<b>4</b>
<b>'Case Notes' / 'Recording'</b>	<b>5</b>
<b>Assessment</b>	<b>3</b>
<b>Care Plan</b>	<b>1</b>
<b>Review Documentation</b>	<b>2</b>

## Appendix D – Participant details

Participant	Detail	Observation	Interview
<b>Informal Carers</b>			
IC01: Maggie	Informal Carer (Friend)	N	Y
IC02: Rose	Informal Carer (Daughter)	N	Y
IC03: David	Informal Carer (Nephew)	N	Y
IC04: Harriet	Informal Carer (Daughter)	Y (observation 9)	Y
IC05: Jackie	Informal Carer (Daughter)	Y (observation 4)	Y
IC06: Lynne	Informal Carer (Daughter)	Y (observation 8)	Y
IC07: Bryony	Informal Carer (Daughter)	Y (observation 10)	Y
IC08: Lois	Informal Carer (Daughter)	Y (observation 17)	Y
IC09: Phillip	Informal Carer (Son)	Y (observation 11)	Y
IC10: Ruth	Informal Carer (Daughter)	Y (observation 6)	Y
IC11: Richard	Informal Carer (Son)	Y (observation 1)	N
IC12: Mandy	Informal Carer (Daughter-in-law)	Y (observation 2)	N
IC13: Ray	Informal Carer (Son)	Y (observation 2)	N
IC14: Gerald	Informal Carer (Son)	Y (observation 4)	N
IC15: Hilda	Informal Carer (Spouse)	Y (observations 7, 12)	N
IC16: Kate	Informal Carer (Granddaughter)	Y (observation 13)	N
IC17: William	Informal Carer (Son-in-law)	Y (observation 14)	N
IC18: Beverley	Informal Carer (Daughter)	Y (observation 14)	N
IC19: Patricia	Informal Carer (Daughter-in-law)	Y (observation 14)	N
IC20: Jean	Informal Carer (Daughter-in-law)	Y (observation 15)	N
IC21: Steven	Informal Carer (Nephew)	Y (observation 16)	N
IC22: Clara	Informal Carer (Niece)	Y (observation 16)	N
IC23: Kris	Informal Carer (Son)	Y (observation 18)	N
IC24: Julie	Informal Carer (Daughter-in-law)	Y (observation 18)	N
<b>Older People</b>			

OP01: Gwen	Older Person	Y (observation 1)	N
OP02: Winnie	Older Person	Y (observation 2)	N
OP03: Clarice	Older Person	Y (observation	N
OP04: Amelia	Older Person	Y (observation	N
OP05: Florence	Older Person	Y (observation 9)	N
OP06: Mary	Older Person	Y (observation 8)	N
OP07: Jack	Older Person	Y (observation 10)	N
OP08: Connie	Older Person	Y (observation 11)	N
OP09: Lorna	Older Person	Y (observation 13)	N
OP10: Olive	Older Person	Y (observation 14)	N
OP11: Sadie	Older Person	Y (observation 15)	N
OP12: Majorie	Older Person	Y (observation 17)	N
<b>Local Authority Staff</b>			
SW01: Adrian	Social Worker	Y (observation 4)	Y
SW02: Chloe	Social Worker	Y (observation 6,9, 17)	Y
SW03: Sarah	Social Worker	Y (observation 8)	Y
SW04: Josie	Social Worker	Y (observation 13, 15)	Y
SW05: Aled	Social Worker	Y (observation 14, 16)	Y
SW06: Alice	Social Worker	Y (observation 18)	Y
SW07: Anne	(Hospital Discharge Social Worker)	N	Y
SW08: Sue	(Hospital Discharge Social Worker)	N	Y
CM01: Janet	Care Manager	Y (observation 1)	Y
CM02: Carole	Care Manager	Y (observation 2)	Y
CM03: Lindsay	Care Manager	Y (observation 7, 10, 11, 12)	Y

TM01: Laura	Team Manager	Y (observation 3, 5)	N
TM02: Ella	Team Manager	Y (observation 3)	Y
TM03: Ross	Team Manager	Y (observation 5)	Y
TM04: Debbie	Team Manager	Y (observation 5)	N
<b>Care Home Staff</b>			
CHM01: Rob	Care Home Manager	N	Y
CHM02: Michael	Care Home Manager	N	Y
CHM03: Chris	Care Home Manager	N	Y
CHM04: Dawn	Care Home Manager	N	Y
CHM05: Elizabeth	Care Home Manager	Y (observation 10, 11)	Y
CHM06: Duncan:	Care Home Manager	Y (observation 8)	N
CHP01: Beth	Care Home Worker	Y (observation 1)	N
CHP02: Ryan	Care Home Worker	Y (observation 2)	N
CHP03: Val	Care Home Worker	Y (observation 9)	N
CHP04: Jo	Care Home Worker	Y (observation 12)	N
CHP05: Sophie	Care Home Worker	Y (observation 14)	N
<b>Health Care Providers</b>			
HCP01: Rhian	Nurse	Y (observation 4, 16)	N
HCP02: Gemma	Nurse	Y (observation 7)	N

## **Appendix E - Information Sheets and Consent Forms**

- 1. Care Home Providers – Consent for Observation**
- 2. Consultee Declaration**
- 3. Health Care Staff – Consent for Observation**
- 4. Care Home Provider – Consent for Interview**
- 5. Informal Carer – Consent for Interview**
- 6. Informal Carer - Observation**
- 7. Older Person – Consent for Observation**
- 8. Social Worker / Care Manager Consent**
- 9. Team Manager: Consent**
- 10. Participant Information Sheet – Health**
- 11. Participant Information Sheet – Informal Carers (Interview)**
- 12. Participant Information Sheet – Informal Carers (Observation and Interview)**
- 13. Participant Information Sheet – Older Person**
- 14. Participant Information Sheet – Social Workers and Care Managers**
- 15. Participant Information Sheet – Care Home Providers (Observation)**
- 16. Participant Information Sheet – Care Home Providers (Interview)**
- 17. Participant Information Sheet – Team Managers**
- 18. Carer / Consultee Information Sheet**
- 19. Participant Information Sheet – Team Managers - Interview**
- 20. Team Manager: Consent Interview**
- 21. Participant Information Sheet – Social Worker (Interview Only)**
- 22. Social Worker Consent – Interview Only**

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### **Care Home Providers – Consent for Observation**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet for this study (dated 16.11.16). I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that the researcher's primary aim within this study is to observe the work of social workers and care managers in relation to the help they provide to informal carers during care home placements for older people
- 3 I understand that my own practice (as a care home provider) is not the primary focus of observation for this research. However, I am agreeable for the researcher to undertake her observations of social work / care management practice whilst I am present and undertaking my own work activities (as detailed within the information sheet dated 16.11.16). I agree to the researcher making written notes as the

observation is undertaken

- 4 I understand that I am free to change my mind about this arrangement at any time. If I change my mind, I will speak to the researcher without delay
- 5 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names removed
- 6 I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
- 7 I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
- 8 I agree to take part in the above study

_____	_____	_____
<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

_____	_____	_____
<b>Name of Person (taking</b>	<b>Date</b>	<b>Signature</b>

**consent)**

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**Consultee Declaration**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

<b>Name of Older Person:</b>	
<b>Name of Person Signing the Declaration:</b>	
<b>Relationship to Older Person:</b>	

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the consultee information sheet for the study (dated 16.11.16). I have had the opportunity to ask questions and these have been answered to my satisfaction

- 2 In my opinion, the person for whom I care would not object to taking part in this study. I understand however, that I am free to change my mind about their involvement at any time and that I will not have to give a reason for my decision. I understand that if I change my mind, the medical and care rights of the person for whom I care, will not be affected.
- 3 I agree that the person for whom I care, should take part in observation for this study (as described in the information sheet – dated 16.11.16). I agree to the researcher making written notes as the observation is undertaken
- 4 I agree that the social worker / care manager may provide the researcher with access to any documentation produced for the placement (e.g. assessment, admission contract and case recording) as described in the information sheet – dated 16.11.16)
- 5 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that the identity of the person for whom I care, will not be known. All information will be anonymised and any reference to individual names removed
6. I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board’s Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
7. I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
- 8 I agree that the person for whom I care should take part in the above study

<b>Name</b>	<b>Date</b>	<b>Signature</b>

<b>Name of Person (taking consent)</b>	<b>Date</b>	<b>Signature</b>

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#### **Health Care Staff – Consent for Observation**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet for the study (dated 16.11.16). I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that the researcher's primary aim within this study is to observe the work of social workers and care managers in relation to the help they provide to informal carers during care home placements for older people
- 3 I understand that my own practice (as an NHS employee) is not the primary focus of observation for this research. However, I am agreeable for the researcher to undertake her observations of social work / care management practice whilst I am present and undertaking my own work activities (as detailed within the information sheet dated 16.11.16). I agree to the researcher making written notes as the observation is undertaken

- 4 I understand that I am free to change my mind about this arrangement at any time. If I change my mind, I will speak to the researcher without delay
  
- 5 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names removed.
  
- 6 I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
  
- 7 I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
  
- 8 I agree to take part in the above study

<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

<b>Name of Person (taking consent)</b>	<b>Date</b>	<b>Signature</b>

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**Care Home Provider – Consent for Interview**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet for the study (dated 16.11.16). I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that my participation is voluntary and that I am free to change my mind at any time and without giving a reason.
- 3 I agree to take part in an interview for this study (as described in the information sheet – dated 16.11.16). I agree to the interview being audio-recorded so that it can be transcribed at a later date
- 4 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names

removed

- 5 I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
- 6 I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
- 7 I agree to take part in the above study

_____	_____	_____
<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

_____	_____	_____
<b>Name of Person (taking consent)</b>	<b>Date</b>	<b>Signature</b>

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#### **Informal Carer – Consent for Interview**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet for the study (dated 16.11.16). I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that my participation is voluntary and that I am free to change my mind at any time and without giving a reason. I understand that my medical and care rights will not be affected by this decision
- 3 I agree to take part in an interview for this study (as described in the information sheet – dated 16.11.16). I agree to the interview being audio-recorded so that it can be transcribed at a later date
- 4 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will

not be known as the data will be anonymised and any reference to individual names removed

- 5 I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
6. I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
- 7 I agree to take part in the above study

_____	_____	_____
<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

_____	_____	_____
<b>Name of Person (taking consent)</b>	<b>Date</b>	<b>Signature</b>

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#### **Informal Carer – Observation**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet for the study (dated 16.11.16). I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that taking part is voluntary and that I am free to change my mind at any time, without giving any reason. I understand that my medical and care rights will not be affected by this decision
- 3 I agree to take part in observation for this study (as described in the information sheet – dated 16.11.16). I agree to the researcher making written notes as the observation is undertaken
- 4 I agree that the social worker / care manager may provide the researcher with access to any documentation produced for the placement e.g. assessment, admission

contract and case recording (as described in the information sheet - dated 16.11.16)

- 5 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names removed
  
- 6 I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
  
- 7 I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
  
- 8 I agree to take part in the above study

_____	_____	_____
<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

_____	_____	_____
<b>Name of Person (taking</b>	<b>Date</b>	<b>Signature</b>

**consent)**

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#### **Older Person – Consent for Observation**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet about this study (dated 16.11.16). I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that taking part is voluntary and that I am free to change my mind at any time, without giving any reason. I understand that my medical and care rights will not be affected by this decision
- 3 I agree to take part in observation for this study (as described in the information sheet – dated 16.11.16). I agree to the researcher making written notes as the observation is undertaken
- 4 I agree that the social worker / care manager may provide the researcher with access to any documentation produced for the placement e.g. assessment, admission

contract and case recording (as described in the information sheet – dated 16.11.16)

5. I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names removed
  
6. I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
  
7. I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
  
8. I agree to take part in the above study

_____	_____	_____
<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

_____	_____	_____
<b>Name of Person (taking consent)</b>	<b>Date</b>	<b>Signature</b>

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#### **Social Worker / Care Manager Consent**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet for the study (dated 16.11.16). I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that taking part is voluntary and that I am free to change my mind at any time, without giving any reason
- 3 I agree to take part in observation for this study as described in the information sheet (dated 16.11.16)
- 4 I agree to take part in the interview for this study as described in the information sheet (dated 16.11.16). I agree to the interview being audio recorded for later analysis

- 5 I agree (that with the expressed permission of the older person and informal carer), the researcher may have access to the documentation produced in relation to the placement (as described in the information sheet dated 16.11.16)
  
- 6 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names removed
  
- 7 I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
  
- 8 I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
  
- 9 I agree to take part in the above study

<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

<b>Name of Person (taking</b>	<b>Date</b>	<b>Signature</b>

**consent)**

9.



Cardiff University School of  
Social Sciences

Glamorgan Building

King Edward VII Avenue

Cardiff

CF10 3WT

Email: [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

Tel: 07534 276 571

**Team Manager: Consent**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet (dated 16.11.16) about this study. I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that taking part is voluntary and that I am free to change my mind at any time, without giving any reason
- 3 I agree to take part in observation for this study (as described in the information sheet – dated 16.11.16). I agree to the researcher making written notes as the observation is undertaken.
- 4 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names

removed

- 5 I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
- 6 I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
7. I agree to take part in the above study

_____	_____	_____
<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

_____	_____	_____
<b>Name of Person (taking consent)</b>	<b>Date</b>	<b>Signature</b>

10.



### **Participant Information Sheet – Health**

#### **“Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”**

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **How will data be gathered for this study?**

In carrying out this study, I will be observing social workers and care managers as they work with older people and informal carers in relation to long-term care placement. With the permission of the older person, informal carer and social worker / care manager, I will be present during assessments, reviews and other meetings where care home placement is being considered. During observations, I will be making written notes and I will be focussing particularly on the social work help and support provided to informal carers.

**Why am I being provided with information about this study?**

It is possible that health care providers (e.g. nursing or therapy staff) may be present during observations. This may arise e.g. where an assessment is undertaken within a hospital setting or where the social worker is observed in providing support to an informal carer within a 'discharge-planning meeting'.

**Taking part in the study:**

The focus of this study is upon the social work practice delivered to informal carers during care home placement. As a part of this process, it is important to observe the support provided by social workers to informal carers within a multi-disciplinary context (i.e. where other professionals are present). Your presence within the observation is valuable in highlighting the specific roles undertaken by social workers when providing support to informal carers during care home placement.

**Please note however: I will not be explicitly observing or making comment upon the work practices of health care providers as a part of this study.**

**Important information:**

The focus of this study is upon the social work support provided to informal carers during care home placement. I do not feel there are any particular risks associated with your participation in an observation. However:

Your involvement in this study is entirely voluntary – it is up to you whether you want to take part.

If you are not in agreement, then I will not undertake any observation whilst you are present. Your relationship with the Local Authority will not be affected in any way as a result of this decision.

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identify will be disclosed.

The identities of all participants within this study – professionals, service users and informal carers – as well as the identity of 'agencies' (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). Your identity will not be known within final reports and publications as the data will be anonymised and any reference to individual names removed.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed

**What if there is a problem?**

If you have any questions please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study you may contact Dr. Sara MacBride-Stewart at Cardiff University (02920 876354) / [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Boards Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

# 11.



## **Participant Information Sheet – Informal Carers (Interview)**

### **“Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”**

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support informal carers need during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions; and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **Taking part in the study:**

I would like to invite you to take part in an interview to talk about your experiences of assisting an older person to move into a residential or nursing home. The interview is an opportunity to ‘tell your story’ of care home placement and to talk about how it feels when someone you care for moves into a residential or nursing home. You will also have a chance to talk about the sorts of things that either helped or hindered when you were in this situation.

If you agree to be interviewed, then the interview will be arranged at a time and place of your convenience. Interviews will last between 30 minutes and 1 hour. With your permission, interviews will be audio recorded so that they may be transcribed at a later date.

**Potential risks:**

I understand that many informal carers find the experience of moving an older person into a residential or nursing home, very difficult. If you feel in any way uncomfortable or upset when I visit with the social worker or during an interview, then please feel free to ask me to stop at any time.

**Important information:**

Your involvement in this study is entirely voluntary – it is up to you whether you want to take part.

You can withdraw from this study at any time prior to the research being written up and you do not have to give a reason for your decision. Your medical or care rights will not be affected in any way by this decision.

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identify will be disclosed.

The identities of all participants within this study – professionals, service users and informal carers – as well as the identity of 'agencies' (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). Your identity will not be known within final reports and publications as the data will be anonymised and any reference to individual names removed.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study you may contact Dr. Sara MacBride-Stewart at Cardiff University (02920 876354) / [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Boards Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

## 12.



### **Participant Information Sheet – Informal Carers (Observation and Interview)**

#### **“Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”**

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **Taking part in the study:**

If you decide to take part in this study, then I would like to be present when the social worker / care manager visits you and to observe how he / she provides you with support in relation to the care home admission. During the observation, I will make written notes of what the social worker / care manager says and does. I will also make written notes of some of the things that you say and do to help me to understand the process from your point of view. Direct quotes will be used as evidence in this study.

With your permission, I would like to have access to the written documents produced by the social worker / care manager in relation to the care home placement (i.e. assessments, admission contract and case recording in relation to the care home placement). This will enable me to understand how social workers / care managers interpret and use the information gathered within assessments and reviews to provide support in relation to care home placements. If possible, I would like to retain copies of the relevant documentation for the duration of the study. Your identity will not be known as the data will be anonymised and any reference to individual names removed. The documents will remain within the Local Authority office.

In some cases, I will ask if you would like to take part in a separate interview to talk more about your experience of assisting an older person to enter a residential or nursing home. If you agree to be interviewed, then the interview will be arranged at a time and place of your convenience. Interviews will last between 30 minutes and 1 hour and will be audio recorded so that they may be transcribed at a later date.

**Potential risks:**

I understand that many informal carers find the experience of moving an older person into a residential or nursing home, very difficult. If you feel in any way uncomfortable or upset when I visit with the social worker or during an interview, then please feel free to ask me to stop at any time.

**Important information:**

Your involvement in this study is entirely voluntary – it is up to you whether you want to take part.

You can withdraw from this study at any time prior to the research being written up and you do not have to give a reason for your decision. Your medical or care rights will not be affected in any way by this decision.

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identify will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of ‘agencies’ (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). All data will be fully anonymised when written up within final reports and publications.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions, please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study you may contact Dr. Sara MacBride-Stewart at Cardiff University (02920 876354) / [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Board's Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

## 13.



### Participant Information Sheet – Older Person

#### “Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **Taking part in the study:**

If you decide to take part in this study, then I would like to be present when the social worker / care manager visits you. I would like to observe in particular, how the social worker / care manager provides support to your informal carer in relation to the care home admission. During the observation, I will make written notes of what the social worker / care manager says and does. I will also make written notes of some of the things said by both you and your informal carer to help me to understand the process from your point of view. Direct quotes will be used as evidence in this study.

With your permission, I would like to have access to the written documents produced by the social worker / care manager in relation to the care home placement (i.e. assessments, admission contract and case recording in relation to care home placement). This will enable me to understand how social workers / care managers interpret and use the information gathered within assessments and reviews to provide support in relation to care home placements. If possible, I would like to retain copies of the relevant documentation for the duration of the study. Your identity will not be known as the data will be anonymised and any reference to individual names removed.

**Potential risks:**

I understand that the experience of moving into a residential or nursing home can be very difficult. If you feel in any way uncomfortable or upset when I visit with the social worker, then please feel free to ask me to stop observing at any time.

**Important information:**

Your involvement in this study is entirely voluntary – it is up to you whether you want to take part.

You can withdraw from this study at any time prior to the research being written up and you do not have to give a reason for your decision. Your medical or care rights will not be affected in any way by this decision.

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of 'agencies' (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). All data will be fully anonymised when written up within final reports and publications.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed

**What if there is a problem?**

If you have any questions, please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study you may contact Dr. Sara MacBride-Stewart at Cardiff University (02920 876354) / [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Board's Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

## 14.



### Participant Information Sheet – Social Workers and Care Managers

#### “Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers or care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **Taking part in the study:**

If you decide to take part in this study, then I would like to **observe** you as you support **2/3** different informal carers who are involved in care home placement for older people. During the observation, I will take written notes of some of the things that you say and do in providing support. Direct quotes will be used as evidence in this study.

As part of the observation I would like if possible, to have access to the written documents that you produce in relation to the care home placement (e.g. assessments, admission contract, case recording

in relation to the care home placement). This will enable me to understand how social workers / care managers interpret and use the information gathered within assessments and reviews to provide support in relation to care home placements. If possible, I would like to retain copies of the relevant documentation for the duration of the study. Your identity will not be known as the data will be anonymised and any reference to individual names removed.

Written consent will be obtained from the informal carer and if appropriate, from the older person for the observation to take place.

During the course of this study, I am hoping to observe the work of social workers / care managers in undertaking assessments, reviews and in attending other meetings where care home placement is being considered.

I would also like to **interview** you to learn more about your placement related work and the support you provide to informal carers during care home admissions. Each interview should last 30 – 45 minutes and can be done at a place and time of your choosing. With your permission, the interview will be audio recorded so that it can be transcribed at a later date.

**Potential risks:**

I do not think that the research can cause you any harm. I will make every effort to avoid disrupting your work. If you feel that a service user or informal carer is uncomfortable during an observation, then please free to ask me to leave at any time.

**Important information:**

Your involvement in this study is **entirely voluntary**

You can withdraw from this study at any time prior to the research being written up and without giving a reason

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identify will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of ‘agencies’ (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). All data will be fully anonymised when written up within final reports and publications.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study, you may contact Dr. Sara Mac-Bride Stewart (02920 876354) / email [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / email [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Board's Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

15.



**Participant Information Sheet – Care Home Providers (Observation)**

**“Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”**

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

**Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

**This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

**Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

**How will data be gathered for this study?**

In carrying out this study, I will be observing social workers and care managers as they work with older people and informal carers in relation to long-term care placement. With the permission of the older person, informal carer and social worker/ care manager, I will be present during assessments, reviews and other meetings where care home placement is being considered. During observations, I will be making written notes and I will be focussing particularly on the social work help and support provided to informal carers.

**Why am I being provided with information about this study?**

It is possible that care home providers (i.e. staff within residential or nursing homes), may be present during observations. This may arise where a review is undertaken within a residential or nursing home and where care home providers are present to discuss the placement with social workers and informal carers.

**Taking part in the study:**

The focus of this study is upon the social work practice delivered to informal carers during care home placement. As a part of this process, it is important to observe the support provided by social workers to informal carers within a multi-disciplinary context (i.e. where other professionals are present). Your presence within the observation is valuable in highlighting the specific roles undertaken by social workers when providing support to informal carers during care home placement.

**Please note however: I will not be explicitly observing or making comment upon the work practices of care home providers as a part of this study.**

**Important information:**

Your involvement in this study is entirely voluntary – it is up to you whether you want to take part.

If you are not in agreement, then I will not undertake any observation whilst you are present. Your relationship with the Local Authority (as a care provider) will not be affected in any way by this decision.

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identify will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of 'agencies' (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). Your identity will not be known within final reports and publications as the data will be anonymised and any reference to individual names removed.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions, please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study you may contact Dr. Sara MacBride-Stewart at Cardiff University (02920 876354) / [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Boards Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

## 16.



### **Participant Information Sheet – Care Home Providers (Interview)**

#### **“Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”**

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **Taking part in the study:**

I would like to invite you to take part in an interview to talk about your understanding of the experiences of informal carers when older people move into a residential and nursing home. The interview is an opportunity to reflect upon your observations of the social work support provided to informal carers at this time (whether this is adequate support).

If you agree to be interviewed, then the interview will be arranged at a time and place of your convenience. Interviews will last between 30 minutes and 1 hour. With your permission, interviews will be audio recorded so that they may be transcribed at a later date.

**Potential risks:**

I do not feel there are any particular risks associated with your participation in an interview. However, if you feel in any way uncomfortable or upset during interview, then please feel free to ask me to stop at any time.

**Important information:**

Your involvement in this study is entirely voluntary – it is up to you whether you want to take part.

You can withdraw from this study at any time prior to the research being written up and you do not have to give a reason for your decision

Your relationship with the Local Authority (as a care provider) will not be affected in any way if you decide not to participate in this study or if you choose to withdraw from the study at a later date.

**What will happen to the information gathered?**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identify will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of ‘agencies’ (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). Your identity will not be known within final reports and publications as the data will be anonymised and any reference to individual names removed.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study you may contact Dr. Sara MacBride-Stewart at Cardiff University (02920 876354) / [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Boards Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

17.



### Participant Information Sheet – Team Managers

#### “Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **Taking part in the study:**

If you decide to take part in this study, then I would like to **observe** the work that you undertake in relation to care home placements for older people (e.g. allocations of referrals for care home placement; panel meetings, authorisation of assessments and reviews in regards to care home placements). During the observation, I will take written notes of some of the things that you say and do in providing support; direct quotes will be used as evidence in this study.

#### **Potential risks:**

I do not think that the research can cause you any harm. I will make every effort to avoid disrupting your work.

**Important information:**

Your involvement in this study is **entirely voluntary**

You can withdraw from this study at any time prior to the research being written up and without giving a reason

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of ‘agencies’ (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). Your identity will not be known within final reports and publications as the data will be anonymised and any reference to individual names removed.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study, you may contact Dr. Sara Mac-Bride Stewart (02920 876354) / email [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / email [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Boards Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

18.



### Carer / Consultee Information Sheet

#### “Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University.

The person that you care for is to be visited by a social worker / care manager in order to help them to make plans for their future care needs. I would like to invite the person that you care for to take part in a research study. An assessment has been made that the patient does not have the capacity to make a decision about participating within this research. Under the Mental Capacity Act 2005, Section 32, a researcher must consult a carer or appointed consultee before including someone within research, when they lack the capacity to consent to that involvement for themselves. To help decide if the person you care for should join the study, I would like to ask your opinion about whether or not he/she would want to be involved. I would ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let me know of any advance decisions they may have made about participating in research, as these should take precedence. If you decide the patient would like to take part, I will include them in the study as long as they seem willing. If you decide the patient would not like to take part, I will not include them in my study.

Before you decide whether the person you care for should become involved in this research, it is important that you understand why the research is being done and what it will involve. Please read this information carefully. If there is anything you are not sure about, or if you would like more information, please ask. Take time to decide whether or not you feel that the patient would want to take part.

If you do not feel that you are able to advise about the patient’s participation, you do not have to.

#### **Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people

2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

**Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

**Taking part in the study:**

If you decide that the person you care for should take part in this study, then I would like to be present when the social worker / care manager visits you together. I will observe in particular, how the social worker / care manager provides support to you - as an informal carer in relation to the care home admission. During the observation, I will make written notes of what the social worker / care manager says and does. I will also make written notes of some of the things said by both you and the person you care for. This will help me to help me to understand the process from your point of view. Direct quotes will be used as evidence in this study.

I would like to have access to the written documents produced by the social worker / care manager in relation to the care home placement (i.e. assessments, admission contract and case recording in relation to care home placement). This will enable me to understand how social workers / care managers interpret and use the information gathered within assessments and reviews to provide support in relation to care home placements. If possible, I would like to retain copies of the relevant documentation for the duration of the study. The identity of the person you care for will not be known as the data will be anonymised and any reference to individual names removed.

**Potential risks:**

I understand that the experience of moving into a residential or nursing home can be very difficult. If the person that you care for becomes in any way uncomfortable or upset when I visit with the social worker, then I will not continue with the observation.

**Important information:**

It is up to you to decide whether the person you care for should become involved within this study. If you do decide that they should take part, you will be asked to sign a declaration.

Even if you decide that the person you care for should become involved within the study at this stage, you are still free to change your mind at any time prior to the research being written up. You do not have to give a reason for your decision. It is important that you know that the medical and care rights of your relative / friend receives will not be affected whatever you decide.

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to the person for whom you care as a research participant and nothing that could reveal their identify will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of ‘agencies’ (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). The identity of the person for whom you care will not be known within final reports and publications as the data will be anonymised and any reference to individual names removed.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions, please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study you may contact Dr. Sara MacBride-Stewart at Cardiff University (02920 876354) / [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has been given approval to commence by [-----] University Health Board’s Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

19.



### **Participant Information Sheet – Team Managers - Interview**

#### **“Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”**

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers and care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **Taking part in the study:**

I would like to interview you to learn more about your work in relation to care home placements (for example how decisions regarding allocation of referrals for care home admission are made; how assessments for care home placement are authorised). Each interview should last 30-45 minutes and can be done at a place and time of your choosing. With your permission, the interview will be audio recorded so that it can be transcribed at a later date.

#### **Potential risks:**

I do not think that the research can cause you any harm. I will make every effort to avoid disrupting your work.

**Important information:**

Your involvement in this study is **entirely voluntary**

You can withdraw from this study at any time prior to the research being written up and without giving a reason

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of ‘agencies’ (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). Your identity will not be known within final reports and publications as the data will be anonymised and any reference to individual names removed.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study, you may contact Dr. Sara Mac-Bride Stewart (02920 876354) / email [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / email [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Boards Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

20.



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Email: MurrayAK@Cardiff.ac.uk

Tel: 07534 276 571

**Team Manager: Consent Interview**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet (dated 03.07.17) about this study. I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that taking part is voluntary and that I am free to change my mind at any time, without giving any reason
- 3 I agree to take part in interview for this study as described in the information sheet dated 03.07.17. I agree to the interview being audio recorded for later analysis
- 4 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names removed

- 5 I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
  
- 6 I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
  
7. I agree to take part in the above study

_____	_____	_____
<b>Name of Participant</b>	<b>Date</b>	<b>Signature</b>

_____	_____	_____
<b>Name of Person</b>	<b>Date</b>	<b>Signature</b>
<b>(taking consent)</b>		

21.



### **Participant Information Sheet – Social Worker (Interview Only)**

#### **“Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice”**

My name is Andrea Cooper. I am a part-time social worker within [-----] and a part-time research student at Cardiff University. I would like to invite you to take part in a research study.

#### **Purpose of the research:**

The research will look at the ways in which social workers or care managers support informal carers when older people are admitted into a residential or nursing home. By informal carers I refer mainly to those family members (although sometimes close friends), who have provided care and support to the older person before they enter a residential or nursing home.

#### **This study has three main aims:**

1. To understand what help and support is needed by informal carers during care home placement for older people
2. To understand what help and support is given to informal carers by social workers and care managers during care home admissions and
3. To determine the effectiveness of that help and support

#### **Potential benefits:**

It is hoped that the findings of this study will inform social work training and practice and will help improve the service received by informal carers during care home placements for older people. The knowledge gained from this study will be shared with informal carers; with social work and health care practitioners, care home providers and with policy makers.

#### **Taking part in the study:**

I would like to **interview** you to learn more about your placement related work and the support you provide to informal carers during care home admissions. Each interview should last 30 – 45 minutes and can be done at a place and time of your choosing. With your permission, the interview will be audio recorded so that it can be transcribed at a later date.

#### **Potential risks:**

I do not think that the research can cause you any harm. I will make every effort to avoid disrupting your work.

**Important information:**

Your involvement in this study is **entirely voluntary**

You can withdraw from this study at any time prior to the research being written up and without giving a reason

**Data storage and confidentiality:**

Throughout the study, any personal data (e.g. names / addresses) will be securely stored on a password-protected computer within my Local Authority office. Copies of social work documentation and handwritten notes will be securely stored within a locked cabinet within my Local Authority office. All other electronic data (including audio-recordings of interviews) will be securely stored within a password protected Cardiff University network.

I will undertake all of the research for this project myself and I will discuss it only with certain other authorised people. This would include my supervisors at Cardiff University (Sara MacBride-Stewart and Alyson Rees). [-----] Research and Development Department may request access to the study data for monitoring and conduct purposes. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identify will be disclosed.

The identities of all participants within this study - professionals, service users and informal carers – as well as the identity of ‘agencies’ (i.e. Local Authority; hospital sites; nursing and residential homes), will be protected through assigning them a pseudonym (false name). All data will be fully anonymised when written up within final reports and publications.

**Limits to confidentiality:**

As a registered social worker, I would be obliged to report any incident observed or discussed which suggests that an older person is at risk of serious harm. In this case, your confidentiality could not be guaranteed.

**What if there is a problem?**

If you have any questions please feel free to contact me on 07534276571 or at [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)

If you are unhappy about any aspect of this study, you may contact Dr. Sara Mac-Bride Stewart (02920 876354) / email [Macbride-StewartS@Cardiff.ac.uk](mailto:Macbride-StewartS@Cardiff.ac.uk) or Dr. Alyson Rees (02920 875261) / email [ReesA1@Cardiff.ac.uk](mailto:ReesA1@Cardiff.ac.uk)

**Who has reviewed the study?**

This study has also been given approval to commence by [-----] University Health Board’s Research and Development Department and by the Wales REC 3.

**Thank you for taking the time to read this information. If you wish to take part in this study, please now sign the attached consent form. You may return the consent form to me in person. Alternatively, please contact me using either my telephone number 07534276571 or email address [MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk) and I will collect the signed consent form from you.**

22.



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Tel: 07534 276 571

**Social Worker Consent – Interview Only**

**Investigating the Experiences of Informal Carers During Care Home Admissions for Older People: Implications for Social Work Practice.**

**Researcher: Andrea Cooper**

**Please initial** each box and then sign and date overleaf to confirm your understanding and consent to taking part in the research.

- 1 I have read and understood the information sheet for the study (dated 03.07.2017). I have had the opportunity to ask questions and these have been answered to my satisfaction
- 2 I understand that taking part is voluntary and that I am free to change my mind at any time, without giving any reason
- 3 I agree to take part in the interview for this study as described in the information sheet (dated 03.07.2017). I agree to the interview being audio recorded for later analysis
- 4 I understand that the data will be used for a PhD thesis and in other publications and reports. Whilst the data may contain direct quotes, I understand that my identity will not be known as the data will be anonymised and any reference to individual names

removed

- 5** I understand that the data collected during the study may be looked at by individuals from Cardiff University or from [-----] Health Board's Research and Development Department, to ensure the study is being conducted in the right manner. I give permission for these individuals to have access to my data.
- 6** I understand that the study lead has a professional obligation to act upon any disclosure which suggests that a vulnerable individual may be at risk of significant harm. In this case, confidentiality could not be guaranteed
- 7** I agree to take part in the above study

\_\_\_\_\_  
**Name of Participant**                      **Date**                      **Signature**

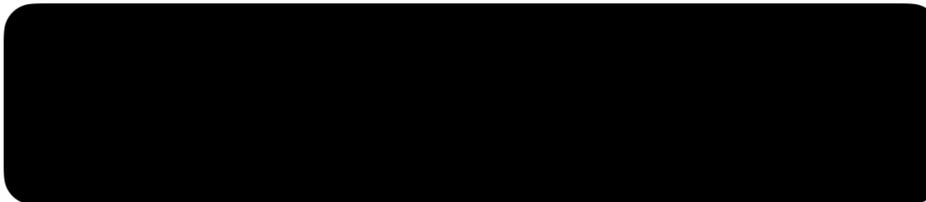
\_\_\_\_\_  
**Name of Person**                      **Date**                      **Signature**

**(taking consent)**

## **Appendix F - REC Approvals**

- 1. Permission to conduct study**
- 2. Letter of access for research**
- 3. Research Ethics Service – confirmation of receipt of documents and approval conditions met**

1.



Mrs Andrea Cooper  
PhD Student  
Postgraduate Diploma in Social Research  
School of Social Science  
Glamorgan Building  
Kind Edward V11 Avenue  
Cardiff University  
CF10 3AT

Dear Mrs Cooper

**Re: CT/705/208240 Informal Carers and Care Home Admissions :  
Implications for Social Work**

Thank you for clarifying the points raised at the Research Risk Review Group (RRRG) meeting. I have pleasure in confirming that this project now has full approval to commence in the [REDACTED]. However commencement of the project should be upon the receipt of ethical approval if required. If the project is a multi site study it is advised that you also obtain approval from all other Health Boards before commencing the project at individual sites.

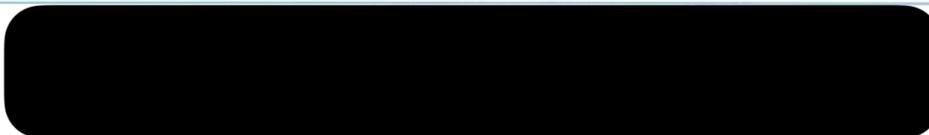
The Group reserve the right to information on the progress of the project at any time and should receive a progress report six monthly and a written report on completion.

Random audits will be carried out to ensure that projects comply with the clinical guidelines of research. Any serious adverse incidents relating to the project should be reported to the R&D office and a Clinical Incident Form filled in.

If your project includes participants or resources from other Health Boards it is your responsibility to contact the relevant R&D Office(s) in order to gain R&D approval to commence. Without individual R&D approval from all Health Boards involved in the study Welsh Risk Pool indemnity will not be afforded to the researcher.

On completion of the project it is important that you inform the Health Board Research & Development office.

It is a requirement of approval that a synopsis of your project and its findings (if not commercially too sensitive) be submitted to the R&D department upon completion. This synopsis can then be placed on the R&D departments' web page to provide a useful R&D resource for other research active professionals across the Health Board.



It is also a requirement that an abstract is submitted for review and possible inclusion in the Health Boards annual R&D conference. This facilitates the distribution of all researchers' findings and any resultant changes in clinical practice.

If your study is adopted onto the Health & Care Research Wales Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that you will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the Health & Care Research Wales CRP, please go to: <https://www.ukctg.nihr.ac.uk/> Once adopted, Health & Care Research Wales CRP studies may be eligible for additional support through the Health & Care Research Wales Workforce. Further information can be found from your NHS R&D office colleagues.

Uploading recruitment data will enable Health & Care Research Wales to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact, Research & Development department.

I would like to take this opportunity to wish you well with your research and look forward to the presentation of your findings.

If you require any further assistance please contact the Research & Development Department. [REDACTED]

Yours sincerely [REDACTED]

Enc. Notification of Start Form, Interim Progress Report Form, Notification of End Form [REDACTED]

2.



Mrs Andrea Cooper  
PhD Student  
Postgraduate Diploma in Social Research  
School of Social Science  
Glamorgan Building  
Kind Edward V11 Avenue  
Cardiff University  
CF10 3AT

Dear Mrs Cooper

**Letter of access for research**

This letter confirms your right of access to conduct research through [redacted] Board for the purpose and on the terms and conditions set out below. This right of access commences on **21<sup>st</sup> November 2016** and ends on **30<sup>th</sup> September 2019** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at [redacted] has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to [redacted] premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [redacted], you will remain accountable to your employer **Cardiff University** but you are required to follow the reasonable instructions of [redacted] in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

**Return Address:** [redacted]



You must act in accordance with [REDACTED] policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Where required by law, your HEI employer will initiate your Independent Safeguarding Authority (ISA) registration, and thereafter, will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity. You **MUST** stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

[REDACTED] will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

[REDACTED]

3.



Gwasanaeth Moeseg Ymchwil  
Research Ethics Service



**Wales REC 3**  
Health and Care Research Support Centre  
Castlebridge 4  
15-19 Cowbridge Road East  
Cardiff CF11 9AB

Telephone : 029 2078 5735  
E-mail : corinne.scott@wales.nhs.uk  
Website : www.hra.nhs.uk

18 November 2016

Mrs. Andrea Cooper  
PhD candidate  
Cardiff University  
School of Social Science, Glamorgan Building  
King Edward V11 Avenue,  
Cardiff CF10 3NB

Dear Mrs. Cooper

**Study title:** Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice  
**REC reference:** 16/WA/0360  
**Protocol number:** SPON 1560-16  
**IRAS project ID:** 208240

Thank you for responding to the REC. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 15 November 2016

**Documents received**

The documents received were as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Informal Carers - Post Admission (Poster / Leaflet)]	Version 2	16 November 2016
Copies of advertisement materials for research participants [Informal Carers - Pre-Admission (Poster / Leaflet)]	Version 2	16 November 2016
IRAS Checklist XML [Checklist_17112016]		17 November 2016
Participant consent form [Informal Carer Observation Consent ]	Version 4	16 November 2016
Participant consent form [Older Person Consent for Observation]	Version 4	16 November 2016
Participant consent form [Social Work and Care Manager Consent ]	Version 4	16 November 2016
Participant consent form [Team Manager Consent ]	Version 4	16 November 2016
Participant consent form [Care Home Providers - Consent (Observation)]	Version 4	16 November 2016
Participant consent form [Consent on behalf of a person lacking capacity for observation ]	Version 4	16 November 2016
Participant consent form [Health Care Staff - Consent ]	Version 4	16 November 2016
Participant consent form [ Care Home Provider Consent for Interview ]	Version 4	16 November 2016
Participant consent form [Informal Carer Consent for Interview ]	Version 4	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Health]	Version 3	16 November 2016

Participant information sheet (PIS) [Participant Information Sheet - Informal Carers (Interview)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet - Informal Carers (Observation)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet - Older People (Observation)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet - Social Workers]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Care Home Providers (Observation)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Care Home Providers (Interview)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Team Managers]	Version 3	16 November 2016

#### Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Informal Carers - Post Admission (Poster / Leaflet)]	Version 2	16 November 2016
Copies of advertisement materials for research participants [Informal Carers - Pre-Admission (Poster / Leaflet)]	Version 2	16 November 2016
Covering letter on headed paper [Cover Letter]		27 October 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		18 July 2016
Interview schedules or topic guides for participants [Informal Carer Interview Schedule]	Version 1	24 October 2016
Interview schedules or topic guides for participants [Social Worker / Care Manager Interview Schedule]	Version 1	24 October 2016
Interview schedules or topic guides for participants [Care Home Provider Interview Schedule]	Version 1	24 October 2016
IRAS Checklist XML [Checklist_28102016]		28 October 2016
IRAS Checklist XML [Checklist_17112016]		17 November 2016
Letter from funder [Letter from ESRC]		10 June 2014
Letter from sponsor		21 October 2016
Participant consent form [Care Home Providers - Consent (Observation)]	Version 4	16 November 2016
Participant consent form [Consent on behalf of a person lacking capacity for observation]	Version 4	16 November 2016
Participant consent form [Health Care Staff - Consent]	Version 4	16 November 2016
Participant consent form [Care Home Provider Consent for Interview]	Version 4	16 November 2016
Participant consent form [Informal Carer Consent for Interview]	Version 4	16 November 2016
Participant consent form [Informal Carer Observation Consent]	Version 4	16 November 2016
Participant consent form [Older Person Consent for Observation]	Version 4	16 November 2016
Participant consent form [Social Work and Care Manager Consent]	Version 4	16 November 2016
Participant consent form [Team Manager Consent]	Version 4	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Health]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet - Informal Carers (Interview)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet - Informal Carers (Observation)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet - Older People (Observation)]	Version 3	16 November 2016

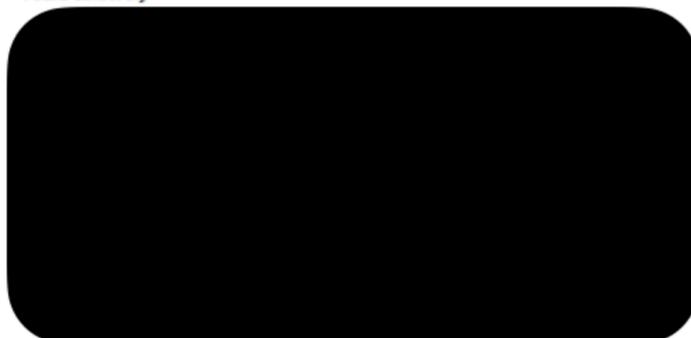
Participant information sheet (PIS) [Participant Information Sheet - Social Workers]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Care Home Providers (Observation)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Care Home Providers (Interview)]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Team Managers]	Version 3	16 November 2016
Participant information sheet (PIS) [Participant Information Sheet Consultee]	Version 2	16 November 2016
REC Application Form [REC_Form_28102016]		28 October 2016
Referee's report or other scientific critique report [Supervisor Review of Study]		25 September 2016
Referee's report or other scientific critique report [Progress Review]		02 September 2016
Research protocol or project proposal	Version 2	21 October 2016
Response to Additional Conditions Met		
Summary CV for Chief Investigator (CI) [C.V Andrea Cooper]		25 August 2016
Summary CV for supervisor (student research)		09 October 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of Research Proposal]	Version 1	27 October 2016

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

16/WA/0360

Please quote this number on all correspondence

Yours sincerely



## Appendix G - Notification of non-substantial/minor amendments for NHS studies

### Partner Organisations:

Health Research Authority, England

NHS Research Scotland

HSC Research & Development, Public Health Agency, Northern Ireland

NIHR Clinical Research Network, England

NISCHR Permissions Co-ordinating Unit, Wales

### Notification of Non-Substantial/Minor Amendments(s) for NHS Studies

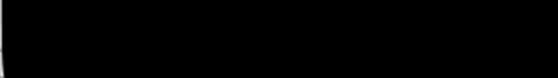
This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are NOT categorised as Substantial Amendments.

**If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.**

#### Instructions for using this template

- For guidance on amendments refer to <http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/>
- This template should be completed by the CI and optionally authorised by Sponsor, if required by sponsor guidelines.
- This form should be submitted according to the instructions provided for NHS/HSC R&D at <http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/which-review-bodies-need-to-approve-or-be-notified-of-which-types-of-amendments/>. If you do not submit your notification in accordance with these instructions then processing of your submission may be significantly delayed.

#### 1. Study Information

Full title of study:	Investigating the Experiences of Informal Carers during Care Home Admissions for Older People: Implications for Social Work Practice
IRAS Project ID:	16/WA/0360
Sponsor Amendment Notification number:	
Sponsor Amendment Notification date:	
<b>Details of Chief Investigator:</b>	
Name (first name and surname)	Andrea Cooper
Address:	
Postcode:	
Contact telephone number:	
Email address:	
<b>Details of Lead Sponsor:</b>	
Name:	
Contact email address:	
<b>Details of Lead Nation:</b>	
Name of lead nation <i>delete as appropriate</i>	Wales
If England led is the study going through CSP? <i>delete as appropriate</i>	N/A
Name of lead R&D office:	

**Partner Organisations:**

Health Research Authority, England

NHS Research Scotland

HSC Research & Development, Public Health Agency, Northern Ireland

NIHR Clinical Research Network, England

NISCHR Permissions Co-ordinating Unit, Wales

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Partner Organisations:  
 Health Research Authority, England  
 NHS Research Scotland  
 HSC Research & Development, Public Health Agency, Northern Ireland

NIHR Clinical Research Network, England  
 NISCHR Permissions Co-ordinating Unit, Wales

**2. Summary of amendment(s)**

This template must only be used to notify NHS/HSC R&D office(s) of amendments, which are NOT categorised as Substantial Amendments.  
 - If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

No.	Brief description of amendment <i>(please enter each separate amendment in a new row)</i>	Amendment applies to <i>(delete/ list as appropriate)</i>		List relevant supporting document(s), including version numbers <i>(please ensure all referenced supporting documents are submitted with this form)</i>	R&D category of amendment <i>(category A, B, C) For office use only</i>
		Nation	Sites		
1	I wish to undertake additional interviews with a small number of 'Team Managers' within the Local Authority (to discuss their perspectives of the work of social workers in relation to care home placements for older people). I anticipate that two or three interviews with team managers will be undertaken. I have obtained permission from the Service Manager within the Local Authority to undertake these additional interviews. I have amended the existing 'Information Sheets' and 'Consent Form' to specifically cover these additional interviews - please see attached.	Wales	[Redacted]	Participant Information Sheet - Team Managers (Interview) (170703)  Team Manager Consent (Interview) (170703)  Team Manager Interview Schedule (170714)	V.1  V.1  V.1
2	I wish to undertake an interview with one of the social workers within the Local Authority who works specifically with 'hospital discharges' (i.e. whose work is focussed upon entirely upon facilitating the discharge of patients from hospital settings.) A number of these patients are likely to be admitted to long-term residential or nursing care. I wish to discuss with the social worker, his/her perspectives on their placement related work. These social workers are based within the Local Authority Care and Support Teams and accordingly, I have obtained permission from the Service Manager within the Local Authority to undertake these additional interviews. I have amended the existing 'Information Sheet' and 'Consent Form' to	Wales	[Redacted]	Participant Information Sheet (Social Worker - Interview Only) (170703)  Social Worker Consent (Interview Only) (170703)  Social Worker Interview Schedule (Hospital Discharge) (170714)	V.1  V.1  V.1

**Partner Organisations:**  
 Health Research Authority, England  
 NHS Research Scotland  
 HSC Research & Development, Public Health Agency, Northern Ireland  
 NIHR Clinical Research Network, England  
 NISCHR Permissions Co-ordinating Unit, Wales

	specifically cover this additional interview – please see attached.			
3				
4				
5				

[Add further rows as required]

**Partner Organisations:**

Health Research Authority, England

NHS Research Scotland

HSC Research & Development, Public Health Agency, Northern Ireland

NIHR Clinical Research Network, England

NISCHR Permissions Co-ordinating Unit, Wales

**3. Declaration(s)**

**Declaration by Chief Investigator**

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment(s) to be implemented.

Signature of Chief Investigator : A. Cooper

Print name: ANDREA COOPER

Date: 14/07/17

**Optional Declaration by the Sponsor's Representative (as per Sponsor Guidelines)**

*The sponsor of an approved study is responsible for all amendments made during its conduct.*

*The person authorising the declaration should be authorised to do so. There is no requirement for a particular level of seniority; the sponsor's rules on delegated authority should be adhered to.*

- I confirm the sponsor's support for the amendment(s) in this notification.

Signature of sponsor's representative:  .....

Print name:  .....

Post: 

Organisation: CARDIFF UNIVERSITY

Date: 2/8/17

## Appendix H - Leaflet and Poster Design



# What does it feel like when the person you care for moves in to a care home?

My name is Andrea Cooper and I am a research student at Cardiff University

If you have provided support to an older person as they entered a residential or nursing home within the last three years, then I'd like to talk to you about your experience

#### **Purpose of my research:**

I am undertaking this research to find out what help is needed by informal carers at times of care home admission. You are an informal carer if you are a family member or a close friend who provided care and support to the older person before they entered a residential or nursing home

#### **My study has three aims:**

1. To understand what support informal carers need during care home placement for older people
2. To understand what help and support is given to informal carers by social workers at this time
3. To determine the effectiveness of the social work help and support provided

#### **Potential benefits:**

I hope that the findings of my study may help to inform social work services support for informal carers



**If you are interested in taking part in this study and would like more information then please contact me (Andrea Cooper) on:**

**[MurrayAK@Cardiff.ac.uk](mailto:MurrayAK@Cardiff.ac.uk)**

**07534 276 571**

Version 2 16<sup>th</sup> Nov 16

# Appendix I – Diagrammatic Representation of Categories and Sub-categories

