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Caring with Integrity: Developing the Conceptual Underpinning of Relationship- Centred Palliative Dementia Care in Care Homes

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the degree of Doctor of Philosophy

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Declaration

I declare that this thesis is of my own composition, based on my own work, with acknowledgements of other sources, and has not been submitted for any other degree or professional qualification.

Julie Elizabeth Watson

Date.....

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Abstract

People with advanced dementia often struggle to maintain relationships and can ultimately experience social death before their physical death. Social death occurs when a person is no longer treated as an active agent in their relationships.

Relationship-centred care acknowledges the relational nature of care-giving and care-receiving, validating the support needs of both care-givers, and the person receiving care. In the context of care-giving and care-receiving, a person with advanced dementia can become viewed as a passive recipient of care. In the context of caring for people with advanced dementia, more needs to be understood about how caring relationships can be sustained until the end of life in a way which challenges the social death of people with advanced dementia, and supports carers.

Understandings of, and assumptions about, the effect of dementia on personhood directly affect the way people with dementia are perceived by others, the quality of their relationships, the quality of their care and the quality of their life. Dementia is often associated with the loss of the person. Kitwood (1997) has been highly influential within dementia care in challenging the loss of personhood, and reconsidering the grounds of personhood, emphasising relationships over cognition. Kitwood's often cited definition of personhood is: 'a standing or status bestowed on one human being, by another, in the context of relationship' (Kitwood 1997 p8). Kontos (2004) however, critiques this social interactionist view of personhood, suggesting it potentially relegates the 'body' to a symbolic position rather than guaranteeing personhood. Her work examines the way that personhood is embodied, and how this persists when a person has advanced dementia. She suggests that attention to the embodied aspects of personhood could act as an important counter to the social death of people with advanced dementia, increasing the scope and opportunities for interpersonal relationships, and improved quality of care and quality of life. Zeiler (2013) and Jenkins (2013) develop this theory further, describing intercorporeal personhood springing forth through, and in, interaction, enabling individuals who cannot express themselves without support to do so in interactions.

The principle aim of this doctoral research is to examine the care-giving/care-receiving relationship, in palliative dementia care, through the theoretical lenses described above. The research took place in a care home called ‘Primrose Hill’ (a pseudonym): a specialist dementia care home (without nursing), with an increasingly frail population with multiple co-morbidities. Fifteen residents died during the 10 months of the study. The research employed an ethnographic approach, using participant observation alongside interviews and group discussions with staff. Attention was given to how people with dementia responded to care and how they were positioned within the caring relationship; were they seen as passive recipients of care or as active agents, objects or subjects? The approach was appreciative in intent, based on the assumption that care home staff, and people with dementia who live in care homes, through their experience of the human encounter, have important things to teach families, and others working in dementia care, including policy makers and care regulators. When articulated and shared, their experiences can challenge the stereotype of dementia as a ‘death that leaves the body behind’.

The empirical analysis revealed three key facets which shape the caring relationship: body work (direct hands-on bodily care); recognising and supporting selfhood; witnessing and responding to suffering. These three facets of palliative dementia care are examined and reveal the way that people with dementia, even in the advanced stages, continue to experience and respond to the world, and those around them, until they die. This is used to develop the conceptual underpinning of relationship-centred palliative dementia care. The Senses Framework (Nolan et al 2006), which sets out the conditions required for relationship-centred care to occur, is expanded to incorporate embodied selfhood and intercorporeal personhood. The research concludes by arguing, using Ethic of Care theory as an interpretive framework, that an expanded understanding of personhood that includes the ‘body’ is vital, not only at the frontline, but also at a political and societal level, if care is to have integrity.

Overview of the Thesis

Chapter One is a reflexive attempt to make visible my own presence in the research from the outset, showing how my previous experience as a palliative care nurse and researcher motivated me to undertake this study of relationship-centred palliative dementia care. I describe my initial exploration of the issue of relationships in the context of dementia and dying.

Chapter Two provides my rationale for the study. Drawing on a broad literature base it shows how people with advanced dementia become marginalised in their relationships and within systems providing palliative care. I review the different responses to the marginalisation of people with dementia but draw attention to the persistent suffering of people with advanced dementia at the end of life. I consider the relevance and also the limitations of language use within current dementia care discourses on the concept of suffering. Focussing on care homes I then explore the benefits and limitations of person-centred and relationship-centred care, making the argument that a fuller understanding of personhood which incorporates the body is required if the social death of people with advanced dementia is to be challenged. How this is mediated at the interpersonal level by wider structural issues is considered. I finish the chapter by identifying current gaps in knowledge and the research questions.

Chapter three describes how I did the study; the research design. I introduce the theoretical framework, the methodological approach, and the methods used including recruitment, data collection and the analytical and interpretative framework. There is an extended discussion of the ethical issues involved in including ‘Adults with Incapacity’ in the study.

Chapter Four gives a ‘thick description’ of the care home where this study took place, including its geography, and the residents and care staff who lived and worked there, some of whom participated in the study. It describes the impact of gradual changes in the resident population due to later admissions to care homes and

specialisation in dementia care. This brings to the surface questions about what ‘care’ entails for people with advanced dementia, themes which are followed up in the next three chapters.

Chapter Five focuses specifically on body work (or direct hands-on bodily care) which was a major way in which residents and care staff interacted in the care home. This chapter attempts to get below the surface to understand what was happening during body work and whether residents were positioned as body-subjects or passive recipients of care.

Chapter Six focusses down further to look at how selfhood is recognised and supported or undermined in the care-giving/ care-receiving relationship, much of which revolves around body work. The place of embodied selfhood and intercorporeal personhood are examined.

Chapter Seven considers another dominant theme in the care-giving/ care-receiving relationship, witnessing and responding to suffering. The interdependency or intertwining of the feelings of the residents and the staff and the implications of this are considered.

Chapter Eight draws out what this study adds to knowledge by responding to the research questions using Ethic of Care theory as an interpretive framework. The implications of this knowledge and recommendations for developing the conceptual underpinning of relationship-centred palliative dementia care in care homes are considered at each level of the caring process. The chapter finishes by reflecting on the research methodology, the study limitations and suggestions for future research.

No man is an island,
Entire of itself.
Each is a piece of the continent,
A part of the main.
If a clod be washed away by the sea,
Europe is the less.
As well as if a promontory were.
As well as if a manor of thine own
Or of thine friend's were.
Each man's death diminishes me,
For I am involved in mankind.
Therefore, send not to know
For whom the bell tolls,
It tolls for thee

John Donne

Act Justly
Love Mercy
Walk Humbly

Micah Chapter 6 Verse 8

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Study Background

1.1 Introduction

This thesis makes an original contribution to knowledge by combining theory with empirical work to develop the conceptual underpinning of relationship-centred palliative dementia care in care homes. Crotty (1998) suggests that researchers have to emerge from behind the barrier of anonymity and own up to their involvement in the research they conduct and the knowledge they produce. Following his suggestion, I therefore begin this thesis by explaining my motivations for undertaking this PhD and critical moments in the early stages. This first chapter is a reflexive attempt to self-consciously address my presence in the research from the outset, making visible how I shaped the direction of the research (Altheide & Johnson 1998, Etherington 2007). I take the position that my presence in the research is inevitable and good research practice is to be aware of, and accountable for, that presence, using it as an interpretive resource leading to ‘responsible knowledge’ (Doucet 2008, Mauthner & Doucet 2003, Siltanen et al 2008).

1.2 The Starting Point

My interest in palliative care stemmed from witnessing what I considered to be bad deaths while working in the renal unit of a large hospital as a newly qualified staff nurse in the early-nineties. One particular death stuck in my mind; a man who was very distressed and agitated until the point of death. It was equally distressing for his wife. The sense that we as a team did not know how to help this family was distressing for me. Months later a colleague bumped into the wife in the street and she was not coping well with the loss of her husband. I had a strong sense that the way he had died might have played a part in this and that more could have been done to help this man and his family at the time of his dying. I had a strong belief that dying is significant as the final milestone in a person’s life, that it is important to get care of dying people right, and also that nurses can potentially play a role in easing some of the suffering around this time.

As a result I was prompted to attend a short course on palliative care at the hospice where I subsequently got a job. Working at the hospice for 11 years I learnt about alleviating suffering at the end of life and, while I still recognised that death is almost always a trial and an emotionally painful part of life, I was inspired by Dame Cicely Saunders, the founder of the modern hospice movement, who said that “We cannot take away the whole hard thing that is happening, but we can help to bring the burden into manageable proportions” (cited in Ellershaw & Wilkinson 2003 Foreword). I witnessed much sadness but the deaths on the whole were ‘good’ in comparison with others I had witnessed in the hospital. I found the work meaningful and rewarding; while the people we cared for had been told they could no longer be cured, they appreciated our care and the sense of comfort and hope it seemed to give them and their families that they had not been abandoned.

Before commencing this PhD I had worked mostly with cancer patients as the majority of people cared for in the hospice had cancer, although we also cared for people with motor neurone disease, and occasionally end stage chronic obstructive airways disease or heart failure. Only very occasionally did we care for people with dementia and, when we did, it was usually because they had a complex symptom related to cancer. I worked on the inpatient unit for one year but most of my 11 years was spent working in the Day Unit for out-patients which was attached to the main hospice. In contrast to what happens in care homes, as will become clear in the findings chapters, we were part of a broad multidisciplinary team including: a medical team, physiotherapy, occupational therapy, counselling, chaplaincy, primary care staff and a large army of volunteers; in a purpose built and well equipped building. The working environment was supportive and friendly with clinical supervision and counselling support for staff available alongside many opportunities for learning and development.

Towards the end of my time at the hospice I undertook two secondments to work as a research assistant on action research projects led by Dr Jo Hockley to develop end of life care in local care homes. My main task was to evaluate the use of two end of life care ‘tools’, namely the Gold Standards Framework for Care Homes

(<http://www.goldstandardsframework.org.uk/care-homes>) and an integrated care pathway for the last days of life which had been adapted as part of the action research from the Liverpool Care Pathway (Ellershaw & Wilkinson 2003, Hockley et al 2005, 2010, Watson et al 2006, 2010). Through this work I became aware of wider debates within palliative care about the need to extend access to palliative care, with hospice care being seen as the 'gold standard', to other care contexts such as care homes and to conditions other than cancer. The challenge of transferring a model of care developed for people dying with cancer in a hospice to people dying with other conditions in other places was beginning to emerge (Froggatt 2001b).

From working as a research assistant and then going back to work in the Day Unit, I was exposed to the stark contrast between the level of multidisciplinary expertise people dying with cancer can access, as opposed to that accessible to people dying in care homes and the consequent high levels of unrelieved and even unnoticed suffering in care homes. While it was still rewarding to be able to help people as a nurse at a one to one level within the hospice, my increased awareness of the wider issues facing the vast majority of dying people (in the UK most people die from causes other than cancer and in hospital or a care home as opposed to hospices, Murtagh et al 2012) left me very unsettled and frustrated.

It was at this point that I became interested in undertaking a PhD as training for a research career. I saw doing research as having the potential to make changes in policy and practice that would enable more people to access palliative care wherever they were and whatever their condition. I was awarded a PhD studentship at the Centre for Research on Families and Relationships with the title 'Living and Dying with Dementia: Supporting Families and Relationships'. There was freedom within this title for me to shape the direction of the research; my previous experience encouraged me to focus on the topic of supporting relationships with people with dementia living and dying in care homes. Looking back, the changes I hoped research might make seem like a somewhat grandiose aspiration. However, while my experience of doing this PhD has opened my eyes to the enormity of the task, and the complexities of knowledge exchange in influencing policy and practice, this still

remains my primary motivation and has kept me going through the many theoretical and practical swamps, dead ends and brick walls I have had to traverse in the new world I had entered of sociological research and dementia care.

1.3 Mapping out the Terrain

Initially I did not know the research design of my PhD would be ethnographic but, from the outset, I intuitively took an ethnographic approach as I sought to understand the peoples and cultures of both dementia care and academic sociology and to establish where I fitted. As I began to explore the vast literature on dementia care I realised that it is only in the last decade that attention has begun to be paid to the role of palliative care in dementia and this seems largely to be initiated by professionals with a background in palliative care (e.g. Sampson et al 2006, Sachs et al 2004) and within palliative care policy which seeks to improve access to palliative care beyond cancer to other conditions, including dementia (Department of Health 2008, 2012, Scottish Government 2008, 2011). With some exceptions (e.g. Hughes et al 2010, Small et al 2007), there seemed to be very little overlap between the dementia care research literature and the palliative care research literature.

In the Scottish policy arena, while end of life care policy included dementia (Scottish Government 2008, 2011), dementia care policy (Scottish Government 2010) very much focussed on living well with dementia with palliative and end of life care there but only implicitly (although it is more explicitly mentioned in more recent policy Scottish Government 2013-2016). I was shocked to read in one dementia care book, which I found extremely helpful in all other respects and is widely cited in the dementia care literature, that “All too often, it is the case that Alzheimer’s Disease and other dementia sufferers are given what has come to be called, “palliative care” which amounts to keeping the “patient” physically comfortable and little else” (Sabat 2001 p338). Sabat goes on to recount a story of a woman who refused to admit her husband to a nursing home because he still knew things: “In effect because he still knew things, she could not in good conscience place him in a situation in which he would receive “palliative care” or be “managed”. In her view, such an action would cause him further torment and therefore harm” (Sabat 2001 p339). This view of

palliative care did not resonate with my own experience of caring for ‘palliative care patients’ but it alerted me to the differing understandings of palliative care.

At a summit held in Edinburgh in March 2011 called ‘Living and Dying Well with Dementia’ bringing together practitioners, researchers and policy makers from palliative care and dementia care, the different language and mindsets of these two groups was clear. Those working within the field of dementia viewed palliative care with suspicion and fear, seeing the terminology as associated with cancer and death, while those working in palliative care saw such suspicion and fear as a denial that dementia is a progressive disease with physical as well as cognitive effects that warrant palliative care. I began to see the gulf that existed between palliative care and dementia care. I sensed that I needed to cross this gulf and move from my safe and familiar palliative care world into the world of dementia care to try to understand more of the mindset.

1.4 Exploring the World of Dementia Care

Thus began my exploration of the world of dementia care. Over a period of months, as I prepared for my first year PhD review, I undertook various activities: met with those working in policy and practice at Alzheimer’s Scotland; attended a support group session for couples affected by dementia run by a community psychiatric nurse; attended two day courses run by Dementia Positive (<http://www.dementiapositive.co.uk/>) on communicating with people with dementia; joined a fortnightly singing group for people with dementia for 10 months; spent time in a specialist dementia care home with a reputation for communicating well and creatively with people with dementia; attended the Scottish Dementia Congress. Throughout this time there were a number of critical moments which have influenced the direction of my research which I will now briefly outline.

1.4.1 Face to Face with People with Dementia

An important part of my journey into dementia care was to spend time with people with dementia as I had very little experience of this. Based at the Centre for Research on Families and Relationships and given the topic of my funded studentship, the

focus of my research was on relationships with people with dementia and I felt that in order to be able to formulate useful research questions I needed to spend time with people with dementia and get a sense of what this was like.

Critical moments for me were as I met people with dementia at a singing group and in the care home I visited who were in the later stages of dementia and had lost their verbal abilities or whose verbal abilities were very limited. I struggled to know how to behave without the usual social norms of asking each other questions in order to begin to form a relationship. This was uncomfortable for me and undoubtedly for the people I was meeting, a situation I reckoned must happen regularly in care-giving/care-receiving situations. It was these challenges that encouraged me to focus my study on the caring relationship between people with advanced dementia and the care staff in a care home, care homes being places where 55% of people with dementia spend the last months of their lives and ultimately die (Murtagh et al 2012). The quality of the caring relationship between people living in care homes and the care staff who work there is known to influence the quality of care and the quality of life of residents (Davis & Brown-Wilson 2007), but there is a lack of understanding of what this actually entails (McGilton & Boscart 2007, McCormack et al 2012).

1.4.2 Thinking about Dementia

Another critical moment was a conversation with a care home manager in which she described dementia as a disability and not an illness. This led me to ask the question ‘What is dementia?’ As I explored the literature addressing this question, I began to understand the different ways of understanding dementia and some of the fears from within dementia care about framing dementia as a disease for which nothing can be done, and the ‘excess disability’ that people with dementia experience because of societal responses to dementia, the social context, and from other people’s reactions (Sabat 2001, Kitwood 1997).

I began to understand the emphasis of the dementia care movement on ‘living well with dementia’ as a corrective to the perceived therapeutic nihilism within the medical world and the huge benefits there have been in terms of improved quality of

life for people affected by dementia as a result. In these early stages of my PhD I had become challenged to think about the problems inherent in defining people by their disease or their cognitive deficits, making it easier to treat people in a superficial or perfunctory way, and failing to see the person and recognise their essential dignity and worth as a human being (Hughes 2011). During this time my own preconceived ideas about people with dementia being verbally uncommunicative were challenged; hearing members of the Scottish Dementia Working Group, all with a diagnosis of dementia, speaking at a conference; reading the first hand experiences of people with dementia who have written books, such as Christine Bryden (2005, 2012) and Robert Davis (1989). I did not expect people with dementia to be able to write a book or speak at a conference. Those in the earlier and mid stages of dementia are finding their 'voice' and they are using it well to challenge stereotypes. I began to understand more about the broad spectrum of people with dementia and the long timescale of its effects.

But as I was learning about the lived experiences and active lives of some people with dementia, I was also meeting others, at the singing group and care home, who had lost their verbal abilities and were also physically frail. I was seeing first-hand the cognitive and bodily effects of advancing disease combined with advancing age. These bodily effects and the implications in terms of the need for 'care' seemed not to be clearly addressed in the rhetoric around dementia as a disability, with its emphasis on rehabilitation, independence and autonomy.

Poor care so often continues to be experienced by older people, including those with dementia, towards the end of their lives in hospitals (Francis 2013), and in care homes (Alzheimer's Society 2012). I was reassured that researching dementia, dying and palliative care was not 'giving up' on people with dementia but rather unmasking the reality experienced by many frail older people with dementia and trying to give them 'voice'.

I sensed that I had moved into 'no man's land' in my thinking. When in the company of palliative care colleagues I would hear the cry that we must think of dementia as a

disease and not a disability. When in the company of those who worked in dementia care the emphasis was on challenging the disease model. I could see both sides. How we think about dementia matters because it determines how care is delivered, priorities are made and the quality of relationships (Downs et al 2006). How a researcher thinks about dementia also matters, particularly when that research is about relationships with people with dementia, as it determines the course of the research.

I began my research with the premise that it is possible to connect with a person with advanced dementia in a meaningful way and aiming to understand more about this in the life of a care home and in the context of care-giving and care-receiving. Hughes (2011) takes the view that we need to take a broad view of dementia: yes, it is a disease and, yes, people with dementia are further disabled by social environments, be that structural and societal factors or the culture and practice in a care home. Rather than adhering to one particular understanding of dementia, I felt that drawing on all the different ways of thinking about dementia would broaden the scope of my research. From a sociological perspective this influenced my research questions in that, not only was I interested in the face-to-face interactions between people with dementia and those caring for them, but also the wider cultural, organisational, social and political forces shaping these interactions.

1.4.3 What is a Person?

As I became more aware of the threat to personhood caused by dementia (Kitwood 1997), with comments such as ‘She’s not the person I married’ or ‘She’s no longer my mother’ exposing the painful sense of loss of families, another seemingly relevant question for people with advanced dementia surfaced: ‘What is a person?’ or ‘What is selfhood?’ A whole new body of sociological and philosophical literature opened up. Helpful within this was the work of Kontos (2004, 2006) who conducted an ethnographic qualitative study of 13 residents with moderate to severe Alzheimer’s disease in a Canadian long-term care facility. Kontos drew attention to the importance of embodied selfhood, i.e. the way in which self is enacted in the movements of the body. She disentangles selfhood from cognitive and relational

categories and positions 'the body' as active and as important as the mind. She emphasises the significance of bodily expressions of subjectivity which demonstrate agency and sociability, even in those who are physically dependent and cognitively impaired. As a nurse I reasoned that thinking more explicitly about the body in this way could be useful therapeutically as a way of broadening the scope for connecting with people with dementia in care-giving/care receiving situations. But the empirical work undertaken by Kontos and sociological/philosophical theories of 'the body' required further exploration in the context of the care giving/care receiving relationship with people with dementia towards the end of life.

In an ethnographic study of people dying of cancer in a hospice, Lawton (2000) explores the links between selfhood and the body. She describes the subtle blending of bodily capacities and relational capacities which comprise personhood. Her thesis concludes that for a human being to be seen as a person they must have certain bodily capacities and attributes such as a bounded, physically sealed enclosed body and the bodily ability to act as the agent of one's own embodied actions and intentions. Her findings suggest that if these capacities are lost, for example, due to leaking wounds or bodily immobility and dependency, then the person falls out of the category of 'person' and becomes an 'object of care'.

I thought these were interesting ideas, as yet unexplored in the field of advanced dementia care, where incontinence, immobility and dependency are common characteristics of advanced dementia (Mitchell et al 2010). I thought it would be interesting to explore how these ideas fitted with Kontos' notion of embodied selfhood. However, I was also disturbed (and probably angry and offended!) by Lawton's view that the staff in hospices, are left caring for an 'object' and her questioning of the hospice ideology of enabling patients to 'live until they die'. It raised questions about what is happening when a nurse or a care worker is caring for someone with advanced dementia, often over a period of many months as they slowly dwindle (Murray et al 2005). Are they caring for a 'person' and what kind of relationship is this? It raised some very fundamental questions about what care is in the context of advancing dementia and physical frailty which led me to read more

about person-centred care, relationship-centred care and the Senses Framework¹ (Nolan et al 2006), and an Ethic of Care (Tronto 1993). An Ethic of Care is a theoretical approach which draws attention to the need we all have for care and integrates practical, moral and political aspects about the place of care in society (Tronto 1993).

At the outset I used the term ‘caring relationship’ to define the relationship between a person with dementia and those who have a duty of care for them. Caring here is not being used as an adjective or an assessment of quality, but rather a statement of fact that the care staff and the person with dementia are in a relationship where care is delivered and received. Understanding what a good quality relationship is and how this can develop, is what I am interested in, particularly the ways the care staff might be able to relate to the person with dementia as a person with subjectivity rather than an object of care. By meaningful I mean a relationship that is significant for both the person with dementia (even in the moment) as well as the care staff.

1.5 Conclusion

As I finish this PhD I remain hopeful about caring for people with dementia at the end of their lives. As I mentioned previously, I sensed the gulf that existed between palliative care and dementia care and felt that it was important to produce knowledge that might be useful to both fields and might in some way be a bridge between them. Further exploration on the notion of the body might speak to dementia care in the context of the personhood movement but also to palliative care with their focus on bodily comfort. I was also interested in the potential of understanding what role the body plays beyond physical care and into emotional and spiritual care, or relational care of the ‘whole person’, a central tenet of palliative care. ‘The body’, therefore, became my theoretical and analytical lens.

¹ The Senses Framework (Nolan et al 2006) sets out the conditions required for relationship-centred care to occur. It is described in Section 2.7.

2 Relationships in the Context of Palliative Care for People Living and Dying with Dementia

2.1 Introduction

In care homes for older people, positive relationships are understood to be at the heart of best practice (Davies & Brown-Wilson 2007, Robinson et al 2010). Interpersonal relationships provide the context within which care is given and received (Brannelly 2006). However, as this chapter shows, in the context of caring for people with advanced dementia in care homes, more needs to be understood about how caring relationships can be sustained until the end of life.

The protracted living/dying interval, the time between when a person with dementia is no longer able to be cared for in their own home, and the time of their death, is where a large part of palliative care for people with dementia takes place in care homes (Joint Improvement Team 2013², Alzheimer's Disease International 2013, Department of Health 2012, Froggatt et al 2011). How people with dementia are perceived by those who care for them is profoundly important within their relationships. Understandings of, and assumptions about, the effect of dementia on personhood/selfhood³ directly affect the way people with dementia are perceived by others, the quality of their relationships, the quality of their care and the quality of their life (Lyman 1993). How people with dementia are perceived by those caring for them matters because, as Kontos & Naglie (2009 p.551) suggest:

‘assuming a loss of selfhood with advanced dementia implies that there is no affront to human dignity in treating those who are cognitively impaired as though they are unable to experience humiliation’ (Kontos & Naglie 2009 p.551)

² The Joint Improvement Team is a strategic improvement partnership between the Scottish Government, NHS Scotland, Convention of Scottish Local Authorities, the Third Sector, the Independent Sector and the Housing Sector

³ Further defined below.

Assuming a loss of selfhood means that it does not matter if we do not explain what we are doing to a person with dementia, or if we treat them roughly or forget to give them a drink because, in this view, they are unaffected by it.

Older people with dementia are one of the most marginalised and excluded groups in society (Wilkinson 2002, Milne 2010), none more so than those living and dying in care homes (Froggatt et al 2011). People with dementia struggle to maintain relationships after diagnosis (Alzheimer's Society 2013) and can ultimately experience social death; social death is defined as the cessation of the individual as an active agent in other people's lives (Froggatt 2001a, Glaser and Strauss 1965, Sudnow 1967). In the context of care-giving and care-receiving relationships, people with dementia can become viewed, rather, as passive recipients of care. As Brannelly (2011 p. 665) suggests, 'being treated as socially dead robs the self of the dignity of a meaningful and bearable death'. Challenging social death is, therefore, an important consideration in the care of people with dementia at the end of life.

The argument of this thesis is that people with advanced dementia continue to experience and respond to the world, and those around them, until they die; recognition of this is fundamental to high quality relationship-centred palliative dementia care, which includes end-of-life care. Understanding how to better support relationships must be a priority in policy, practice and research as the number of people affected by dementia increases worldwide to a predicted total of 115 million by 2050 (Alzheimer's Disease International, 2013). Only then will we challenge 'social death' or as Kitwood & Bredin (1992 p.280) put it 'death that leaves the body behind' and its consequences for human dignity.

The aim of this chapter is to review the literature on relationships in the context of caring for people living and dying with dementia in care homes. The purpose of the literature review was to understand the broader context and to examine relevant theoretical perspectives on dementia care, palliative care for people with dementia, the role of the caring relationship, and other empirical research in this area in care homes, identifying gaps in the knowledge base and providing the rationale for this

study. It draws on a broad literature base and included any material which might provide insights relevant to the overall study aim of understanding relationships in the context of caring for people living and dying with dementia. This included original research, review articles, discussion articles and books. Initial searches of published literature employed various combinations of terms such as ‘Dementia’, ‘Alzheimer’s’, ‘Dementia Care’, Palliative Care’, ‘End of Life Care’, ‘Relationships’, ‘Relationship-Centred Care’, ‘Care Homes’, ‘Nursing Homes’, and ‘Residential Homes’. Initial searches were limited to the year 2000 onwards but this was not rigid and relevant papers which were older than this were used. The international literature was explored but limited to English Language. Databases used included Medline, ASSIA, CINAHL, Web of Science, PsychoInfo, Scopus, and Social Science Index. I was alerted to new literature through email alerts from relevant publications⁴. Snowballing techniques were used whereby the reference lists in articles highlighted further articles or books which were then examined. Further work by key authors who emerged as seminal thinkers or active researchers in the field, for example Tom Kitwood, Julian Hughes, Pia Kontos and Elizabeth Sampson, were accessed and read. Grey literature as well as dementia care and palliative care policy documents, both UK and Scottish, informed the literature review. The scope of the literature examined developed organically throughout the research process as important aspects, gaps in knowledge and the focus of the research became more defined.

The synthesis of the literature in this chapter firstly examines how people with dementia become marginalised within their relationships and within systems providing palliative care. Secondly, it spotlights the social psychological framework for understanding relationships with people with dementia, and provides an in-depth critical analysis of person-centred and relationship-centred care. Thirdly it examines empirical work on caring relationships in care homes. Fourthly, it considers the

⁴ Journals included: Palliative Medicine, Dementia, Health and Social Care in the Community, Ageing and Society, Sociology of Health and Illness, BMJ Supportive and Palliative Care, Palliative and Supportive Care, Journal of Advanced Nursing.

concept of personhood/selfhood and the centrality of embodied selfhood and intercorporeal personhood in relationships. Finally, it concludes by showing how this theory is important for understanding the lived experience of people with advanced dementia within their relationships and the need for more research on this concept in relation to practice in care homes.

2.2 Dementia and the Process of Marginalisation

In Western clinical practice dementia⁵ is used as an umbrella term for a number of different disease classifications, the most common of which is Alzheimer's disease (AD). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5 2013) categorises dementia as a Major Neurodegenerative Disorder. To meet the criteria for Major Neurodegenerative Disorder:

‘...an individual must have evidence of significant cognitive decline (for example, decline in memory, language or learning), and the cognitive decline must interfere with independence in everyday activities (for example, assistance may be needed with complex activities such as paying bills or managing medications’ (Alzheimer's Association 2014 p.5).

Dementia is associated with at least one of the following: loss of speech or understanding of written or spoken word (aphasia), loss of ability to perform purposeful movements (apraxia), loss of ability to recognise objects (agnosia) or disturbance in executive functioning. Social or occupational function is also impaired (Alzheimer Europe 2015). It becomes immediately apparent that a person experiencing any of these deficits as a result of the disease process will face challenges in their interactions with other people and in functioning in day to day life. A biomedical approach to dementia care focuses on alleviating symptoms, enabling treatment to take place and evaluating the impact of interventions on the symptoms of dementia (Innes & Manthorpe 2012).

Although some would argue that dementia would be better understood as part of

⁵ The umbrella term ‘dementia’ is used throughout this thesis rather than specific types of dementia

normal ageing and not a disease (Whitehouse & George 2008), diagnosis is widely recognised as important for accessing support and is supported within dementia care policy (Department of Health 2009, Scottish Government 2010, 2013-2016).

Diagnoses are made with some degree of certainty and can be used to predict certain types of deterioration and forms of treatment or resources which may help. Diagnosis is important for differentiating between different types of dementia: dementias caused by some hormonal imbalances or vitamin deficiencies are reversible; some treatments are licensed for the symptoms of Alzheimer's disease; the use of anti-psychotic medication can have potentially serious side-effects for people with Dementia with Lewy Bodies.

A diagnosis of probable dementia is made from a variety of tests that include: brain imaging, screening for co-morbid conditions and cognitive testing. The Mini-Mental State Examination (MMSE) is the most commonly used cognitive test (Folstein et al 1975, SIGN 2006). The MMSE breaks cognitive function down into discrete elements such as attention, memory, perception, and learning which can be measured objectively, uncontaminated by situational factors or social cues. However, the diagnostic process and the diagnostic label of 'dementia' has far reaching implications.

A person with dementia depends heavily on the social context for information and cues which helps them to behave in a coherent way (Sabat 2001). In everyday life the cognitive functions measured by the MMSE do not occur in isolation to each other and isolated from their context; the MMSE test situation is itself a social context which could confound or contaminate performance and may exaggerate weaknesses and fail to acknowledge personal strengths (Stokes 2008).

Standard measures used in the diagnosis of dementia are underpinned by a positivistic epistemology; people are diagnosed with dementia because, on average, they perform significantly worse in a statistical sense than 'normal' counterparts on tests which measure, for example, attention and perception (Sabat 2001). The epistemological neutrality of biomedicine has been questioned in that the idea of

‘normal’ has taken on a moral quality as a state to which we should strive and that is also better (Lock & Nguyen 2010). This has a major impact on how people with dementia are viewed as they are positioned as ‘abnormal’ giving the impression that there is a stereotypical person with dementia when, actually, every person is affected differently.

The diagnostic label of dementia implies certain deficits and the danger is that the person becomes defined by these deficits (Hughes et al 2006, Sabat 2001). The medical label of dementia can blind professionals and families to the remaining potential of the person (Lyman 1993); the MMSE does not measure, for example, expressions of generosity or love for others. A recent survey which explored public attitudes and knowledge of dementia showed that:

- 46% of those surveyed thought that ‘as soon as someone is diagnosed with dementia, they are not treated as a human being any more’
- 75% thought that ‘once they have dementia the person you knew eventually disappears’
- 73% thought that ‘people with dementia are like children and need cared for as you would a child’
- And 83% thought that ‘there comes a time when all you can do for someone with dementia is keep them clean, healthy and safe’ (ESRC Update 2011).

Fontana & Smith (1989) associate the progression of dementia with the ‘unbecoming’ of self and Davis (2004) suggests the progressive nature of dementia is the ‘very splintering of the sedimented layers of being until ultimately there is nothing left (2004 p.375). The following quote is taken from a recent BBC interview of a relative of a person with advanced dementia who lived in a care home:

There was no point in going (to visit). I didn’t want to see my dad like this. All I was looking at was a cavity of what my father was...he had no idea who I was, who my mum was. ...I don’t want to see him like this, in this vegetable state (BBC Archive October 2014)

This quote points to the predominant cultural stereotype which views people with advanced dementia as ‘already dead’ (Small et al 2007). Negative stereotypes create filters through which people with dementia see themselves (Hughes et al 2010). Sabat (2001) suggests that if people diagnosed with dementia see themselves in terms of what they cannot do it weakens their sense of self-worth and self-esteem and increases their sense of being burdensome. The label of dementia can condemn people to the stigma of a ‘spoiled identity’, where a person becomes seen as socially ‘abnormal’ and, therefore, in danger of being considered as less than human (Goffman 1968). The combined effects of the disease process and stigma profoundly affect quality of life (Milne 2010).

The root cause of the stigma experienced by people with dementia is pinpointed by Post (2000) who coined the term ‘hypercognitive culture’ to describe our contemporary culture which holds rationality, cognition, and memory as core aspects of the self. When dementia leads to the loss of these aspects of selfhood, the person is diminished in the eyes of society. This view overlooks other aspects of being human such as emotional, spiritual, relational, and aesthetic aspects. The conditions are thus created whereby people with dementia become increasingly marginalised within their relationships and in the social world. Implicit within this ‘hypercognitive’ view is a Cartesian duality, influenced by the thinking of Descartes from the 1600’s, which separates the mind from the body, leading to the famous formulation ‘I think, therefore I am’ (Hughes 2011). The Cartesian split between mind and body is implicated in many areas of Western thought particularly epistemology, moral agency and rationality (Benner 2000).

2.3 A Response to Marginalisation

A purely biomedical view diverts attention from the impact of social and environmental barriers, cultural processes and policy frameworks which systematically contribute to the disablement of people with dementia (Wilkinson 2002, Innes 2009). In response, a critical social gerontological understanding of dementia seeks to highlight the discrimination faced by people with dementia (Innes

& Manthorpe 2012); this has contributed to a seismic shift in dementia care policy and practice away from the biomedical model.

A rights-based approach and attention to active citizenship is central to a critical social gerontological perspective. Citizenship addresses issues of power and the social position people with dementia occupy in society, seeking to influence political discourse and promote social inclusion (Bartlett & O'Connor 2007). An increasing number of people with dementia are uniting in collective action, challenging marginalisation and influencing policy and practice change and societal attitudes about people with dementia. Members of groups such as the Scottish Dementia Working Group (<http://www.sdwg.org.uk/>) and Dementia Advocacy and Support International (<http://dasninternational.org/>) are positioning themselves as active citizens rather than 'tragic victims of a disease' (Bartlett & O'Connor 2007, Bartlett 2014). This movement has been highly effective, directly influencing current UK and Scottish National Dementia Strategies (Department of Health 2009, Scottish Government 2010, 2013-2016, Innes & Manthorpe 2012). This is encapsulated in David Cameron's Prime Minister's Challenge on Dementia (Department of Health 2012) which states that:

'As a society, we must make sure that people with dementia, their carers and families can be active citizens with the potential to live well with dementia at every stage of the condition.' (Department of Health 2012 p.12)

The policy drivers to develop 'dementia friendly communities' where people with dementia are supported to live well is part of this approach (Scottish Government 2013-2016). Challenging institutional models of care in favour of community orientated approaches is integral to this movement.

A critical social gerontological perspective pays close attention to the power of language to influence how people with dementia are treated by others, how they see themselves and their experience of either empowerment or disempowerment. Thus negative language, the so-called public face of stigmatisation (Milne 2010), and the connotations of terms such as 'dementia sufferer' or the adjective 'demented' are challenged for their stigmatising effect (Swaffer 2014, Sabat et al 2011). Terms such

as these have silenced people with dementia but there is a change in that people with dementia are now more likely to be referred to as ‘people with dementia’ and recognised as having a voice. There is a growing emphasis on finding innovative ways to include the perspectives of people with dementia in research and practice (Wilkinson 2002, McKillop & Wilkinson 2004, Scottish Dementia Working Group 2014). However, Bartlett (2014 p.641) recognises there is a risk that ‘people with dementia who are not verbally fluent, visible, mobile and self-confident remain stigmatised and discriminated against’.

2.3.1 An Unintended Consequence of the Response

Dementia care policy and practice underpinned by a critical social gerontological understanding has tended to focus more on people with dementia in the earlier and mid-stages of the disease. People who are living with advanced dementia warrant more attention. This is beginning to be addressed in strategies currently being developed (Alzheimer’s Scotland 2014 personal communication). Hertogh (2010) suggests that an emphasis in dementia care on the early and mid-stages gives the impression that dementia is a static disease that can be stabilised, when in reality this is rarely the case. Rather, we need to acknowledge the full range of variation across the spectrum of dementia and also embrace the fundamental mortal nature of human beings (Gwande 2014). Focusing on the negative pole of dementia encourages stigmatisation and exclusion because it highlights cognitive deficiencies and dependency and ignores enduring capabilities. On the other hand, promoting an exclusively positive image is ethically and politically problematic as it masks the reality experienced by many frail older people with advanced dementia (McLean 2011). An unreflective emphasis on independence is problematic. While empowerment through promoting self-care may be the right goal for people in the early or mid-stages of dementia, as dementia progresses, it can stigmatise and divert attention away from thinking about what good care entails for those who become dependent on others for help; people age and care needs evolve. This includes people in the later stages of dementia who are dying.

Gilleard & Higgs (2000) suggest we live in a society where the loss of capacity for self-care is perceived as the most serious of identity flaws. In this view only an autonomous life is seen as a life worth living (Small et al 2007). This view devalues 'care', those in need of care and those who deliver care (Barnes 2011). An Ethic of Care approach acts as a corrective to this view (Tronto 1993). Tronto (1993) seeks to present a view of care that integrates practical, moral and political aspects about the place of care in society. This will be explored later in this chapter in Section 2.6.2. She challenges the view that any of us are autonomous independent human beings:

‘...part of the human condition is that our autonomy occurs only after a long period of dependency and that in many other ways we remain dependent on others throughout our lives’ (Tronto 1993 p.162).

For example, working parents, who for the sake of argument are in well paid jobs, depend on paid child-care to enable them to do their jobs. The well paid work has higher prestige and is more highly valued than the child care and power is unevenly distributed. But the working parents are dependent on this 'care', as is the economy. By drawing attention to the need we all have for care, an Ethic of Care approach challenges the stigmatisation experienced by people who are dependent on help with bodily care such as washing and dressing e.g. people with advanced dementia, and those who provide such care. Tronto (1993) makes the argument that all human beings have needs that others must help them meet; human beings are interdependent beings and Tronto suggests that:

‘...we need to rethink our conceptions of human nature to shift from the dilemma of autonomy or dependency to a more sophisticated sense of human interdependency’ (Tronto 1993 p.101).

Failure to acknowledge this has consequences. In the UK, people with dementia and their families are seldom informed of the terminal nature of their illness and do not have the opportunity to discuss their future goals and wishes in relation to their care (Thune-Boyle et al 2010). The presence of dementia, whatever the cause of death, has implications for the person's experiences at the end of their life and also their access to palliative care. The prolonged nature of dying with dementia is at odds with

the way palliative care services are organised around a terminal event rather than a longitudinal process (Jerant et al 2004). Together these factors create another form of social exclusion for people with dementia who are described as ‘hidden’ and ‘the disadvantaged dying’, experiencing poor access to high quality palliative care (Audit Scotland 2008, Brazil et al 2004, Birch & Draper 2008, Hall et al 2011, Sachs et al 2004, Robinson et al 2006, Alzheimer’s Society 2012, Sampson et al, 2006, Aminoff & Adunsky 2005, Marie Curie Cancer Care 2014).

2.4 Palliative Care, Dementia and the Problem of Suffering

Palliative care is defined by the World Health Organisation (WHO) as:

An approach that improves the quality of life of people and their families facing the problems associated with life-threatening illness, through the prevention and relief of *suffering* by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO 2002 Website)

The WHO (2002) principles of palliative care are that it:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patients’ illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy,

and includes those investigations needed to better understand and manage distressing clinical complications

The concept of suffering and the relief of suffering is core to the definition and purpose of a palliative care approach. Suffering is defined as ‘the bearing or undergoing of pain or distress or tribulation’ (Oxford English Dictionary 2014). There is open acknowledgement within a palliative care approach that living and dying with a progressive disease can lead to physical, psychosocial and spiritual distress which, if unrecognised and unrelieved, can lead to potentially avoidable suffering and poor quality of life. Dementia is a progressive and ultimately terminal disease and the average survival period following diagnosis is eight to ten years, although people often die from other causes before their dementia reaches the end-stage (Jolley 2010).

As described above, within the critical social gerontological understanding of dementia the use of language such as ‘suffering’ in relation to people with dementia has been challenged; this is due to its associations with negative stereotypes and narrow biomedical views of dementia leading to stigmatisation and therapeutic nihilism in the absence of a cure. A review of research which examined the experiences of people living with dementia (de Boer et al 2007) challenges the assumptions that dementia is a state of dreadful suffering; rather the insidious onset and gradual progression allows adaptation and adjustment to the changing situation. However, de Boer et al (2007) acknowledge that the experiences of those people with dementia described in their review article were those who were able to verbally communicate their feelings relatively well in interviews, indicating they were not yet in the advanced stages of dementia. They caution that their findings should not be extended to people in all stages of dementia.

The contested nature of the concept of suffering in relation to dementia may partially explain why until recently there has been little overlap between dementia care and palliative care in both policy and practice (Sampson & Robinson 2009, Ryan and Ingelton 2009) and gaps remain in knowledge and practice on delivering palliative

care to people with dementia (Birch & Draper 2007, Marie Curie Cancer Care and Alzheimer's Society 2014, Marie Curie Cancer Care 2015). A retrospective study of case notes which compared the care received by patients with and without dementia who died during acute hospital admissions found that those with dementia received fewer palliative care medications and fewer palliative referrals than those without dementia and less attention was paid to their spiritual needs (Sampson et al 2006). This is despite the evidence showing that physical suffering is common in people with advanced dementia and that there is an increase in distressing symptoms towards the end of life, the frequency and pattern of which are similar to those with terminal cancer (Mitchell et al 2010). McCarthy et al (1997) reported that the most frequent symptoms experienced by people with dementia in the last year of life were: mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%) constipation (59%) and loss of appetite (57%) and that people with dementia experienced these symptoms for longer than people with cancer. There is evidence that people with dementia persistently experience under recognition and under treatment of pain consistent with the levels of their co-morbidities and other conditions which would indicate pain (Husebo & Corbett 2014). This is despite the availability of a number of validated non-verbal assessment tools based on behavioural observations (Zwakhalen 2006). These studies show that people with dementia do experience physical, emotional and spiritual suffering but it takes longer for it to be noticed and addressed compared to people with cancer, which raises questions about why this should be the case.

As described earlier, challenging stereotypes of people as 'tragic victims of a disease' (Bartlett & O'Connor 2007, Bartlett 2014) has been highly effective in improving life for people living with dementia. However, if suffering is the antithesis of quality of life, then the findings of the studies in the paragraph above would suggest that people with advanced dementia do experience unrelieved suffering. It may be that because people with advanced dementia, who often have difficulty expressing themselves verbally, do not complain or ask for help then it is assumed in busy care environments that they are therefore comfortable. There is a fine balance to be achieved between challenging negative stereotypes of 'suffering victims' which

entrench the marginalisation of people in the earlier stages of dementia and challenging poor access to care which might relieve suffering for people with advanced dementia.

A shift is required from Cartesian assumptions which would suggest we can only know another's experience if they talk about it and that somehow people with advanced dementia experience the world less fully than those who have cognitively ability. Without this shift, people with advanced dementia may continue to have pain, psychosocial and spiritual needs overlooked due to assumptions that either they do not have these needs or the impossibility of accessing their subjective experience in the absence of speech. This topic is returned to in Section 2.11 of this chapter.

Recognising that people with advanced dementia may suffer is important from the perspective of sustaining caring relationships with family and paid carers.

Compassion is defined as 'the feeling or emotion when a person is moved by the suffering or distress of another, and by the desire to relieve it' (Oxford English Dictionary 2014). Suffering needs to be recognised in people with dementia, who may be unable to express it verbally, in order for it to be relieved. If family or paid carers are not equipped to relieve suffering, or it is compounded by the context of care, they may avoid interacting with the person (Bernard & Creux 2003). Suffering is exacerbated when it is ignored, misunderstood or dismissed as inevitable (Katz & Johnstone 2006). Arbore et al (2006) suggest that by distancing from the person's suffering, a carer loses the ability to help the person make meaning of their struggle and this can mean sick and dying people are left isolated and alone in their pain and suffering. To silence suffering in discourses on dementia could have the paradoxical effect of increasing suffering caused by social isolation, further marginalising people with advanced dementia.

This thesis takes the position that people living and dying with dementia in care homes are likely to experience physical, psychosocial and spiritual suffering and that palliation of this, or a 'palliative care approach', is a priority of care in care homes. However, it is also acknowledged that 'suffering' is not a neutral term and

unreflective use of the term can be detrimental to people with dementia by perpetuating negative stereotypes. The term 'suffering' is therefore used with care in this study.

2.5 The Moral Challenge of Dementia

The moral challenge of dementia is twofold (Post 2000). Post (2000) suggests the first moral challenge requires that we overcome the stigma associated with dementia by being with the person with dementia in caring ways that draw upon their remaining emotional, relational and creative capacities. This means not giving up on people with advanced dementia and promoting quality of life, recognising the ways they continue to experience and respond to the world and those around them until they die. The second moral challenge is that we need to think ethically about how to avoid burdening people with dementia with invasive medical treatments so that suffering is not prolonged and the end of life and dying is recognised. Getting the balance right between these two strands is where the moral challenge lies (Post 2000). Balancing these two strands is the moral challenge for all palliative care but to date palliative care for people with advanced dementia in the UK has largely focussed on the second strand.

In this thesis I focus on people with dementia living and dying in a care home: marginalised people in a marginalised place (Froggatt et al 2011). The main focus of policy, research and practice development on palliative care for people with dementia in care homes has been on implementing systems to:

- Prompt good assessment and management of symptoms
- Prompt open communication about death and dying with families
- Help professionals to identify deterioration and dying
- Avoid unnecessary hospital transfers and burdensome treatments (Badger et al 2009, Hockley et al 2010, Finucane et al 2013, Kinley et al 2013, Scottish Government 2008, 2011, and Department of Health 2008).

This approach is helping to enable more people to die comfortably and naturally in their preferred place of care (Badger et al 2009, Hockley et al 2010, Finucane et al 2013). While there will be times when people with dementia will benefit from hospital admission and discrimination must be guarded against, aggressive treatments for pneumonia or tube feeding are of limited benefit in advanced dementia (van der Steen et al 2002; Pinderhughes & Morrison 2003; Mitchell et al 2004; Pasma et al 2005; Helton et al 2006).

The oldest old age group (over 85 years) in care homes is rising (Scottish Care Home Census 2013, Perrels et al 2014). The large majority of people in this age group have multimorbidity which is associated with higher mortality, increased disability, declining functional status and a lower quality of life (Formiga et al 2013, Shippee et al 2012). The combination of conditions complicates disease processes and increases the complexity of dementia care (Mercer et al 2012). While disease staging of dementia can be helpful in providing structure to help people understand what is happening (Spector & Orrell 2010), precise staging in this age group is less important than recognizing that people with a diagnosis of dementia die with, as well as from, dementia (van der Steen et al 2013). The presence of dementia has implications for their experience of dying.

While avoiding futile interventions and balancing overtreatment with undertreatment so suffering is not prolonged is part of the moral challenge, supporting quality of life over the prolonged period people often live with advanced dementia (Froggatt & Payne 2006) is a moral imperative. Maintaining relationships and avoiding social death is central to this and requires more attention within palliative care approaches in care homes.

A social psychological approach to understanding dementia has emerged alongside the critical gerontological approach as a corrective to a narrow biomedical view (Innes & Manthorpe 2012). Key figures within this movement are Kitwood (1997) and Sabat (2001). Although it has been criticised for failing to locate individual experiences within wider social, political, cultural and economic realms which act as

barriers to people with dementia being active citizens (Innes & Manthorpe 2012, Bartlett & O'Connor 2007), in the context of the face to face care-giving/care-receiving relationship with people with advanced dementia in a care home a more in-depth exploration of this approach is required; its important contributions and limitations are now examined.

2.6 A Social-Psychological Perspective on Dementia

Kitwood (1997) uses the term 'malignant social psychology' to describe care environments which damage the personhood of people with dementia. This was based on research he undertook using a critical incident technique informed by social interactionism. When a 'malignant social psychology' operates dementia becomes the filter through which an observer interprets behaviour, putting pathology in a privileged position. Emotional or disruptive behaviour is put down to pathology rather than considering other factors such as the environment which may be causing the behaviour (Hughes et al 2010). This contributes to an environment and relationships which exacerbate the effects of neurological impairment; the 'dialectical interplay' between neuropathology and a malignant social environment (Kitwood & Bredin 1992).

Kitwood believed that distressed behaviours such as shouting, crying or hitting, were legitimate responses to assaults on personhood rather than part of the disease process. Clearly, these behaviours could also be due to physical problems, such as pain, but what is important is that Kitwood brings the lived or subjective experience of people with dementia to the fore. This is important and will be explored further later. Elements of a malignant social psychology which assault the self-worth of a person are:

- Treachery (using deception to force compliance)
- Disempowerment (not allowing to use abilities they have)
- Infantilisation
- Intimidation

- Labelling - (using ‘demented’ as basis for explaining behaviour)
- Stigmatization (treating as if diseased or different)
- Outpacing (talking or acting at too fast a pace for the person with dementia)
- Invalidation (failing to acknowledge feelings or subjective reality)
- Objectification (treating as if a lump of dead matter)
- Ignoring
- Imposition (forcing to do something, denying choice, overriding desire)
- Withholding (refusing to give asked for attention)
- Accusation (blaming person due to lack of ability or their misunderstanding)
- Disruption (intruding suddenly or disturbingly on action or reflection)
- Mockery
- Disparagement (telling someone they are worthless etc.) (Kitwood 1997 p.46/47)

Care contexts or relationships which foster these practices create a malignant social environment which undermines personhood. One of Kitwood’s important contributions was to recognise the intrinsic moral worth of persons and challenge the loss of personhood in dementia by reconsidering the grounds of personhood⁶.

Kitwood defines personhood as:

‘a standing or status bestowed on one human being, by another, in the context of relationship’ (Kitwood 1997 p8).

Cassell (1976 cited in Katz & Johnson 2006) suggests that suffering in illness springs from a person’s perception that he or she is disintegrating and losing their identity. Supporting personhood, therefore, would seem to be an important aspect of palliative care for people with dementia as a means of relieving suffering. Kitwood (1997) suggests that a central task of dementia care is the preservation of personhood and he

⁶ Dewing (2008) and Millett (2011) draw attention to the contested nature of the terms selfhood, personhood and identity and the differences between them. The difference between selfhood and personhood is beyond the scope of this thesis; a pragmatic approach is taken and the terms are used interchangeably. Identity is understood in a philosophical sense to mean a unique individual identity which is unchanged by dementia in a numerical sense in that they are still ‘counted’ as the same person. Aspects such as personality or abilities may change (Millett 2011).

situates this within a psychosocial framework. Positive person work such as validating and celebrating can support personhood. The emphasis on understanding people with dementia in terms of relationship is important not because this is all that is left to them but because this is characteristic of all our lives (Hughes et al 2006). As dementia progresses others must take the initiative in meeting the person's need for:

- Attachment – the need for secure bonds with carers
- Comfort – the need for relief of pain and sorrow, closeness and tenderness
- Identity – the need to be known by others as the same person as always
- Occupation – the need to be involved in the process of life
- Inclusion – the need to have one's standing as a social person recognised (Kitwood 1997)

Kitwood's work has been highly influential in dementia care and in the development of person-centred care which is now a guiding principle in practice and health and social care policy (McCormack et al 2010). Although it seems that person-centred care is understood and practiced in a number of different ways, recurring patterns and themes in relation to person-centred practice are: knowing the person's life story, honouring choices and preferences, building mutual trust and understanding, developing therapeutic relationships, authenticity, meaningful activity, and the creation of a therapeutic environment (McCormack 2004, McCormack et al 2010, McGilton et al 2012).

A therapeutic environment which supports a culture of person-centred care for people with dementia would include a physical environment that: supports functional ability; maximises orientation; creates familiarity and home likeness; provides optimal sensory stimulation; provides opportunities for social interaction; and supports privacy and personal control (Chaudhury et al 2013).

2.6.1 The Persistence of Self

Sabat (2001, 2010), a social psychologist, gathered information on his interactions with his patients with dementia at an Alzheimer's Day Centre and, guided by social constructionism, identified three types of selves persisting in people with dementia. The first self he describes is the self of personal identity expressed as first person pronouns such as 'I' and 'me' and this is found to be enduring even in advanced dementia. The second self is related to the attributes of a person, past and present, their lived experiences and all the things they've done; other people have a role in paying attention to the life narrative of the person. The third type of self, described by Sabat, is that which is socially constructed with others and requires community. This is profoundly important for people with dementia as it is to do with how others see them now and can be inhibited or facilitated by the behaviour and practices of others and the community at large. Sabat (2001) systematically collected data identifying the capacities which remain in people with dementia:

- The capacity to experience shame and embarrassment
- The capacity to experience pride and maintain dignity
- The capacity to feel concern for the well-being of others
- The capacity to formulate personal and group goals
- The ability to use extralinguistic forms of communication to compensate for linguistic impairment
- The ability to communicate effectively when others help
- The capacity to manifest and experience selfhood in a variety of ways
- The capacity to manifest indicators of well being
- The capacity to experience and the ability to work effectively at maintaining feelings of self esteem

- The capacity for spiritual awareness and expression (Sabat 2001)

Sabat (2001, 2010) highlights how the effects of dementia are more than neuropathological changes in the brain; they are influenced also by the way the person with dementia is positioned in relation to others in the social world and the psychological effects of living with dementia.

‘Excess disability exists when a person with dementia’s functional incapacity is greater than that warranted by their neuropathological impairment... but is rooted in the social world they inhabit’ (Brody cited in Sabat 2001 p93).

The possibilities for minimising those limitations, Sabat (2001) would suggest, are greatest in the social domain. This is similar to the notion of Kitwood & Bredin’s (1992) ‘dialectical interplay’ described earlier. The Bio-Psycho-Social model (Sabat 2008, 2012, Spector & Orrell 2010) which incorporates psychosocial and biological factors into the experience of people with dementia has subsequently developed, although it was originally described in the 1970’s by Engel (Hughes et al 2006).

Sabat’s three types of selves are useful in that they help to operationalise identity in people with dementia i.e. their need to be known by others as the same individual and not a different individual. However, they are limited by the omission of a spiritual self and the under-representation of how, for example, through dress or adornment we choose to represent, hide or change aspects of ourselves (Kelly 2010). Neither Sabat (2001), nor Kitwood (1997), address how personhood can be supported until the end of life, beyond a superficial level.

2.6.2 Limitations of Kitwood’s notion of Person-Centered Care

While Kitwood is rightly acknowledged as a pioneer in the field of dementia care and his approach ‘groundbreaking’ at a time when people with dementia were completely marginalized, he is not without critics. Kitwood’s (1997) methods have been criticized for being unavailable to public scrutiny, flawed, lacking validity and pseudo-scientific (Adams 2005, Dewing 2008, Davis 2004). His use of proxy accounts from carers of people with dementia has been questioned for their accuracy.

Also, the social interactionist perspective is criticized for oversimplifying communication in the context of dementia (Adams 2005).

In practice, person-centred care has been difficult to progress (McCormack et al 2012) with tensions between the rhetoric and reality (Venturato et al 2011). There are concerns that the term ‘person-centred care’ has become debased and has lost its original value as a guiding principle (Nuffield Council on Bioethics 2009).

McCormack et al (2012) suggest person-centred care has become confused with consumerism, emphasising choice and independence, which in the context of advanced dementia is problematic. A better understanding of the practice context which supports person-centred care is required (McCormack et al 2010). In addition, the ways that the practice context can contribute to suffering by undermining personhood needs to be acknowledged and better understood (Francis 2013, Forbes-Thompson & Gessert 2006). However, blaming the immediate care environment, without an adequate understanding of how it is shaped by wider socio-political forces, must be avoided (Bartlett & O’Connor 2007).

The focus of this study is on the care-giving/care-receiving relationship, but it is important to locate this in the wider context of care. Tronto (1993) seeks to present a view of care which integrates practical, moral and political aspects about the place of care in society. She proposes a broad definition of care:

‘...a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web’ (Tronto 1993 p. 103)

In so doing she brings in the notion that care is not just about a dyadic relationship between a care-giver and a care-receiver, but functions socially and politically within a wider culture. Tronto (1993) identifies four levels of care:

- Caring about – noticing the need to care in the first place
- Taking care of – assuming responsibility for care
- Care-giving – the direct meeting of needs of care

- Care-receiving – the response to receiving care

‘Caring about’ is noting the existence of a need and making an assessment that this need should be met at a political level. ‘Taking care of’ assumes some responsibility for the identified need, determining how to respond to it, believing that action can be taken (Tronto 1993 p.106). For example, if we as a society notice that there are people starving in the world, but feel it is too big a problem and do not take any responsibility for addressing it, then the process of caring for starving people is disrupted. Thinking about these levels of care raises the question of whether we as a society recognise that people with advanced dementia need palliative care and how we go about assessing and meeting that need.

In Scotland (and the UK as a whole) there is a level of ‘caring about’ in that care is provided for people with advanced dementia who need 24 hour care, predominantly through care homes run by for-profit private sector organisations on a market based model, with a smaller number of local authority and voluntary organisations providing care on a not-for profit basis (Scottish Government 2014). The National Care Home Contract (2006) seeks to standardise contracts and ensure transparent and consistent approaches to funding care (Scottish Government 2014). The National Care Standards (<http://www.nationalcarestandards.org/> 2015) augmented by the Standards of Care for Dementia in Scotland (Scottish Government 2011) and a regulatory regime, operated via the Care Inspectorate, aims to ensure an acceptable quality of care is provided.

However, as a task force assigned to explore the future of residential care in Scotland identified, problems persist with a significant minority of care homes continuing to provide poor quality care (Scottish Government 2014). The care home sector is experiencing financial fragility for a number of reasons: savings targets in local authorities leading to an increasing gap between public and private funding of care⁷;

⁷ Of the £10.3 billion yearly social care expenditure in the UK, £4.5 billion comes from local authorities and the remaining £5.8 billion from people with dementia and their families. The total cost of dementia care in the UK is £26.3 billion. The remaining costs are paid by the NHS (£4.3 billion) and unpaid care by families which equates to £11.6 billion (Alzheimer’s Society 2014).

rising food and fuel costs; increasing regulatory requirements such as a higher specification for physical environments; lack of investment in care homes which reflects the real cost of care. All of this impacts on the delivery of person-centred care for people living and dying with dementia in care homes.

Regulatory frameworks dominated by risk avoidance and clinical markers, such as the prevention of pressure sores, while vitally important, do not have corresponding markers for how these translate into person-centred practices which support personhood (McCormack et al 2012). Physical care is recognised as important in providing a 'way in' to meaningful engaged relationships within a person-centred nursing framework (McCormack & McCance 2006). However, Kontos et al (2010) found that care staff broke rules enshrined in care standards as a strategy to individualise care because full compliance with rules constrained their ability to do so. For example, requirements to have two care staff in the room to wash someone often meant the person with dementia felt 'ganged up on' so care staff would call each other for help only when it was required to transfer the person (Kontos et al 2010). Regulatory frameworks do not have a clear understanding of the concept of personhood and the 'silent harms' that can be inflicted as a result of an over emphasis on risk avoidance (Clarke et al 2011). A re-evaluation of 'what is harm?' is required (Forbes-Thompson & Gessert 2006).

Kitwood (1997) believed that the greater part of dementia care does not require input from nursing and this view has influenced the development of health and social care for people with dementia and some care homes having no on-site nurses. Although Kitwood does not deny dying, he at the same time does not address the bodily effects of dementia, advancing age, and associated multimorbidity which makes dying with or from dementia complex. This is a problem. As people with dementia are staying at home for longer, care homes, including those without on-site nurses, are caring for older people with more complex needs who are at the end of their lives who do require in-put from nurses (Care Quality Commission, 2011/2012, Scottish Care Home Census 2013, McVey et al 2013). Internationally it is recognised that there is a lack of knowledge and skills about end of life care in care homes, with families

voicing concerns about the quality of care (Vohra et al 2006) and families affected by dementia having unmet support needs themselves (Henning et al 2010, 2013).

McGilton et al (2012) suggest that a radical shift in direction is required in the priorities of regulators and care providers and the competencies of nurses⁸ in long term care settings. Nurses, McGilton et al (2012) suggest, must move beyond task orientation and be given opportunities to develop as leaders. This would include role modelling, challenging sociocultural values which tolerate inadequate resources to care for older people, entering into a dialogue and advocating in the policy arena and in organisations, and understanding regulations and where barriers can be challenged (Siegel et al 2012).

Coming back to the level of care-giving and care-receiving, a final criticism of Kitwood's work is his emphasis on other people holding people with dementia in relationship as a way of sustaining personhood. Davis (2004) in a paper exploring the sociological and philosophical constructions of dementia suggests that the emphasis on relationships as a means to sustaining personhood and self as described by Kitwood (1997) has negative repercussions for carers and families. He suggests that they may feel a burden of guilt if they feel the person no longer exists and that they are responsible for the dissolution of their personhood by failing to hold them in relationship, which in turn prevents the initiation of the grieving process. He suggests that legitimacy should be given to the views of carers who no longer recognise the person with dementia as the person they once were. Davis (2004) suggests that:

‘While it is imperative that the sufferer is treated with dignity until the close of life, the relatives would be better to be removed from this final process. For then they might be allowed to determine with courage that there is nothing left of their past together in a way that grants them an opportunity to mourn’. (Davis 2004 p.378)

⁸ McGilton et al (2012) is about nursing but the competencies in care homes without nurses also requires consideration.

Gilleard & Higgs (2000) suggest that the 'mortality of the mind' may be very resistant or unyielding to any attempt, as that made by Kitwood (1997), to blur, redefine or transform its meaning. They too give a warning about the consequences of attempts to 'recivilise' dementia in that the burden of responsibility may be placed on *individuals* such as family members rather than paying attention to the malignant social psychology embedded within institutions and wider society.

Davis' solution of simply removing the relatives from the final stages of the life of a person with dementia is contentious. Nor indeed is it an option for those who are paid to care for people with advanced dementia. Admittedly the situation of paid carers is different from family carers who have known the person over a lifetime and will be acutely aware of losses. Nevertheless, paid carers' understanding of personhood has far reaching implications for people with dementia. Lyman (1993) in an ethnographic study of Alzheimer's day care centres found that both care providers and care recipients are 'wounded birds, whose daily work revolves around loss, uncertainty and the struggle to stay in control and be understood by others' (Lyman 1993 p185/186). A link between caregiver well-being and the quality of compassionate care is recognised (Maben et al 2012). Nolan et al (2004), while sharing Kitwood's aim of enhancing the inner subjective state of the person with dementia, extend this to the inner subjective state of the family and carers and a shift from emphasising individualism to relationship-centred care.

2.7 Relationship-Centred Care

In the context of institutional care, Nolan et al (2006) highlight limitations in person centred care as described by Kitwood and also more recent developments of the approach (McCormack 2004). Quoting Brechin (1998a), Nolan et al (2006 p.32) suggest that 'care is centred around interpersonal relationships which impact on the identity and sense of self of everyone involved.' They advocate relationship-centred care which validates both those receiving and giving care. Putting an emphasis on relationship-centred care creates a paradigm shift, moving the focus from just being on the person with dementia to creating an 'enriched' environment in which the support needs of the staff as well as the family are kept upfront alongside those of the

person with dementia. Nolan et al (2006) have developed and empirically tested the Senses Framework in an extensive longitudinal study involving qualified nurses, student nurses, older people and family carers. They suggest that all parties, the person receiving care, family carers and paid carers should experience relationships that promote a sense of:

- Security – to feel safe
- Belonging – to feel part of things
- Continuity – to experience links and connection
- Purpose – to have a personally valuable goal(s) to aspire to
- Achievement – to make progress towards these goals
- Significance – to feel that ‘you’ matter as a person (Nolan et al 2006 p.8).

The fundamental premise is that good care which is relationship-centred can only be delivered when the ‘senses’ are experienced by all parties (Ryan et al 2008).

Many UK care homes have a problem with a high staff turnover which undermines efforts to develop practice and establish caring relationships; the average turnover rate is just under 20% and rising (National Care Forum 2014). Nolan et al (2006) suggest that the Senses Framework, in conjunction with a relationship-centred model of care, has the potential to provide greater therapeutic direction for staff working in such settings. Focusing on the Senses Framework may help to understand how care work can become more satisfying and rewarding, and make it more possible for care workers to support the selfhood of people with dementia without them(selves) being consumed or burned out in the process.

It has been shown that organisations which create caring environments and focus on relationships have higher patient and staff satisfaction and productivity (Koloroutis 2004). The three crucial relationships Koloroutis (2004) identifies are care providers’ relationships with patients and families, care providers’ relationship with self, and care providers’ relationships with colleagues. This builds on work from the United States which suggests that current healthcare systems fail to acknowledge the

importance of relationships as the foundation of any therapeutic or healing activity (Tresolini et al 1994). Relationship-centred care is in keeping with the recommendations of the Nuffield Council on Bioethics (2009) which suggests that caring for people with dementia includes caring for the carers, and that more research is required on how health and social care staff can best be supported as they provide care which genuinely respects the personhood of everyone with dementia.

McCormack et al (2012) recognise the value of making explicit the centrality of relationships, which the framework of relationship-centred care brings, although they see this more as a shift in language rather than being different to person-centred care; McCormack et al (2012) argue that, conceptually, relationships are a key part of the philosophy of personhood and person-centred care. Hughes et al (2008), in examining the themes inherent within different types of 'centredness' in healthcare (including person-centred care and relationship-centred care), found that at the level of content they overlap significantly.

In practice, relationship-centred care has faced similar challenges to person-centred care in terms of overcoming barriers in local contexts and from wider socio-political forces (McCormack et al 2012, Venturato et al 2011). Adams (2005), while agreeing with the importance of relationship-centred care, suggests the Senses Framework does not provide sufficient conceptual or analytical understanding of 'relationships' and does not describe fully how good relationships develop or are maintained within dementia care triads. Triads are made up of the person with dementia, one or more family carers and a professional carer.

Adams & Gardiner (2005) describe two types of communication within triads with people with dementia. Firstly, enabling dementia communication occurs when family and professionals help the person with dementia express their wishes and see them as being able to do so. Secondly, disabling communication occurs when they prevent the person with dementia from expressing their wishes or see them as being unable to do so. The authors liken this to malignant social psychology with broad implications which extend beyond the sense of self to the position within a triad and within wider

society. They suggest that the experience of people with dementia and their carers is continually being socially constructed through the interplay of conversational and social practices undertaken by dementia care triad members. Work done to date by Adams and others such as Forbat (2003) has been with people with early or mid-stage dementia.

Ryan et al (2008) have used the Senses Framework as an analytical lens to understand factors which help achieve successful respite care for people with dementia, carers and support workers. In responding to the criticisms posed in the above paragraph, they suggest their findings illustrate that the Senses Framework does in fact show how good relationships develop within dementia care triads. The Senses Framework has also been developed in other ways. To enhance care in care homes, Brown-Wilson et al (2013) found that developing residents' biographies was useful in supporting staff to create a sense of significance and continuity for people living with dementia in care homes. In the context of family support in end of life care, Nolan & Ryan (2011) suggest the 'Senses' can be applied in the way shown in Box 1 below:

Box 1 'Senses' enabling relationship-centred care (Nolan & Ryan 2011)

- Sense of Security: for both carers and staff to feel safe to raise difficulties and sensitive issues in a supportive and facilitative environment
- Sense of Belonging: for both carers and staff to feel part of a valued group who share similar values and beliefs
- Sense of Continuity: to be able to establish relationships over time and to be able to relate the current situation to both the past and the future
- Sense of Purpose: to recognise the complexity of end-life-care for family carers and to work actively with them to prepare them for their role and their loss, now and in the future, to enrich their remaining time with their loved one and to reduce the latter's suffering and to enhance the positive aspects of caring
- Sense of Achievement: for the above to be seen as important and valued outcomes of care
- Sense of Significance: for end-of-life care with family carers to be seen as valued and important, something that really 'matters'

The extensive work involved in developing the Senses Framework (Nolan et al 2006), I think, provides a convincing argument for its usefulness in considering the conditions required for relationship-centred care to occur. It is returned to in Chapter Eight Section 8.5.3, where it is developed to incorporate the findings from this study.

A small amount of empirical work has explored the nature of the caring relationship in care homes, highlighting different types and functions of relationships. Studies which provide useful insights are now examined.

2.8 Relationships in Care Homes

Brown-Wilson et al (2009) using participant observation, interviews and focus groups with staff, families and residents in three care homes identified three types of relationships:

- First, pragmatic or functional relationships were those that focussed on the task of delivering care
- Second, personal and responsive relationships were those that focussed on understanding the resident as a person. This could occur during care delivery or outwith care delivery in more social encounters
- Third, reciprocal relationships recognised that staff, residents and families were part of a wider community so the focus shifted beyond the resident to recognise the needs of family members and staff. This type of relationship included negotiations between staff, residents and families which demonstrated an understanding and appreciation of each other's needs, which in turn made communal living more achievable

The importance of understanding and valuing everyday caring routines as an important starting point for developing positive relationships, and not simply as mechanisms for meeting the needs of the organisation, was a key finding of this study (Brown-Wilson et al 2009). The nature of these interactions greatly influenced relationships in the care home more generally. Residents also sought interactions which did not just focus on their needs or problems but were more social in nature, focussing rather on sitting down and chatting (Cook & Brown-Wilson 2010). Brown-Wilson et al (2009) found that while residents and families did actively make contributions to relationships, staff needed to provide opportunities for, and acknowledge these contributions if relationships were to develop. When residents shared personal information it was found that interactions moved from focussing on the task of care, to an opportunity for social exchange (Cook & Brown-Wilson 2010). Declining cognitive skills were seen as a barrier. This is particularly pertinent for people with advanced dementia as this will require an approach which includes

attending to non-verbal communication within a context where people with dementia are seen as being able to contribute to a meaningful relationship.

McGilton & Boscart (2007) conducted interviews in two long-term care facilities and found that care providers, residents and families had different views about what a close relationship entails:

- Care providers valued reciprocity, being appreciated and emotional connection with residents
- Residents valued care-providers acting as their confidants
- Families valued the actions staff took to present a caring attitude and transmit a genuine sense of concern for their relative

The study also found a lack of resources to nurture relationships in terms of time and staffing levels matching the increasing complexity of care and workload levels.

Another study with care providers identified that touch, mutual confirmation and care-givers' values were important in caring relationships with people with dementia (Rundquist & Severinsson 1999).

In a study which identified a positive association between care provider's positive relational behaviours⁹ and the positive mood and affect of residents with dementia, it was found that the most effective relational behaviours were most often observed during interpersonal interactions where direct care was not being provided and that positive relational behaviours were much more challenging for care providers during direct care activities such as mealtimes (McGilton et al 2011). McGilton et al (2011) suggest that conceptually this is important as it indicates which situations present challenges to care providers' ability to relate well.

⁹ Positive relational behaviours were defined in 3 domains:

1. Staying with the resident during the care episode
2. Altering the pace of care by recognising the person's rhythm and adapting to it
3. Focussing the care beyond the task

Bowers et al (2001), in interviews with nursing home residents, found that as people became physically frailer their description of quality care became more focussed on maintaining physical comfort. This required attending to very small and often invisible bodily changes which staff often did not notice. In the context of advanced dementia, where physical frailty is increasing and the person may not be so able to verbalise what will make them comfortable, even closer attention to bodily cues will be necessary. It is in the context of relationships that these subtle changes as signs of 'well-being' or 'ill-being' can be recognised (Dewing 2002).

The Namaste Care Programme seeks to engage people with advanced dementia through compassionate care, sensory stimulation, shared activity and increased social interaction¹⁰. In an action research study in six care homes it has been shown that in care homes with strong leadership, adequate staffing and good nursing and medical care, Namaste Care can improve the quality of life by reducing behavioural symptoms (Stacpoole et al 2014). Including families in the programme helps to support families through the realities of disease progression, while providing opportunities for families to recognise aspects of their relative which persist and provide opportunities to engage in meaningful ways during visiting.

Beginning to emerge in the empirical work on care practice and relationship-centred care, as described above, is an engagement with the concept of, and persistence of, personhood as core to caring relationships. In the context of advanced dementia the concept of personhood requires further attention within relationship-centred care. How the concept of personhood is understood within care-giving/care-receiving relationships where the quality of the relationship between the care giver and care receivers, who are living and dying with dementia, is central, and is what my own research aims to address. As Hughes (2013a) urges, we could dismiss the philosophy

¹⁰ Up to eight residents spend two hours in the morning and two hours in the afternoon, seven days a week in a dedicated Namaste space with an assigned Namaste worker. A calm ambience is created with music, scents and greenery. Elements of the programme include the presence of others, pain management, sensory stimulation, food treats/hydration, meaningful activity, life story, care staff education, family meetings and care of the dying. The afternoon session follows a similar pattern with varied activities. (Stacpoole et al 2014, Thompsell et al 2014).

of personhood as too theoretical if it weren't for commonly heard comments such as 'he's not the person I married' and the persistent reports of poor quality dementia care in hospitals and care homes. Rather:

'Personhood is a philosophical concept and one that underpins legal theory: but it is more than conceptual because the standing of the person is a brute fact of health and social care as well as legal practice (Hughes 2013a p.5).

McCormack et al (2012) suggest that if nurses, and no doubt this must include all those working in health and social care, do not have an understanding of the concept of 'personhood' then the essence of personhood will be lost in the zeal to implement particular models or frameworks such as person-centred care or relationship-centred care. Hughes (2011) suggests that to get to the 'essential' person is not about models of care but to stand in the right relation with the person. This is described as making our human encounters matter in an authentic way.

Hughes (2011) introduces the idea of the Situated Embodied Agent view of personhood as a way of standing in right relation to people with dementia. Drawing on the philosophy of Heidegger (1962), Hughes uses the terms 'Being-in-the World' and 'Being-With' to elaborate on the idea of human persons being *situated* in the world with other people in a particular place, in a particular social and cultural setting and at a particular time in history. He talks about human persons as being embodied, drawing on the work of Kontos (2003, 2004). A key element of Kontos' (2003, 2004) phenomenological view of human beings is their bodiliness; we are in the world through the vehicle of our body. Kontos focuses on embodied selfhood, bodily know-how and gestural significance (which is a sign of *agency*) persisting in those even with advanced dementia.

2.9 Embodied Selfhood

Kontos (2003, 2004) critiques the social interactionist and social constructionist formulations of self, as described by Kitwood and Sabat respectively, which conceptualise the generating source of personhood as the presence of others. She suggests that their view, whereby personhood emerges in the social context,

potentially relegates the 'body' to a symbolic position rather than guaranteeing personhood. Kontos (2005) even suggests that when the body is seen exclusively as a medium through which to access selfhood, for example, through non-verbal means such as touch, this denies the body any intentionality or agency apart from cognition; this means the body is given instrumental status only, making the assumption that the body is passive and a mere container for the self rather than a constituent of the self.

Kontos (2003, 2004) conducted an ethnographic study of 13 residents with moderate to advanced Alzheimer's disease in a Canadian long-term care facility. She describes how she saw residents aware of their surroundings, engaged with the world, acting and interacting with purpose and meaning despite cognitive impairment. She suggests that her observation of 'selfhood' persisting in the face of severe cognitive impairment is because selfhood resides in corporeality, or in the body. She explores what she considers to be the corporeal source of these aspects of personhood by drawing on the philosophical theory of Merleau-Ponty (1962) and Bourdieu's (1990) sociological theory on the logic of practice, focusing on his concept of habitus.

Firstly, drawing on the work of Merleau-Ponty, she suggests an innate or primordial origin of selfhood emanates from the body's power of natural expression and manifests in the body's inherent ability to apprehend and convey meaning and show intentionality in bodily movements (Kontos 2003, 2004). She describes how the pre-reflective body is directed towards the world without requiring reflective understanding of the manner in which it is directed; for example, drawing on the illustration given by Merleau-Ponty (1962 p.105), if we are stung by a mosquito we do not need to look for the itchy spot but can find it right away, reaching with a 'phenomenal hand'¹¹ to the correct spot on the 'phenomenal body'. Or babies, in their first attempt to reach for an object, do not need to look at their hand but at the

¹¹ Merleau-Ponty called our pre reflective being-in-the world 'perception' or embodied consciousness. Phenomenology in his view is a description of 'perception' or of the world as perceived. Merleau-Ponty did not see the human subject as a detached ego or consciousness as in the Cartesian view but part of the world they experience and actively involved in it as a body-subject (being-in-the world) (Matthews 2002).

object (Merleau-Ponty 1962 p.149). The body 'knows' how to perform; it does not rely on cognition (Kontos 2005).

Kontos (2003, 2004) observed in her study that movements of the body, facial expressions (smiles and frowns), eye behaviour (blinking, winking, direction and length of gaze and pupil dilation) and posture all carry implication and meaning:

'they played a large role in inter-personal communication and often conveyed praise, blame, thanks, support, affection, gratitude, disapproval, dislike, sympathy, greeting or farewell...and were intentional, communicative, informative and interactive' (Kontos 2003 p.835).

Kontos (2003, 2004) says this shows that people in the later stages of dementia continue to experience and engage with the world and people around them and can engage mutually with others at a *pre-reflective* level.

Merleau-Ponty (in Zeiler 2013) describes how repeated motor activity can result in certain actions or patterns of behaviour becoming 'sedimented' in our bodies. The body is a living memory pad with the active presence of the past within it, demonstrated in Kontos' study by the performance of religious rituals. Memory is not confined to the brain but is embodied in the muscles, nerves and sinews of the body (Kontos 2006).

Swinton (2014) also describes how in worshipping with forgetful people with dementia, sharing in the Eucharist or greeting each other with the peace of Christ, he realised that the habit of a life time of Christian worship is inscribed or sedimented in the body and does not depend on cognitive abilities. This is the opposite of Cartesian duality where the mind and the body are seen as separate.

As well as drawing on the philosophical theory of Merleau-Ponty, Kontos (2003) draws on the sociological theory of Bourdieu (1990), particularly the concept of *habitus*, to explain embodied selfhood:

Habitus comprises dispositions and forms of know-how which function below the threshold of cognition and are enacted at a pre reflective level (Kontos 2003 p. 841)

A socio-cultural lens suggests that the body is in the social world and the social world is in the body. Kontos (2003) describes the way that ‘selfhood resides in bodily dispositions that are acquired, for the most part, in the structured social context of one’s upbringing, with selfhood manifesting in one’s gestures and behaviours’ (Kontos 2003 p. 174) - for example, etiquette and class distinction. The writer Alan Bennett captures this starkly in his description of his Auntie Kathleen who has dementia:

‘Surrounded by the senile and the wrecks of women as hopelessly, though differently, demented as she is, she still clings to the notion that she is somehow different and superior. Corseted in her immutable gentilities she still contrives to make something special out of her situation and her role in it... This is my chair. They always put me here because this corner’s that bit more select’ (Bennett 2005 p.87-88)

Kontos, therefore, distinguishes between primordial (Merleau-Ponty) and socio-cultural (Bourdieu) aspects of selfhood visibly embodied in her study participants. She then argues that the primordial and socio-cultural aspects of corporeality endow selfhood with an observable coherence and capacity for improvisation and spontaneity. When propensities and movements of the body are attended to, coherence and distinctiveness and significant gestures which are signs of agency can be discerned in people with dementia (Kontos & Martin 2013).

Kontos (2003) is not suggesting that her theory of embodied selfhood, as just described, is a substitute for the mind or relationships (and I would also add the spirit) but that, if we fail to pay attention to the embodied nature of human existence as a fundamental aspect of our humanity, then ‘we ignore a vital aspect of personhood that persists for those with dementia’ (Kontos 2003 p.193).

Kontos recognises that the social interactionist and social constructionist foundation of much dementia care, as influenced by Kitwood and Sabat, where the origins of

self are guaranteed through social interaction, are a crucial critique to the predominant paradigm that dementia leads to the loss of selfhood (Fontana & Smith 1989, Davis 2004). However, Kontos argues that the social interactionist and social constructionist views of selfhood are too narrow a discourse on selfhood and are flawed; even in the absence of social interaction, selfhood persists by virtue of its corporeal nature and that to overlook embodied selfhood is to fail to embrace fully the personhood of people with dementia. Crucially, people with dementia, even in the advanced stages, can convey their subjective state and bring a degree of intentionality and creativity to social engagement because of their embodied nature. Even in the absence of cognitive impairment, the pre-reflective body is fundamental to the whole of selfhood. Kontos suggests that this is ignored in the social interactionist and social constructionist view, although this is not to say that isolation does not undermine selfhood.

Importantly, Kontos (2005) suggests that if embodied selfhood was recognised in everyday life and in caring environments, meaning would be attributed to a greater range of behaviours. This would broaden the scope and opportunities for the development of relationships and act as an important counter to social death.

Although the people in Kontos' (2003, 2004) study had moderate to advanced Alzheimer's disease and some were physically frail, she does not explicitly address the issue of the failing, dying or dependent body and the impact on embodied selfhood.

2.9.1 Embodied Selfhood and the Failing or Dying Body

Lawton (2000), in an ethnographic study of dying cancer patients in a hospice setting, studied the theoretical relationship of the Western self to the 'body'. She begins her exploration of the dying process by describing how the 'body' is part of an individual's self identity and that selfhood/personhood is fashioned and expressed through the medium of the body. She cites a number of studies which recognise that the body can become a problem in illness and old age because of the current emphasis on the body being constitutive of self, thus contributing to the rise in anti-

ageing technologies. However, she suggests that the exact impact of bodily deterioration on selfhood has not been explored.

From her observations of the effects of advancing cancer, she suggests that for selfhood to be maintained, in the context of contemporary England:

‘certain specific bodily capacities and attributes must be possessed: the most important being a bounded, physically sealed, enclosed body... and also the bodily ability to act as the agent of one’s embodied actions and intentions’ (Lawton 2000 p.7).

Lawton suggests that bodily deterioration is implicated in the process which leads to social death. She describes in harrowing detail the disintegration of the body from particular forms of cancer which result in the uncontrolled leakage of bodily fluids. She concludes that as the person with cancer loses the bodily attribute of boundedness and, as a result, agency of their embodied actions, they ‘fall out of the category of personhood’ (p7) and that those caring for them are left caring for a mere body and not a person.

Merleau-Ponty’s (1962, 1968) theory on the body is helpful in countering Lawton’s argument in ways that are important for people with dementia. Merleau-Ponty talks about how:

‘Objects are ‘in the world’ in a perfectly straightforward sense, the same sense in which biscuits are ‘in the tin’: that is, they are spatially contained in it. But the sense in which experiencing subjects, such as ourselves, are ‘in the world’ is different’ (Merleau-Ponty cited in Matthews 2002 p.48).

Merleau-Ponty (1962 cited in Matthews 2002 p. 55) suggests that a person is an experiencing subject and that, in order to be the subject of experience, they must be ‘an embodied person, a human being rather than a mere mind’. He says that:

‘...to be a ‘self’ is to be a living creature that is in the world through the vehicle of one’s body’ (Merleau-Ponty cited in Matthews 2002 p.69).

This is what Merleau-Ponty refers to as a body-subject: ‘Our bodies are both objects in the world, which can be perceived like other objects, and at the same time the means by which we perceive things’ (Matthews 2006 p.166). For example, when my right hand touches my left hand while it is touching something, for example a woolly blanket, my left hand is a feeling subject (sentient or phenomenal - feeling the woolly blanket) and also an object that is being touched by my right hand (sensible). Also, when we shake hands with another person, we at the same time feel ourselves touched as well as touching. The body is, at one and the same time, a phenomenal body and an objective body. Merleau-Ponty (1968) says that our body is a being of two leaves: ‘from one side a thing among things and otherwise what sees and touches them’ (Merleau-Ponty 1968 p.136). The term he uses to describe this crossing over is ‘the chiasm’ (Merleau Ponty 1968 p.257).

This is important for people with dementia within the theory of embodied selfhood; illness and decline and death are part of being a person, so bodily deterioration in itself does not in a philosophical or moral sense make us less human (Dekkers 2010).

Lawton (2000) found that from the perspective of the cancer patients in her study, being dependent on others for immediate bodily care led to a loss of selfhood. When patients reached this stage, their death followed shortly afterwards. This is consistent with the typical dying trajectory of someone with cancer where rapidly declining function is closely followed by death; there was an association between readiness to die, giving up on life and a loss of selfhood. This may be different in dementia and indeed other conditions, where low function and dependency can last for years. This presents challenges for supporting selfhood for those who are physically dependent over a long period of time. A more nuanced examination of the link between the body, selfhood and dependency is required in the case of people dying with dementia in care homes.

Even if the body is falling apart and becoming dependent on others, which in reality is the case with all human beings, particularly at the end of life, the fact that we can only live in and through our body means that our status as a person, a subject and not an object, is a given while we are alive; we continue to be a person who experiences and responds to the world. As Benner & Wrubel (1989) suggest:

‘The notion of the body as a way of knowing and as integrated with the mind can have profound implications for the care of the body during extreme breakdown. In this view, the body is not ever an object, the body is continuous with the person. This should have a profound impact on our treatment of the body and in providing messages of comfort and activity through the care of the body.’ (Benner & Wrubel 1989 p.53)

Body work is paid work that focuses directly on the bodies of others: assessing, diagnosing, handling, treating, manipulating, and monitoring (Twigg et al 2011). It is a core part of the care-giving/care-receiving relationship within health and social care. Within social care Twigg (2000) suggests that body work has become silenced and hidden, despite being a central dimension of carework, because to emphasise the body as against the person was seen to diminish the individual and to lessen and reduce them as social beings. An understanding of selfhood and whether the person receiving care is understood to be an object of care or an experiencing body-subject is vital, yet this has received very little analytical attention in dementia care empirically.

Jenkins (2013), drawing on Weiss (1999), identifies limitations in the concept of embodied selfhood as described by Kontos; he points out that while Kontos’ work is useful in highlighting the pre-reflexive aspects of the self, it is important to remember that bodies do not exist in a pre-social state, but are constituted and experienced through socio-interactive behaviour. Kontos & Martin (2013) describe how recognising embodied selfhood means that behaviours that may have been previously overlooked become noticed, increasing the scope and opportunities for interpersonal relationships and improved quality of care and quality of life. Jenkins

(2013) and Zeiler (2013) develop this theory further, referring to the concept of interembodiment or intercorporeality.

2.10 Intercorporeal Personhood

Using the example of a joint musical activity between a person with dementia (Gladys) and a person without dementia (Naomi), Zeiler (2013) shows how Gladys, who has major difficulty expressing herself outside the shared space of intense musical activity involving singing and tapping out the beat of the music, can express herself through the joint activity together with Naomi

(<https://www.youtube.com/watch?v=CrZXz10FcVM>). Zeiler (2013) suggests that this results in intercorporeal capabilities which spring forth through and in the interaction, enabling individuals who cannot express themselves without support to do so in interactions. In the example used this depends on Gladys and Naomi having an openness to each other, perceiving each other's bodily expressions and responding, creating a shared space of dynamic intercorporeal engagement (Zeiler 2013). Zeiler (2013) describes this as intercorporeal personhood, a crucial feature of human existence and co-existence for all of us.

Zeiler (2013) does not suggest the merging of persons, but questions the assumption that capabilities, which it could be argued are necessary for personhood, are the property of one single individual only but rather *spring forth in joint activity*:

‘The joint activity makes it possible for the participants in the activity to qualify as distinct yet thoroughly relational persons because it allows both of them to express themselves as unique-subjects-acting-together in a joint fashion’ (Zeiler 2013 p139).

This draws on the philosophical underpinnings of embodied selfhood described by Kontos (2003, 2004) and combines it with, and gives a philosophical underpinning to, Kitwood's (1997) ideas of holding the personhood of people with dementia through relationship.

Zeiler (2013) does not pretend there are no losses in dementia but rather says it is possible to grieve *and* engage in activities that help others retain a fragmented

personhood. She suggests that dementia care should be organised in such a way that people with dementia can express themselves in interactions with others as persons. Jenkins (2013) suggests this dissolves the distinctions between the carer and the cared for and creates a 'we' which supports the selfhood of the residents and is rewarding for the care-giver and the care-receiver. This is different from the reviving or fixing of the premorbid self but creates an emerging new rich montage of selves.

In the context of body work, as distinct from social or pleasurable activities such as music making, it seems that the idea of intercorporeality becomes more complex. In the context of caring for dependent patients with cancer, Lawton (2000) describes how the body of the 'dependent' patient became assimilated into the 'I can' of the person who can act (the carer) thus creating a new corporeal unit. The body of the patient becomes enmeshed with the carers' own sense of self to the extent that the carer can feel 'trapped' by the immediate physical requirements of the patient and unable to live their own life or have time to meet their own needs. If resources are insufficient and care-givers must subordinate their own caring needs to those of the person they are caring for, for example the nurse who doesn't get any breaks during a shift, care-givers can become enraged about their own unmet needs (Tronto 1993).

While an understanding of intercorporeality can be harnessed in a positive way for people with dementia, each person in the care-giving/care-receiving relationship is affected by it. There is a need for care staff to be supported in caring for dependent people so that their own sense of self is not undermined or lost in the process, leading to burnout. This comes back to the importance of relationship-centred care as described above.

Kontos' (2003, 2004) study undertook observation in a care home during programmed activities, Jewish holiday celebrations, meal times and during unscheduled activities such as walking in hallways or sitting in living rooms. Empirical work is required to understand more fully the nature of embodied selfhood and intercorporeal personhood in the context of care-giving and care-receiving, particularly hands-on body work. This could form the basis of new insights into the lived experience of people with advanced dementia and their carers and provide a

more robust conceptual underpinning for relationship-centred palliative dementia care.

2.11 The Visibility of the Lived Experience

Care as practice involves more than good intentions. It requires a deep and thoughtful knowledge of the situation and of all the actors' situations, needs and competencies.....and a knowledge of the context of the care process (Tronto 1993 p.136/137)

This is important because it can expose the dynamics of care-giving and care-receiving and inform whether the perception of need at the 'caring about' and 'taking care of' level is accurate. If the local context is misunderstood, and the complexity of care-giving and care-receiving is underestimated, 'caring about' and 'taking care of' at a societal level will fall short.

It is now recognised that the subjective experience of those with mild and moderate dementia can be accessed, particularly when the focus is on feelings rather than facts (Wilkinson 2002, Hellstrom et al 2007). However, there are fewer examples in which the subjective experiences of those with *advanced* dementia are included. Inclusion of the perspective of the person with advanced dementia themselves is vital if we are to understand their experience of facing the end of their lives and the factors which would ease their suffering.

Understanding the subjective experience of people with advanced dementia requires standing in right relation to them as people and understanding them as Situated Embodied Agents (Hughes 2011). Matthews (2006) describes how the hyphen in the phrase 'body-subject' is important:

'The hyphen in the expression body-subject indicates that these two elements in what it is to be a person are not separate from each other: that being embodied affects the nature of human subjectivity; while being connected with human subjectivity has a bearing on the nature of the human body. A person is not a 'subject' loosely attached to a 'body', as in Descartes dualistic view of mind and body as separate and distinct things, but a unified being who expresses their 'subjective' thoughts, feelings and so on in bodily form – in

speech, in gesture, in behaviour, in interactions with their environment, both human and natural, and so on. Subjectivity exists, in this view, not in some kind of 'inner world', divorced from everything physical. Subjectivity exists in these physical expressions...A person seen as a body-subject is thus neither simply a piece of biological machinery, nor a pure consciousness, but a unity of the two: a consciousness that expresses itself through bodily activity and a body that is among other things a vehicle for expressing thought' (Matthews 2006 p.172/173).

People with dementia continue to experience and respond to the world and demonstrate affective or emotional responses: laughing, crying, expressing frustration and disappointment and showing signs of happiness, sadness, anger etc. (Millett 2011). The body is not merely a physical object amongst others but conveys meaning which derives from its connections to a person's life as a whole (Hughes et al 2006). This is very important for people with dementia as it means we have access to understanding their lived experience because it is *visible*, at least partially so.

Crossley (1995), drawing on the philosophical theory of Merleau-Ponty (1962, 1968) and the sociological theory of Goffman (1972), suggests that because human beings are all part of the same shared and mutually accessible world, subjectivity is not private and unavailable but worldly and publicly available through observation of behaviour. Through this our subjectivities are available to each other in a shared world. If this were not so we would only ever regard other people as objects in 'our' world. This challenges the assumption that the mind is an inner world separate from the body: it is possible, at least in part, to understand another's experience. Hughes (2011) suggests the significance of a human smile is what it is, because it is a smile on a human face. Hughes quotes the philosopher Wittgenstein: 'the human body is the best picture of the human soul' (Hughes 2011 p50). This challenges the Cartesian assumption that:

'The mind or subjectivity is a different substance to the body, is located privately within the body and is only directly available from within...by means of introspection' (Crossley 1995 p.142).

This has important implications for relationship-centred care for people living and dying with dementia. Empathy is ‘the ability to understand and appreciate another’s feelings and experience’ (Oxford English Dictionary 2014). The body mediates our access to the world (Benner 2000) therefore, we can understand and appreciate another’s feelings and experience in an embodied way. It does not depend on them telling us because we can see it in their facial expressions, body posture and behaviour such as wailing. Through the movements of the living body we can emphatically grasp something of the feelings of another person. This is called bodily empathy (Finlay 2006) and the foundation of this is the theory of intercorporeality; the overlapping of sentient – sensible beings which is the basic form of human being-in-the-world (Crossley 1995). While we must be cautious not to appropriate the ‘voice’ of people with dementia, projecting our own views onto them, drawing on the philosophical theory of intercorporeality offers a practical and humane way to improve the care of people with advanced dementia (Hughes 2013a). It would allow us to be open to engaging with people with advanced dementia, to ‘listen’ to their experiences and to respond to those who may be communicating suffering in the last stages of their lives and in their dying.

2.12 Conclusion

This literature review began by tracking the processes by which people with advanced dementia become *invisible* in their relationships and within care systems delivering palliative care. While the contributions of social psychological frameworks and person-centred care are recognised as important, relationship-centred care is argued to be a necessary development. More needs to be understood about how caring relationships which challenge social death can be sustained until the end-of-life within relationship-centred palliative dementia care which seeks to recognise and relieve suffering and promote quality of life until the end of life. A more robust theoretical underpinning which incorporates embodied selfhood and intercorporeality is required. The theory of embodied selfhood and intercorporeality is used to argue that people with advanced dementia continue to experience and respond to the world and those around them until they die and that an understanding of their lived experience, including their suffering, is possible because it is *visible*.

Recognition of this is fundamental to high quality relationship-centred palliative dementia care but a number of questions remain about how this theory translates into practice settings:

- How does the practice context of a care home shape relationship-centred care and the way selfhood is supported or undermined?
- How is embodied selfhood and intercorporeal personhood enacted in day to day life in a care home and in the context of body work?
- What is the role of embodied selfhood and intercorporeal personhood in ensuring people with advanced dementia remain active agents in their relationships until the end of life?
- What role does embodied selfhood and intercorporeal personhood play in relationship-centred palliative dementia care and how can this be developed?
- How can the theory of embodied selfhood and intercorporeal personhood inform a methodology to understand relationship-centred care from the perspective of people with advanced dementia towards the end of life and their carers in a care home?

3 Research Design: Researching the Care-Giving/Care-Receiving Relationship in the Context of Advanced Dementia

3.1 Introduction

This chapter describes the methodological approach used to examine the care-giving/care-receiving relationship between people living and dying with dementia and the care staff in a care home. The aim was to understand this from the perspective of both people with dementia and the staff caring for them, rooting this in the local care home context but considering how this might be shaped by the wider health and social care context in Scotland. While the overall aim was to examine the care-giving/care-receiving relationship in palliative dementia care, the following research questions were posed at the end of the previous chapter as gaps in current knowledge, and these guided the research:

Research Questions

- How does the practice context of a care home shape relationship-centred care and the way selfhood is supported or undermined?
- How is embodied selfhood and intercorporeal personhood enacted in day to day life in a care home and in the context of body work?
- What is the role of embodied selfhood and intercorporeal personhood in ensuring people with advanced dementia remain active agents in their relationships until the end of life?
- What role does embodied selfhood and intercorporeal personhood play in relationship-centred palliative dementia care and how can this be developed?
- How can the theory of embodied selfhood and intercorporeal personhood inform a methodology to understand relationship-centred care from the perspective of people with advanced dementia towards the end of life and their carers in a care home?

Crotty (1998) suggests that looking at recognised approaches and established theories and paradigms can help us build theoretical scaffolding for our research.

This research is informed by Merleau-Ponty's (1962, 1968) phenomenology of perception and his notion of intercorporeality, and also critical theory, which are now explored.

3.2 Phenomenology and Intercorporeality

Phenomenology is the study of how people experience the world. It was founded by Husserl in the 19th century but has been developed in diverse directions by others, including Heidegger and Merleau-Ponty (Hammersley 2004). Husserl tried to understand experience by focussing on pure consciousness by a process of 'bracketing' the objective existence of the world. Social scientists influenced by this branch of phenomenology seek to gain access to people's common-sense thinking and to interpret their actions and their thinking from their point of view (Bryman 2012). This branch of phenomenology is often used to understand the experience of living with an illness or receiving health care (e.g. Hardy et al 2014). However, its usefulness is limited in the context of advanced dementia as it usually draws heavily on interviews. The phenomenology I focus on, developed by Merleau-Ponty (1962, 1968), provides an alternative suitable for people with advanced dementia who have lost their verbal skills. Merleau-Ponty differed from Husserl in that he thought the life world is a pre-given or everyday world that is there before we experience it and cannot be 'bracketed'; Merleau-Ponty's phenomenology is about understanding rooted in ordinary lived experience. He views the human subject, not as a detached ego (as in the Cartesian view described in the previous chapter), rather that human beings are part of the world they experience and experience it in the course of active involvement in it pre-reflectively, before beginning to theorize about it. Merleau-Ponty did not see phenomenology as a retreat into pure subjectivity; he puts the human subject at the heart of the world and does not reduce the world to human thoughts about it:

'The phenomena with which human beings are presented in their experience are then no longer the contents of the inner self but are the things themselves as they appear not simply to me but to any human perceiver who occupies the same position' (in terms of historical epoch and social setting) (Matthews 2002 p. 40)

Merleau-Ponty (1962 cited in Matthews 2002) called our pre-reflective experience of being-in-the world 'perception'. Being-in-the-world, originally an Heideggerian concept, is part of a two way interaction between ourselves and the rest of the world. The world is more than a spatial container of our existence but the sphere of our lives as active, purposive beings who respond to it and act on it. The subject of experience must be an embodied person, a human being rather than a mere mind: a body-subject. This is important because it includes people with dementia with cognitive impairment who, as explained in the previous chapter, continue to inhabit and experience the world and the people around them in embodied ways. This raises the possibility of being able to understand the experience of another without them being able to tell us about it. This leads to the notion of intercorporeality.

The root of intercorporeality is that we live in a shared visible world. Merleau-Ponty (1968) uses the example of a customs officer; when a customs officer recognises a traveller he has been given a description of, it is because we have a shared consciousness of the visible world which exists (Merleau-Ponty p.146 calls this 'the flesh'; the coiling over of the visible upon the seeing body). There is coherence between what we see and what others see. This allows us to be open to visions other than our own, things we have not seen but are described to us by someone else.

Crossley (1995) gives another example:

'If I see a chair it is not the case that there are two chairs ie. one in the external world and one in my mind's eye. There is one chair and I see it. In this sense my perceptual field is not an inner, private realm. It is the possibility of my participating in a common visual space. If the other person sees the chair I see, it is not that there are three chairs, not two. There is one chair that we both see. We share in a vision. We participate in an 'intermundane space' which does not belong to either of us as such but to which we ourselves belong as visible beings. (Crossley 1995 p.144)

Merleau-Ponty (1968) says that the human body as a visible thing is contained within the full spectacle of all visible things and describes an intertwining of one with the

other. This has important implications for how we see other people, including people with dementia. When we look at a person with dementia and they look at us:

...we belong to the perceptual field of the other and they belong to ours simultaneously without this involving two separate worlds or planes of reality. I must be simultaneously the perceiver and the perceived and so too must she. This intertwining or 'chiasm' is the basic form of intercorporeality... the basic form of human-being-in-the world. (Crossley 1995 p.144)

Chatterji (1998 p.358), in an ethnographic study of a person with dementia writes that 'For me he becomes a voice through our interactions together, face-to-face'. If a person with dementia is smiling we can see they are happy, if they are crying or unsettled we know they are suffering; we know what we are looking at because we live in a shared visible world which has coherence. Using Merleau-Ponty's philosophy of phenomenology and intercorporeality to underpin this research design means I can have access to, and understand something of, the lived experience of people with dementia and care staff within the care-giving/care-receiving relationship which I am able to share with others.

3.3 Critical Theory

Critical theory as a philosophical stance originated in the Frankfurt School of social theory in the 1950's. The critical tradition is evolving, supporting the ideologies of many critical theorists (Kinchloe & McClaren 2000). They share a common view that the constructed meanings within our cultural inheritance support particular power structures, resist moves towards greater equity, contributing to oppression and injustice (Crotty 1998). 'Actors' may be unaware of the social structures which influence culture, but these structures will nevertheless influence how they act (Carspecken 1996, Georgiou & Carspecken 2002); while actors may act with volition, their actions are conditioned by a series of system relations (Smyth & Holmes 2005). Critical inquiry questions current ideology and discourse, and initiates action with the aim of social justice. It examines the ways that the economy, race, class, gender, ideologies, discourses, age, education, religion and other social

institutions and cultural dynamics construct a social system. It attempts to identify who gains, and who loses, in certain situations and practices which are enabling or restrictive (Kinchloe & McClaren 2000). Any research which aspires to be critical must be connected to an attempt to confront the injustice of a particular society or public sphere within it (Kinchloe & McClaren 2000). I was interested in undertaking a study which, as well as adding to understanding might also contribute to change. As such this project does not claim to be neutral; it seeks to serve the interests of people living, dying and working in care homes, marginalised and often mistrusted places within society (Becker 1967, Froggatt et al 2011). Critical theory is, therefore, a useful scaffold for this research because it provides a space to think about how care-giving and care-receiving in the context of dementia and care homes is mediated by wider social, political, cultural and economic factors.

3.4 Methodological Approach

Given the importance of understanding the ‘visible’ lived experience of people with dementia and those who care for them, as well as the impact of the care home context on relationship-centred care, it seemed fundamental to immerse myself in the everyday life of a care home to see what was happening; ethnography underpinned by an abductive research strategy was therefore employed. Abduction is a process by which the researcher enters the social world of the phenomena in question and generates social scientific accounts from everyday accounts. This is an interactive process involving the researcher in alternating periods of immersion and withdrawal for reflection and analysis, generating theory as an intimate part of the research process (Blaikie 2010) and linking this with practice. The different types of ethnography and the ethnographic approach I adopted are now described.

3.4.1 Ethnography

Broadly speaking, ethnography is where the researcher immerses themselves in a social situation and collects real world observations in a pragmatic, reflexive and emergent way and produces insights about actions and events placed in context (Greenhalgh & Swinglehurst 2011). Ethnographic research is a way of contextualising intellectual debates and involves an ongoing attempt to place specific

encounters, events and understandings into a fuller and more meaningful context (Tedlock 2000). Ethnography can fill in the gaps in everyday knowledge, making it real and specific, as well as undermining assumptions and stereotypes. The ethnographer does this by describing in detail, providing an informed analysis and interpretation and acting as a thoughtful and curious witness (Jepson 2012 Personal communication).

Traditional ethnography is a form of research that asks questions about the social and cultural practices of groups of people. Historically, ethnography was associated with colonialism, with researchers from dominant colonising countries collecting information and using it for power and domination. Contemporary trends in ethnography have shifted it from its colonial and positivistic roots and attempts are now made to take account of the social positioning of the researcher in relation to the research participants (Jordan & Yeomans 1995).

The recognition of the role of the researcher's 'self' as the research tool has meant that reflexivity now plays an important part in qualitative research practice including ethnography (Coffey 1999). Reflexivity in qualitative research is a 'continuous endeavour' (Gough 2003), whereby the researcher turns a critical gaze on themselves at all stages of the research process, to examine and make transparent how they, and intersubjective elements, influence and transform the research process and its outcomes (Finlay 2003, Etherington 2007).

The main criticism of contemporary ethnography is that it captures only the phenomena of everyday life, without understanding inner relations, causal processes and generative mechanisms, which may be invisible to actors. Subjective experience is everything and this can reinforce assumptions and myths. It assumes that only individuals exist and they construct their own reality. The underlying methodological influences on contemporary ethnography are symbolic interactionism and ethnomethodology which have been criticised for methodological individualism (Jordan & Yeomans 1995).

Institutional ethnography, as espoused by Dorothy E Smith (2006), is partly helpful in addressing this problem. Institutional ethnography begins with people's everyday lives but connects the micro social processes with the wider socio-political context in order to see how the everyday happens as it does. However, since it is the researcher's job to reveal the sources of power and domination, Jordan & Yeoman (1995) suggest that a tension in the power relationship between the researcher and the research subjects remain unresolved.

Critical ethnography seeks to understand actual practices and meaning but also to get beneath surface appearances and understand these in light of wider social structures, systems and ideologies. In critical ethnography, the researcher is not a neutral observer. Instead, they aim to challenge the status quo and transform the 'taken-for-granted', anomalies, contradictions and myths and address oppressive forces through dialogue, informing both the researcher and the respondents (Harvey 1990). This is in contrast to other forms of ethnography which presuppose a one way flow of information which leaves respondents in the same position after having shared their knowledge. In contrast, critical ethnography moves from 'what is' to 'what could be' by redefining a social situation (Hardcastle et al 2006). It begins with an ethical responsibility to address processes of unfairness or injustice within a particular *lived* domain and a compassion for the suffering of living beings (Madison 2005).

The marginalisation of people with dementia in their relationships leading to challenges in relationship-centred palliative dementia care in care homes is such a situation. However, I became aware of Appreciative Inquiry (AI) at a Royal College of Nursing Research Society lecture by Professor Brendan McCormack (McCormack 2011) entitled 'Human flourishing through nursing research and development: seeing, appreciating and making use of what is right in front of us'. The emphasis on being appreciative was appealing and I began to consider doing ethnography drawing on the principles of AI.

3.4.2 Ethnography with Appreciative Intent

Appreciative Inquiry (AI) is a form of action research within the participatory research paradigm and intentionally studies ‘what works’ in organisations based on the assumption that in any organisation, something works, aiming to explore how and why it works so that it can happen more often (Moore 2008). There is a small but growing body of work which suggests that within health and social care, proper systematic analysis of what works may be better at producing quality care than focussing on what needs to be fixed. A body of work is developing whereby AI is being used as a research framework rather than an organisational development tool (Reed 2007, Dewar and Mackay 2010).

Traditionally AI happens in four phases: discovery phase, dream phase, design phase and destiny or delivery phase (Reed 2007, Moore 2008, Dewar and Mackay 2010).

The essence of AI is that by intentionally focussing on the positive:

“It changes conversations and relational space that characterise the status quo by infusing intentionally worded, affirmative inquiries and focussing on narratives of success to explore some affirmative topic and release pent up energy and ideas that people have not felt encouraged or able to express previously” (Ludema & Fry 2008 p.291).

This is based on the social constructionist assumption that people invent and create their organisations and communities through conversations which create patterns of action and grow in the direction of what they most persistently ask questions about (Ludema & Fry 2008). Appreciative Inquiry intentionally focuses on transformation, by shifting the focus from ‘problems’ to ‘what works’.

The principles of Appreciative Inquiry are as follows:

- *The constructivist principle* – that words make worlds - what people talk about creates patterns of action and growth

- *The positive principle* – always starting with the positive because if you start with the problems you never get to what works
- *The anticipatory principle* which is building on the positive which is already occurring which then helps people to think about the future in a particular way which they are then more likely to move towards
- *The simultaneity principle* – the inquiry itself is an intervention because it can bring about change through different ways of thinking and doing
- *The poetic principle* – which is about bringing subjectivity and people's stories to the fore (Reed 2007)

I liked the idea of intentionally seeking to understand what was working in developing and maintaining relationships with people with dementia in the context of care-giving and care-receiving, how that happens, what motivates it, what sustains it and what challenges have to be overcome. But I still wanted to be inclusive of people with advanced dementia. Reed (2007) suggests it is possible to use the principles of AI without going through the AI cycles. I began to consider undertaking ethnography with an appreciative intent, although this was not something for which I could find an exemplar within the research methodology literature. The theory of intercorporeality illuminated a way forward.

In order to participate in the life of what is being studied, the role of one of the actors in the field has to be taken up and explored (Jenkins 1994). What emerged is that I took on the role, at least partially, of a care assistant, helping to feed and wash, sit with and walk with residents. As I took on this role, I realised that my own inter-embodied interactions with the residents centred around care were revealing and helped me not only to 'appreciate' the residents by getting to know them but also to appreciate what it was like to relate to them, what was difficult, and crucially, 'what worked'. I judged this by the way that residents responded, particularly their expressions, either verbal or non-verbal, of whether they seemed settled or distressed. My own 'phenomenal' experience of hands-on care was a way of getting *inside* the caring relationship, giving me some insight into the way that care staff

learn how to relate to residents and a basis from which to explore their experience in more depth. Tedlock (2000) describes this as a shift from participant observation to the observation of participation. This is a shift from an objectifying methodology to an intersubjective methodology which entails a representational transformation where ‘self’ *and* ‘other’ appear in the ethnographic narrative.

Working with the staff and residents in hands-on care gave me opportunities for understanding the phenomenology of caring and micro-noticing of practices which may have gone unnoticed by the staff (Dewar 2011). While there were some opportunities to discuss actions or ask questions in real time, these were limited by concerns about talking over the residents or taking the staff away from the residents; these often felt like ‘snatched’ conversations which did not quite finish. I found that time set aside for group and one to one discussion was necessary as discussed in Section 3.5.8.2.

Ethnography with an appreciative intent could pose a problem methodologically; by focussing on ‘what works’ it may seem to only give a partial account by ignoring problems (Grant & Humphries 2006). My aim was not to ignore things that were less good in practice but rather to gain a deep appreciation of what practice entails and to understand ‘what works’ within the context of care homes, while retaining a critical eye. This sits alongside a body of work on care in care homes and stands as a corrective to studies which focus on problems and barriers to good practice, which are well documented.

3.5 Methods

3.5.1 Choosing a Care Home

In the Scottish Census of Registered Care Homes in Scotland (Scottish Government 2009) 66.6% of care homes were independent (privately owned for-profit), 18.4% were run by the local authority or the NHS and 15% by the voluntary sector (not for profit). Table 1 below summarises the different ‘types’ of care homes and was used as a theoretical sampling frame in guiding the selection of a care home.

Table 1: Theoretical Sampling Frame of 36 ‘Types’ of Care Homes

Specialist Dementia Care Home									
	Independent			Local Authority/NHS			Voluntary Sector		
	L	M	S	L	M	S	L	M	S
With Nursing	1	2	3	4	5	6	7	8	9
Without Nursing	10	11	12	13	14	15	16	17	18

Non Specialist									
	Independent			Local Authority /NHS			Voluntary Sector		
	L	M	S	L	M	S	L	M	S
With Nursing	19	20	21	22	23	24	25	26	27
Without Nursing	28	29	30	31	32	33	34	35	36

Large=over 50 beds M=20-50 beds S=<20 beds

Initially, since the focus of my study was on dementia and palliative care, I aimed to recruit a care home with ‘nursing’, as this is where those with advanced dementia are more likely to live (Bebbington et al 2001, Goodman et al 2012). My inclusion criteria were:

1. Registered care home within the geographical area (to reduce travel costs)
2. Independent Sector – this represents the highest proportion of care homes
3. Care homes with ‘nursing’ and residents with a diagnosed dementia in the advanced stages and a specialist registration for dementia care
4. A willingness and ability to commit to the study from management and staff
5. Between 20-50 beds to enable wide inclusion of staff in a manageable way
6. Assessed as having a good standard of care by the Care Inspectorate (graded 4 or above on all quality themes including palliative care)

The Scottish Care Homes Directory (Scottish Care 2012) lists care homes in Scotland and records whether they have ‘nursing’ or not; this database was scrutinised, identifying 58 care homes within the geographical area with ‘nursing’, and 40 without ‘nursing’. I began the process of examining the Care Inspectorate reports of the care homes with nursing and between 20-50 beds. However, during

this time, through a contact with a fellow researcher, I had an expression of interest in the study from the Head of Older People’s Service of a large voluntary organisation providing specialist dementia care with two care homes within the geographical area. These care homes did not meet my criteria for having ‘nursing’; however I decided to explore further the statistics gathered by the Care Inspectorate on the number of deaths in care homes with and without nursing. The Care Inspectorate do not distinguish between care homes with or without nursing in the data they collect, but, using information from the Scottish Care Homes Directory (Scottish Care 2012), it was possible to distinguish them, although this was an approximation due to the fact that some care homes have mixed beds. A summary of these statistics are shown in the Table 2 below:

Table 2: Approximation of Deaths in Care Homes (all types) in the geographical area (Compiled from Care Inspectorate Statistics available by request)

	Care Homes with Nursing		Care Homes without Nursing	
	2010	2011	2010	2011
Deaths in Care Home	657	768	121	142
Deaths in Hospital	126	136	85	89
Total Deaths	783	904	206	231
Total Beds (Years show different numbers due to missing data)	2335	2916	1221	1281
% Deaths in Hospital	16%	15%	41.2%	38.5%
% Residents Dying in year (Total deaths/Total beds x100) (Assumes beds full)	33.5%	31%	16.8%	18%

The shaded area of the table shows that, in the two years examined, care homes with 'nursing' do indeed have a higher death rate than those without nursing; for example, in 2011 the death rate in care homes in this area with 'nursing' was 31%, compared to 18% in those without nursing, indicating a frailer population. What is also interesting is that these residents in care homes (with nursing) are much more likely to die in the care home than in hospital, with, in 2011, 15% of all care homes (with nursing) deaths occurring in hospital, compared to 38.5% of deaths in care homes (without nursing) occurring in hospital. However, one of the care homes who could potentially host the study through the voluntary organisation expressing an interest had death rates of 27.5% and 32% in the last two years which is comparable to that in care homes with nursing. All of these residents died within the care home. Its status as a specialist dementia care home may account for this higher death rate. The care home had 40 beds, met the requirement for a good standard of care in Care Inspectorate reports, and combined with the death rate, met the inclusion criteria. In Table 1 this care home would be classified as Type 17, meeting the criteria for theoretical sampling.

I met with the Head of Older People's Services of the Voluntary Organisation to explain the study and gain permission to approach the care home managers to invite them to participate. Throughout this recruitment process I stressed they had been approached because they had a good standard of care and expertise in dementia care and, therefore, provided opportunities to understand good practice. The head of the service granted me permission to meet the care home managers of Primrose Hill¹². The initial meeting with the manager and deputy manager was very positive and they were interested in being part of the study. Key to identifying their suitability for the study was that all their residents had a diagnosis of dementia and they wanted all their residents to die in the care home as opposed to hospital if at all possible. To me this indicated a willingness to engage with issues around palliative care and recognition of its importance. Also, some of their residents were in the later stages of dementia and others were frail and declining due to comorbidities.

¹² Pseudonym used from here on

It is important in these initial recruitment meetings that gatekeepers are given a clear and transparent explanation of the research objectives and the commitment required, as far as is possible within a research design which is evolving and dynamic, so that the initial process of informed consent can begin (McKillop & Wilkinson 2004, Dewing 2007, Bartlett and Martin 2002). The managers were given a folder of information including a summary of the study, the implications for the care home and copies of the invitation letter, information sheets and consent forms for all participants. A meeting was arranged for two weeks later, giving the managers the opportunity to be fully informed about the study before agreeing to take part.

At a second meeting with the manager, the procedure for safeguarding in the event of my witnessing bad practice was discussed (Goodman 2012 Appendix 1) alongside the mechanisms by which participants in the study would be given emotional support should any aspect of the study cause emotional upset, given the sensitive nature of the topic. At the end of this discussion the care home managers agreed to host the study and granted me permission to access the care home to recruit participants, both residents and staff.

3.5.2 Ethnography, Ethics and Incapacity in a Place called 'Home'

The Adults with Incapacity (Scotland) Act (2000) is an Act of the Scottish Parliament which safeguards and protects the property, finances and personal welfare of adults (people aged over 16) who are incapable due to mental disorder or inability to communicate. It allows a person, such as a relative, friend or partner, to make decisions on someone's behalf. The inclusion of Adults with Incapacity due to dementia within the study meant that ethical approval was legally required through the NHS Scotland A Research Ethics Committee (NHS REC) before I could begin fieldwork.

The study satisfied Part 5 of the Adults with Incapacity (Scotland) Act (2000)¹³ and ethical approval was granted (reference no. 12/SS/0116 Appendix 2). Ethical approval was also granted by the University of Edinburgh School of Social and Political Science. Research governance approval was granted by the City of Edinburgh Council. This is required because Local Authorities have a duty of care to residents of all care homes through their funding arrangements.

The use of ethnography, whilst justifiable in terms of my research questions and the opportunities it provides for not only hearing the voice but seeing the lives and interacting with the social worlds of people with dementia, did raise issues which needed to be negotiated with the NHS REC. Care homes are complex settings in a number of ways. Actors in this setting are the residents who live there, the staff who work there and the families or friends who visit. They are private spaces in that they are 'home' to the residents but are also a workplace and a place where a public service is provided and therefore, subject to outside monitoring and inspection, for example, from the Care Inspectorate and Social Work who have a duty of care to those they fund, (which in Scotland includes free personal care). Care homes, even those which are private, provide a publicly funded service and accountability is required. Research has a role to play in care homes, developing the evidence base as a means to ensuring good care of people in care homes. To neglect this, it could be argued, is an ethical issue in itself. However, negotiating the requirements of the NHS REC in this setting, with the added challenge of including people who lack capacity, and with a committee unfamiliar with ethnography as a research design, was not straightforward.

Three of the main guiding principles of the NHS REC are that research participation should be voluntary, that informed consent should be obtained prior to beginning the research and that no harm should be done. Some social scientists argue that, particularly in ethnographic research, the bureaucratic anticipatory nature of NHS REC makes ethnographic research almost impossible (Murphy & Dingwall 2007).

¹³ Part 5 of the Adults with Incapacity (Scotland) Act (2000) sets out the code of practice for the inclusion of adults with incapacity in research and the conditions which need to be met.

By anticipatory it means that the implications of the research, its methodology and the research questions can be anticipated in advance (Parker 2007). Some would argue that this is not possible in ethnography for the following reasons: the focus and design of ethnographic research is emergent; the extended period of time that ethnographers spend in the setting developing trusting relationships and negotiating participation where consent is a relational and sequential process rather than a contractual agreement; the nature and positioning of risk in ethnographic research; the power relationships between researchers and participants; and the public and semi-public nature of the settings normally studied in ethnographic research (Murphy & Dingwall (2007).

It could be argued that the magnitude of risk in observing the general organisational routine and everyday life in communal areas of a care home, one of the methods I used, is minimal or even negligible. I did not initially think I would require written informed consent for residents to be included in this aspect of the study. The NHS REC however made this a requirement. I complied with this after taking advice from experts at the National Institute for Health Research (Enabling Research in Care Homes Project) and personal communication with Professor Claire Goodman who manages a large care home project at the University of Hertfordshire (<http://www.evidem.org.uk/> 2014).

Burgess (2007) argues that the social dimensions of health research are important and the potential for harm, e.g. emotional harm, does exist and a perception of reduced risk is not a reason for reduced responsibility of researchers to seek informed consent. It is possible, through an invasion of privacy, to do moral wrong, even if physical or emotional risk is negligible. Schragg (2009) suggests that, if the distinction between harm and moral wrong is collapsed, there is a danger of ethnographers overlooking the moral significance of the invasion of privacy and the effects of inflated insight that can come about through the research process and subsequent publications. Because care homes are private spaces as well as public spaces, the potential for imposing on someone's privacy increases the potential for moral wrong.

Bureaucratic anticipatory ethical review however, also is limited, particularly in the context of including people with dementia. Richardson & McMullan (2007) suggest that a more appropriate ethical theory is virtue ethics which shifts the emphasis from ‘what should I do?’ to ‘what sort of person should I be?’ emphasising ethics as process. This agrees with the work of Dewing (2007) on particularistic inclusionary consent, and also Guillam & Gillam (2004) on ‘ethically important moments’, and leads to person-centred research practice. There is no evidence that ethics committees do lead to more ethically conducted research and Parker (2007) calls for more empirically informed bioethics.

Bureaucratic informed consent is intended to allow research participants to make their own assessment as to whether taking part in research is in their best interests. In the context of adults who lack capacity to consent this becomes more complex. Paternalistic attitudes of ethics committee in their efforts to protect vulnerable adults may actually exclude the very people who would benefit most from taking part in research by leading to an inadequate evidence base for their care or a poor understanding of their lived experience. The exclusion of people with dementia from research can occur through the cumbersome paperwork which is beyond what staff in a care home can cope with. Proxy consent in itself is not always reliable as it assumes that an individual’s values are known and understood by another person (Buchanan & Brock 1989 cited in McCormack 2003). The values of those on research ethics committees perhaps also need to be scrutinised as they may be influenced by a ‘hypercognitive culture’ (Post 2000) and hold reductionist views of dementia as being a disease which is the ‘very splintering of the sedimented layers of being until ultimately there is nothing left (Davis 2004: 375). They may, therefore, not see the value of including people with dementia in research. This was not my experience and indeed the Adults with Incapacity (Scotland) Act (2000) should protect against this.

My own view is that research ethics documentation can be used in a positive way to build respectful research relationships in the ethnographic tradition when researching health and social care settings in the UK where documentation is already part of the culture and expected. If there was no documentation this may be a cause for alarm.

Boulton & Parker (2007) suggest that participants may see consent procedures as signals of regard and of respect for autonomy and as evidence of good governance which contribute to their confidence in the institution and trust in the researchers, giving them a sense of security about the study. My own experience is that while some explanation was required of the need for participation to be voluntary, and for written informed consent, these principles were quickly grasped and were seen as a safeguard by managers although less so by care staff who seemed more suspicious. The way these particular relationships were negotiated is discussed further in Section 3.5.6.

Researchers have a responsibility to protect the organisations they work in from complaints and in the care home setting this includes ensuring all stakeholders are fully aware of and informed about the research and have the opportunity to withdraw if they so wish. The transparency it brings may minimise suspicion and prevent misunderstandings and is a way of gaining trust and support from care homes who may not be used to taking part in research (Vass et al 2003). The NHS REC review can be considered to be preventative ethics, aiming to anticipate and divert potential problems. However, it is only a first step.

As Murphy & Dingwall (2007) point out, the successful execution of ethnographic research depends on establishing and maintaining a long term relationship of trust with research hosts and negotiating ongoing consent which can be a fragile relationship which may be under jeopardy as the research unfolds. Continuing data collection depends on on-going cooperation and negotiation of consent is continuous. Satisfying the ethical committee is not the be all and end all of ethical practice, nor does it address unanticipated ethical dilemmas (Murphy & Dingwall 2007). The ways in which I negotiated the three guiding principles of the NHS REC in the field are now discussed.

3.5.3 Gaining and Maintaining Informed Consent from Participants

3.5.3.1 Residents

All residents were eligible for inclusion in general observation. The criteria for selecting residents for focussed observation (described in Section 3.5.8.1) are as follows:

- People with a recorded diagnosis of dementia and the following common indicators of 6 month mortality in dementia: difficulties with mobility, in need of help with all activities of daily living, incontinence, no consistently meaningful conversation, poor food intake, recent weight loss (Gold Standards Framework Prognostic Indicator Guidance 2014).
- Have a lack of capacity established and where the necessary Adults with Incapacity (Scotland) Act (2000) paperwork is held by the care home
- A guardian, welfare attorney or relative (not acting in a paid capacity) can be identified who, based on his/her knowledge of the person with dementia, could provide an opinion as to whether they would have consented to take part.

Prognostic indicators for dementia are poorly defined and staff were also asked to consider which residents they felt were declining. In terms of legislation, if a person is deemed under the Adults with Incapacity (Scotland) Act (2000) to be unable to give informed consent, then consent must be obtained from a guardian, welfare attorney or relative. All of the residents lacked capacity to consent, therefore, written informed consent was required from their guardian, welfare attorney or relative in accordance with the Adults with Incapacity (Scotland) Act 2000. In most cases this was a relative.

Forty invitation letters (Appendix 3) were sent out by the care home manager to the relatives who were asked to get in touch with me by email or telephone if they wanted further information. Twenty one relatives responded. I then either emailed or posted them information sheets. Four residents were specifically selected for focussed observation and they were sent a different information sheet (Appendix

4&5). I followed up with a phone call or a meeting providing the opportunity to ask questions. I also presented a short talk about the research at a relatives meeting attended by 18 relatives¹⁴. Relatives were asked to consider what they thought the person themselves would want and to respect any views expressed about research participation contained in an advanced directive, if one existed. Twenty relatives gave written informed consent (Appendix 6) including those of the four residents invited to take part in focussed observation (Appendix 7). A further four of the 20 residents were invited to take part in focussed observation several months into the research and they also agreed. With hindsight, it might have been more straightforward to invite all the residents to participate in focussed observation. I did not do this as I was uncertain if relatives, or indeed the NHS REC would agree to this and did not want to jeopardise the study.

Even with the written informed consent of a guardian, welfare attorney or relative, Alzheimer Scotland (2000) suggest two further principles to be followed:

1. Whatever the degree of dementia, the person with dementia should be made aware, as far as possible, of what will be involved.
2. If the person with dementia is not willing to participate then he or she should not be recruited to the research project (even if it is a relative's wish that they participate).

This is consistent with the ethical principles set out in the Declaration of Helsinki (2004) relating to medical research which accords people who lack the capacity to consent the right to express their autonomy in the form of assent (lack of objection) or dissent. Attention to verbal and non-verbal signs of distress is suggested as a form of behavioural or embodied consent. McKillop & Wilkinson (2004) suggest the researcher should 'become a body language expert' and to recognise if the person is tiring and they need to stop. A sympathetic presence, responding to cues that maximize the person's opportunity to participate or decline, is described by

¹⁴ I did not know who these relatives were at the time. Some but not all of them gave consent for their relative. Others who did not attend the meeting also gave consent.

McCormack (2003) as a necessary condition for person-centred research. In light of this, for those residents for whom consent had been obtained from a relative, time was taken to get to know them and to establish a basis for ongoing consent as described by Dewing (2002). A basis for ongoing consent was recorded for all residents (Appendix 8). If at any point a resident seemed distressed by my presence, I withdrew. An adapted information sheet suitable for people with dementia and approved by the NHS REC was developed for use if considered appropriate on an individual basis (Appendix 9).

All relatives were aware of the research project because they had received an email about it from the manager and also through regular updates in the care home newsletter. A poster with my picture and contact details was also on the front door of the care home (Appendix 10). On each visit to the care home I wore a university identification badge and introduced myself to all relatives, residents and staff, including agency staff. There were a number of deaths of residents during the time of the study and consequently new residents moved into the care home, all of whom lacked capacity. The managers felt that it was inappropriate to invite these residents to take part in the study until they had settled in and the staff had established a relationship with them and their family. I had to respect this decision, although at the time it was frustrating. Families were made aware of the research study taking place through the care home newsletter which was emailed to all families. No relative objected to the study taking place and I took this to be tacit agreement to my presence in the care home from all families.

3.5.3.2 Staff

All staff were eligible for inclusion. During the preliminary phase all the staff including ancillary staff were given opportunities to hear about the study both verbally in groups or one to one and given an invitation letter (Appendix 11) and written information (Appendix 12). Thirty three staff consented to take part, most of whom gave written informed consent (Appendix 13) and the remainder verbal informed consent. Within this group there were different levels of engagement: some in observation only; some in observation and/or group discussion and /or interviews.

I was given a list of 47 staff names at the outset of the study. Relief staff were not included in this list and I am unsure of the total number of staff as this varied throughout the study due to a natural turnover. Those who participated included some who were there at the beginning of the study and some who came to work in the care home during the time of the study. Because of the unpredictable nature of ethnography, I continued to re-negotiate consent verbally throughout the course of the research. I emphasised that taking part in any aspect of the study, including observation, was voluntary, they could withdraw at any time and only those who consented would have their data included.

3.5.4 Confidentiality

All participating residents and staff were given pseudonyms and the name of the care home was also changed. Identifying information such as specific roles were removed. All the data collected were securely stored either in locked drawers or password protected computers in Edinburgh University, meeting the requirements for Data Protection. To avoid problems with the breaking of confidentiality, its importance was explained at the outset and groundrules set for group discussions in an attempt to maintain confidentiality and allow those involved to speak freely. Responsibility for maintaining confidentiality becomes shared (Reed 2007). All organisations have internal issues which may come to light during research and need to be handled with discretion. In reflecting back and discussing findings with the staff an appreciative intent was paramount. However, it is difficult to guarantee confidentiality in ethnographic research and those connected with the care home may possibly recognise elements within the final account.

3.5.5 Minimizing Harm

As a researcher in a care home for vulnerable adults, it was necessary for me to undergo disclosure through the Protection of Vulnerable Groups (Scotland) Act (2007). My registration as a nurse provided a safeguard to residents with whom I was involved in hands-on care. I also undertook the Moving and Handling training provided by the care home.

This research dealt with an emotive topic and participating staff were at potential risk of emotional distress and confrontation with potentially painful issues such as mortality, ageing and bereavement. Taking part in group discussions or informal dialogue may have disrupted their coping strategies and heightened awareness of feelings such as loss or guilt (Sinding & Aronson 2003). The exploration of emotion was an integral part of the ongoing dialogue and a source of rich data, as emotions are a way of understanding the world and an interpretative resource (Gray 2008, Bondi 2005). However, I also made myself available to talk to staff out with 'data generation'. If anyone was upset by any of the discussion, which happened twice, I later checked how they were. At the outset it was agreed with the managers that their usual procedures for supporting staff could be accessed; the managers were the first line of support and it was agreed I could refer any member of staff I was concerned about as a result of taking part in the research to them in the first instance. The organisation also had a counselling service available to all staff if required. It was agreed that I would refer any issues arising for family members or residents as a consequence of taking part in the research to the care home staff initially. Additionally, all staff and families had the opportunity to speak in confidence to an external person (my first supervisor) in relation to any issues which arose as a result of taking part in the research and this contact was on the information sheet, as was the procedure for making a complaint about the research. Any research work has the potential to overload care home staff who are already heavily burdened (Froggatt et al 2009, Luff et al 2011). The care of residents has to be their priority and I understood and respected this.

At the outset of the study there were 20 residents in the care home for whom I did not have consent for participation in the research and more moved in during the study. I have not used any personal data relating to these residents in writing up, although at times I recorded fieldnotes of a general nature which may have involved them and some of them are referred to (by pseudonym) within staff quotes. Also over a period of 10 months it was difficult, and even unethical, not to interact with these residents, especially since at times I was able to help by sitting with someone who was upset. My sense was that most residents did not distinguish me from the staff.

Although I wore a badge which I showed people and explained I was from the university, all the staff wore their own clothes so I was not obviously distinguishable from them. Often residents would ask me for help. At times I was able to help, but there were aspects that I could not help with and I would try then to get a member of staff for them. On every visit to the care home I took a reflexive approach in an attempt to behave in a way which caused no harm or exploitation of staff or residents. I discussed issues about which I was uncertain with my supervisors.

Researchers too must consider the emotional risks they face as a result of undertaking research. Researchers committed to reflexivity, developing research relationships, and the interests of participants, particularly when the topic is sensitive, may be at higher emotional risk than researchers taking a more distant, objectivist stance (Sampson et al 2008). Using reflexive fieldnotes I paid attention to the emotional effect the research was having on me. Honest and open dialogue with my supervisors was important. I also met several times with a clinical/emotional supervisor who was a teaching fellow in dementia care from the Department of Nursing.

3.5.6 Getting to Know Each Other: Establishing Relationships and Negotiating my Role

In care home research, good practice guidelines advocate systematic preparation in order to avoid pitfalls (Dewing 2009). A key part of the preliminary phase involved spending time with staff, family and residents within the care home introducing myself and explaining the study. This preliminary phase is important for establishing a context for interaction (Angrosino & Mays de Perez 2000), and building trust and reciprocal relationships with those involved in the research. Thomas (1993) suggests the researcher needs to be friendly, honest and able to communicate to others in their language.

While the managers seemed to trust me and gave me open access day and night, it took some time to gain the trust of some of the care staff; some seemed uncomfortable with my presence throughout. One concern I was aware of was that I

would think they were doing things wrong, such as ‘moving and handling’. I continually stressed that my intention was not to judge, but to understand their work, positioning them as the experts. I realised that having an outsider intentionally observing their practice made some of them feel very vulnerable.

I felt duplicitous because, while I made much effort to cultivate a friendly and helpful presence, sometimes bringing them chocolates and cakes to thank them for letting me in, I had my notebook in my pocket. Walshe et al (2012) refer to this as the ‘pretence’ of being a participant observer. Kvale (2006) suggests that researchers ‘masquerading’ as friends may mask the power exertion in so-called caring consensual dialogues. This was uncomfortable and I had to learn to live with this feeling.

I made every attempt be open and transparent about what I was doing and regularly posted up examples of the data I was generating on the whiteboard I installed in the staff office, with an emphasis on bearing witness to achievements. Putting positive comments on the wall was a way of foregrounding these practices and affirming the worth of the staff, their ability and potential (Appendix 14). Rapid feedback of findings can avoid disillusionment with the process (Davies et al 2009, Luff et al 2011). Alongside feedback via the whiteboard, I also wrote research updates for staff and families for the care home newsletter (Appendix 15). I had 8 update meetings with the managers over the course of the fieldwork. These meetings were important due to the emergent and fluid nature of ethnography: I discussed ways in which the direction of the research was changing slightly from that originally described in information sheets. Since leaving the field I have met once with managers and once with staff to discuss emerging findings (Appendix 16).

Reinharz (1997) describes three types of selves which we bring to the research field: the research-based self, the brought self and the situationally created self. My research based self included being a PhD researcher, a former palliative care nurse, someone keen to understand and listen and enter into dialogue. My brought self

included being a woman, white and British. Negotiating a situationally created self is an important aspect of the preliminary phase and can take a number of forms.

Gomm (2008) describes how the role occupied by the researcher, or the 'angle of view' within the setting is important as it shapes what the researcher is able or not able to see and study. While I privileged my registration and experience as a nurse to gain access and credibility, I found that I played this down in my effort to emphasise their expertise. In the first couple of weeks of the study my role was an observer but as the staff became used to me being there they would often ask me to help out, for example, feeding someone or sitting with someone who was unsettled and needed company. Here I was taking on some of the roles of a care assistant and not a registered nurse.

I was aware that the form of participation could get in the way of observing and keeping fieldnotes, but often I was 'helping' in communal areas such as the dining room or lounges where most activity was happening. Having something to do made 'observing' more comfortable for me, and I think also the staff and residents, than if I was purely observing.

Maintaining good relationships was paramount and I was always mindful that I was a guest in the care home and I did not want to jeopardise this. At the same time, however, there were occasions when I felt that because of their lack of training, some aspects of care were being missed and my efforts to focus on the positive made it difficult for me to know what to do about this initially. I took the approach of acknowledging that I could see clearly how difficult their job is and how busy they are in a sympathetic way. I think this did give people permission to then talk about the aspects of their job that were difficult.

In terms of intervening, as time went on there were occasions, for example, when I reported to staff, that I thought someone might be in pain. I was very aware of the number of residents in the later stages of dementia spending long periods of time without much interaction with anyone for various reasons which are discussed in the

findings section. This was difficult to observe and I often spent time keeping residents company. There were times when I was with care assistants doing hands on care when I would show them how to do things differently if I felt they were doing something wrong, such as the way they were lifting someone. I was aware that, as a nurse, my own behaviour towards residents may have been observed by the staff and throughout fieldwork I tried to model good practice as best I could in all my interactions with the residents and staff.

3.5.7 Reflexivity

I recognised I was not an objective participant observer and I had to bring to consciousness, as much as I could, my own assumptions, values, habits and skills and how these shaped my focus and interpretations (Jenkins 1994). I was also ‘acting’ in the field, in terms of delivering hands-on care and in my dialogue with the staff. It was important that I interrogate my assumptions and the lenses through which I saw things, as Doucet (2008) suggests, that the theoretical and epistemic communities to which we belong can influence our work in subtle and explicit ways. I considered my orientation from the planning stages through to what I observed in the field, how I acted and how I wrote up. I took reflexive notes as part of writing fieldnotes on every visit but wrote them in a different font (See Section 3.6.1). I considered how, for example, my background as a nurse influenced how I saw people in the field or framed events, what drew my attention, how I prioritised topics and how it shaped my interactions with others (Sanjek 1990). I took the standpoint that reflexivity is used to self-consciously address the presence of the ‘knower in the known’, seeing the data not as collected but as co-produced (Gray 2008). This process means that research can be understood not only in terms of ‘what’ has come to be known but also ‘how’ it has come to be known (Altheide & Johnson 1998, Etherington 2007), making visible and demystifying the construction of knowledge (Pillow 2003). This standpoint acknowledges that we can only ever contribute to understanding in a partial, provisional and perspectival way and that to think otherwise is potentially dangerous as it can privilege the knowledge of those in powerful positions (Doucet 2008, Mauthner & Doucet 2003, Siltanen et al 2008).

3.5.8 Generating Data: Looking, Listening and Being Present

A number of methods were used to generate data and these are described below. A timeline of when each of these methods was employed is shown in Appendix 17.

3.5.8.1 Participant Observation

From November 2012 to August 2013 I visited the care home for two sessions per week averaging three hours but sometimes longer. This allowed time for writing fieldnotes, reading and reflecting as I underwent research training as a novice researcher and in keeping with an abductive research strategy. I made 68 visits, plus 10 during the recruitment phase, and spent 207 hours in the care home, by which time I felt confident that my observations were representative of daily life in Primrose Hill. I was interested in what happened at different times of the day, evening and night and conducted observation around the clock¹⁵. I was given open access and I wrote the times I would be present in the staff diary in advance.

One of the effects of advancing dementia is gradual loss of verbal skills. Although a number of observational tools have been developed to help capture the standpoint of residents in care homes who have dementia (e.g. PANICOA 2011) the nature of the research questions demanded a more flexible and open approach. The recording of fieldnotes is described in Section 3.6.1. I conducted various levels of observation. Spradley (1980) describes 3 phases of participant observation which I used as a guide:

1. Descriptive observation – provides the researcher with an orientation to the field. It is used to grasp the complexity of the field and to develop more concrete research questions and lines of vision
2. Focussed observation – narrows perspective on those processes and problems which are most essential for your research questions

¹⁵ Breakdown of shift observation: 27 early shifts (91 hours), 27 late shifts (81 hours), 6 night shifts (25 hours), remaining hours were visits for meetings or ad hoc visits to follow-up specific issues.

3. Selective observation – towards the end of fieldwork data collection is focussed on finding further evidence and examples for the types of processes and practices found in the second step

Initially, I stationed myself in communal areas of the care home observing the daily organisational routine and what people were doing, both staff and residents. I took time to understand the geography of the building and drew a plan. I was invited to sit in on staff handovers and also attended a staff meeting. I found attending handovers useful for knowing what was happening in the care home, particularly if a resident was sick or dying.

Early on in the fieldwork period the staff began to ask me if I would sit with residents who were agitated or if I would like to help to feed a resident. I often spent time ‘watching over’ residents in one of the lounges which could not be left unattended and I also attended ‘special’ events such as activities taking place in the activity room, a church service and the Christmas Party. Lofland & Lofland (1995) describe participant observation as involving the interweaving of looking and listening, watching and asking. After several months of getting to know the staff and residents, I began to focus more on observing the interactions between staff and residents. I also began doing focussed observation in bedrooms with the residents for whom I had consent. This involved helping the staff get residents up, washed and dressed in the morning and back to bed in the evenings.

Observations, both general and more focussed were appreciative in intent, using an approach I piloted at a singing group for people with dementia at which I conducted an evaluation as an assignment for a research training module ‘Qualitative Methods: Ethnographic Fieldwork’. At the singing group I observed the ‘body’ of people with dementia before, during and after the singing and noted how they changed. This ‘pilot’ was a way of learning how to write about the body, articulating taken-for-granted or ‘obvious’ movements of the body and bodily expressions.

In the care home I noted encounters where there was a good connection between people and where the person with dementia was calm, or became calm, or displayed

other signs of well-being such as smiling, as well as gestures such as hand holding, hugging, eye contact/gaze, or winking. I observed the ways the person with dementia demonstrated their subjectivity or agency through their behaviour and any word/noise exchange between staff and people with dementia, the difference this made and the ways in which the person with dementia was positioned in relation to others. This could include whether contributions made by the person with dementia were being noticed and acknowledged, and whether they were being facilitated to take part in an interaction. I focused on what each person in the interaction was doing, articulating movements of the body which I may normally have taken for granted. Other ways of connecting, for example, through the active use of music or touch, were noted. Inevitably, there were also difficult encounters between staff and residents with a flair of temper from the resident or inattention from care staff. I also noted these and the situations which gave rise to them.

I also noted my own interactions with residents, for example, if I was feeding someone, I noted what I was doing, how the interaction went, what worked or what was difficult and what it felt like. I used this as a basis from which to explore the staff's experience of similar interactions.

3.5.8.2 Group Discussion and Interviews

Ethnography as a collection of methods is by nature emergent, fluid and pragmatic. Several months into my fieldwork, six residents died in quick succession and the staff were deflated and exhausted. I knew all the residents who died and I thought reflecting on these deaths would be a good opportunity to understand more from the staff perspective of what the ending of the caring relationship is like. With the agreement of the managers, I arranged a group discussion with each of the 3 teams, grounding the discussion in these concrete examples. Froggatt et al (2009) suggest that, since care staff spend most time with residents, they have the greatest potential to influence care home life and should, therefore, be given centre stage in projects such as this.

Group discussions are recommended when complex behaviours, motivations and social norms of which participants may not be consciously aware are explored and allow differences in views to be directly and explicitly discussed (Lewis 2003). Bryman (2008) suggests that group discussions or focus groups have a role in allowing the voices of marginalised people to be heard and can be empowering. I structured each group discussion around a reflective cycle (St Christopher’s Hospice 2013) and used questions to guide the discussion (Appendix 18). Each group was digitally recorded with permission and transcribed verbatim. Thirteen day time care staff participated in a group discussion as shown in Table 3:

Table 3 Characteristics of Participants in Group Discussions

	No. of Participants	Role	Gender
Group 1	4	Team Leader ¹⁶ – 1 Care Worker - 3	2 Female 2 Male
Group 2	4	Team Leader – 1 Care Worker - 3	4 Female
Group 3	5	Team Leader – 1 Care Worker – 1 Care Assistant - 3	5 Female

Group discussions took place immediately after the afternoon handover as the team was coming on shift. Each lasted around 45 minutes.

I realised that in order to get the opportunity to clarify what I was observing, and understand more about the perspective of the care staff, that interviews were necessary. It was easier for one person to be off the floor at any one time, than a group. Over a number of months I conducted interviews with 24 staff (3 pairs and 18 one to one). The interview outline is shown in Appendix 19. These were digitally

¹⁶ These roles are described in Section 4.4

recorded with permission and fully transcribed verbatim including broken English. These lasted between 15 minutes and 45 minutes. Characteristics of staff who took part in interviews are shown in Table 4:

Table 4: Characteristics of Participants in Interviews

Status	Number
Team Leader	4
Care Worker	10
Care Assistant	6
Activity Co-ordinator	1
Domestic	1
Cook	1
Hairdresser	1
Day Staff	19
Night Staff	5
Female	18
Male	6

3.5.8.3 Documentation

With the permission of the managers I also looked at the care plans and documentation kept about the residents for whom I had written consent. Notes were taken and written up more fully as fieldnotes and formed part of the overall analysis. I was interested in looking at which aspects of care were foregrounded in day to day continuation notes and whether embodied aspects of personhood were written about, for example the way residents communicated in embodied ways. Continuation notes also helped me keep track of things that had happened on days when I was not there, for example, if someone had been seen by the doctor. Data is included in the analysis in the results sections (Chapters Four, Five, Six, and Seven). I looked at the layout of care plans and which aspects of care were included as a way of understanding what was important in the care home. This gave insights into the context of the care home and which aspects of care dominated day to day life. I was also interested in which documents guided palliative and end of life care within the

care home and whether residents had advance care plans or DNACPR documentation, indicators of a palliative care approach. This data is shown in Appendix 23 as discussed in Section 4.3.

3.6 Making Sense: Ethnographic Writing, Analysis and Interpretation

This section describes the iterative processes I used to make sense of the data I generated; the writing of ethnographic fieldnotes; various approaches to grasp what the data was saying; finally, the use of analytical lenses to provide further illumination and interpretation.

3.6.1 Writing Fieldnotes

Each time I visited Primrose Hill I carried a small palm sized notebook in my pocket. I felt uncomfortable openly writing in this notebook, aware that it drew attention to my role and worried that it might stifle the usual behaviour of staff. I tended to take short ‘scratch’ notes in the office. At handovers I wrote notes openly like everyone else.

After each three hour period of fieldwork in the care home I left to write detailed fieldnotes in a word document which I then uploaded to NVIVO¹⁷ on a password protected university computer as well as keeping a hard copy in a locked drawer in the university. A thick description of the context (Chapter Four) shows that I have ‘been there’ (Geertz 2001), increasing credibility and allowing others to make judgements about the authenticity and transferability of the findings (Schofield 1993, Ritchie & Lewis 2003). I wrote fieldnotes chronologically, giving an account of what I had been observing from the beginning to the end of each fieldwork period, using my scratch notes as an aide memoire.

I interspersed descriptive notes with reflexive notes and reflections, issues to follow up, emerging themes and also notes on and references to literature which might be

¹⁷ NVIVO is a type of software for managing qualitative data

relevant to analysis on particular themes. I used different fonts to differentiate the different types of fieldnotes. A sample of fieldnotes taken in the descriptive phase of observation is shown in Appendix 20. At the beginning of fieldwork I was careful to write thick descriptions of the context and my first impressions before these became diluted by my time in the field (Emerson et al 1995). Observation visits were restricted to approximately three hours, rather than longer, in order to maximise my memory of events and to try to record as accurately as possible what was happening. I see my fieldnotes as referring to a set of real events in the material world with descriptive validity (Whitaker 2010), the reality of whose occurrence would be shared (Stanley 1993). However, the act of writing fieldnotes constructed events in the field in that I have noticed, remembered, selected and emphasised some events and not others, guided by my research questions.

The writing of fieldnotes is indistinguishable from analysis as the process of writing fieldnotes identifies gaps and issues to be followed up as well as contributing to the process of making sense (Sanjek 1990). Writing fieldnotes also contributes to theoretical moulding; there is a constant moving between observation, conversation and group discussion, writing and interpretation (Sanjek 1990).

3.6.2 Drilling into the Data

During the early days of fieldwork I had a sense that I was in danger of generating a mass of data with insightful observations of a mainly anecdotal nature; I needed to move beyond this to more in-depth analysis and interpretation. I began to explore various approaches to analysis.

I considered grounded theory: Timmermans & Tavary (2007), drawing on the work of Cathy Charmaz, suggest that when grounded theory is used in ethnography it gives priority to a phenomenon or process rather than a description of the setting. This can enhance ethnographic work because of the emphasis on thinking conceptually and working towards theory building, making more of a substantive contribution. This inductive approach suggests early coding moves the analysis

forward, giving analytical momentum and guiding fieldwork to areas which require more attention.

After two months of fieldwork I therefore took a week out from fieldwork to read and reread my fieldnotes to see what was there and try to develop a coding frame. Up until this point I had been using real names of residents and staff in my fieldnotes as a way of remembering who was who. I began by anonymising all my data with pseudonyms and organising the data into folders for interviews, observations, meetings with the managers, staff and residents. I had a number of false starts with attempting to develop a coding scheme for initial themes; rather than helping me explore my data, it seemed to fragment it. More importantly it did not seem to reflect my research questions.

My next step was to explore narrative analysis¹⁸ within ethnographic research as a possible way forward. In Mattingly's (1998) ethnographic work with occupational therapists she talks about how the therapists hoped that 'something happened' during therapy that was healing. Healing here is used in its broadest sense and does not necessarily mean physical healing but the relief of suffering in an holistic sense. Mattingly (1998) describes these as emergent narratives, or the small dramas or rituals of the everyday, which may have deep phenomenological import. I was interested in the idea of exploring the narrative structure of action rather than discourse and the way that some stories are not told so much as enacted or embodied as described by Mattingly (1998) and Mattingly & Garro (2000). This seemed to make sense in the context of caring for people with dementia where often interactions are not based around words but around embodied actions.

As I was doing fieldwork I began to pay more attention to these so called emergent narratives and what the 'something' might be that both residents and staff hoped

¹⁸ This is in contrast to analysis of narratives where data consists of narratives and analysis produces categories which move from stories to common themes (Bruner 1991, Polkinghorne 1995).

might happen in their encounters. This began to illuminate how the ‘something’ they hoped for that would bring healing was being challenged by the changes taking place in the care home as a result of specialising in dementia care and wider changes in health and social care leading to an older and frailer population.

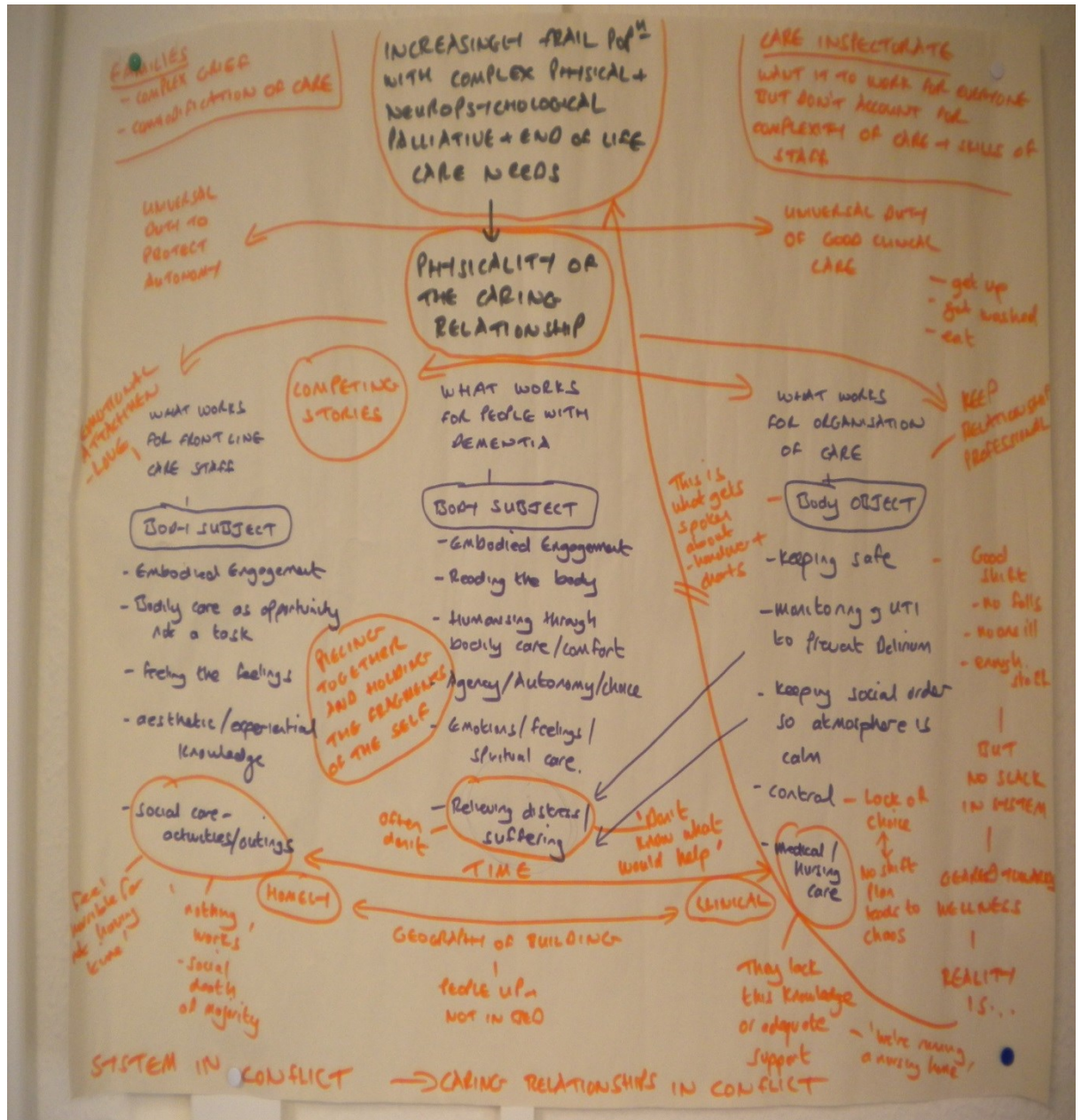
I created chronological case studies of each of the residents in my study, compiling all the data I held on each person, whether through observation, my own interactions with them, things staff said in relation to them, and extracts from documentation related to them. I used this as a way of forming a more coherent ‘story’ of each person over time and looking at my data from another angle as a way of revealing something new. It seemed to give the residents a louder ‘voice’ within the data, bringing them to the fore as key players or protagonists in the caring relationship and distilling the key factors shaping their relationships with the care staff.

3.6.3 The Distillation of the Story

I realised I needed to look more at my data to see what was there, but with more focus on my questions rather than being too open. I created a new coding framework and important within this was a code to encapsulate the various types of interaction staff and residents were involved in which eventually contained 24 subcodes. Other dominant codes were ‘emotions’ the different ‘needs’ of residents, and the ‘organisational context’. I then summarised these codes to identify the parameters of each one and distilled them into 3 overarching themes which emerged as key facets of palliative dementia care. These form the basis of Chapters Five, Six and Seven. I read through all my fieldnotes again as a way of checking that the coding frame was comprehensive. At the end of this process I was able to draft a ‘mind map’ (See below) of what I felt was happening in the data which guided the next step which, in keeping with an abductive research strategy, was to redescribe what I saw happening in the social world in the language of social scientific discourse (Blaikie 2010). This merges interpretative validity, how I interpret what the data means to those involved, with theoretical validity by going *beyond* what is valid for individuals while remaining grounded in data to support any claims (Whitaker 2010). I returned to the data and used theory on the body, particularly Kontos’ (2003) theory on embodied

selfhood, Zeiller (2013), Jenkins (2013) and Merleau-Ponty's theory on intercorporeality as analytical lenses and Tronto's (1993) Ethic of Care as an interpretive framework.

Mindmap



3.6.4 The Trustworthiness of the Findings

It is important to consider the trustworthiness of a study, or the degree to which we can have confidence in the interpretation of the findings (Olesen 2000). In

ethnographic research, plausibility and credibility are also important indicators of the quality of the research (Altheide & Johnson 1998). A number of strategies employed within this study ensure the trustworthiness, plausibility and credibility of the findings. The extended period of time in the field and the rich description of the context shows that I have ‘been there’ (Geertz 2001). This allows others to make judgements about the authenticity and transferability of the findings (Schofield 1993, Ritchie & Lewis 2003). All interviews and group discussions were digitally recorded and fully transcribed to ensure accuracy. Detailed fieldnotes were taken and a sample is shared in Appendix 20. These have descriptive validity (Whitaker 2010) in that they refer to a set of real events, the reality of whose occurrence would be shared (Stanley 1993). The reflexive approach (See Section 3.5.7) I have taken throughout shows how I have constructed events in the field in that I have noticed, remembered, selected and emphasised some events and not others, guided by my research questions and my own position within the research: ‘good ethnographies show the hand of the ethnographer’ (Altheide & Johnson 1998 p. 301). Plausibility is achieved by transparency in analysis and interpretation and the presentation of multiple voices and perspectives. I used an analysis diary to track the various approaches to analysis outlined in the previous section, and interpretative insights. This, and the sharing of emerging findings with participants as a means of member checking, adds to the interpretative validity of the findings. The integration of theory on the body into the design, fieldwork and analysis of the study provides theoretical validity.

3.7 Conclusion

This chapter has set out, in detail, the theoretical framework and methodological approach this study employed in researching the care-giving/care-receiving relationship with people with dementia in a care home. The ethical complexities of using ethnography in a care home with people who lack capacity have been addressed as has my position within the research. The next four chapters explore the findings of the study.

4 The Care Home Context – Changing People in a Changing Place

4.1 Introduction

In this chapter I describe the care home in which I undertook ethnographic fieldwork between November 2012 and August 2013. This thick description of the context shows that I have ‘been there’ (Geertz 2001) and allows others to make judgements about the authenticity and transferability of the findings (Schofield 1993, Ritchie & Lewis 2003).

Primrose Hill¹⁹ is a specialist dementia care home which provides personal care (without nursing) to 40 residents with dementia. It is a ‘not for profit’ care home run by a voluntary organisation which provides care and support to a number of vulnerable groups including older people affected by dementia. To bring Primrose Hill to life I begin this chapter by describing the geography of the building which is usual practice in ethnographic research as it not only helps to picture the scene but is relevant to the analysis of the care-giving/care-receiving relationship. I then give short pen portraits of the residents who took part in this study. I go on to describe the staff group working in the care home, some of whom were involved in the study, the staffing levels and staff skills.

Primrose Hill converted to a specialist dementia care home in 2009 having previously been a residential care home for older people. This specialisation, and a number of other factors in the wider health and social care system, meant the care home was living through a period of transition where the needs of the residents were becoming more complex and there were more deaths. The implications of these changes for daily life in the care home are examined. These contextual factors are important in shaping the care-giving/care-receiving relationship. The changes that Primrose Hill was experiencing allow some analytical purchase in considering what

¹⁹ All names are pseudonyms

care for people with advanced dementia entails and this chapter lays the foundation for subsequent chapters.

4.2 The Geography of the Building

The geography of a building is central to the way that care is delivered and an important factor in enabling person-centred care (Twigg et al 2011, Chaudhury et al 2013). Primrose Hill was a large converted Victorian house on two floors situated in its own grounds in an affluent residential area of a Scottish city. Appendices 21 and 22 show drawings of the floor plan. A driveway open to a busy road provided access to the building. Towards the side of the house sloping downhill there were mature well-kept gardens with pathways and seats at regular intervals and a summer house. The main house was accessed via the front door which was locked. Staff had an access code and all visitors rang the bell. There was a sign saying the door would be answered within 3 minutes. The front door opened into a large carpeted high ceilinged hallway.

There were three large south facing lounges on the left hand side of the hallway each with large bright bay windows overlooking the gardens to the side of the house. One was a 'music' lounge where music played most of the time from a computer. The middle lounge was the quiet lounge which, during my time, was converted into a sensory room where the staff could do hand massages and manicures for the residents or where families and staff could spend quiet time with residents. The third lounge was the TV lounge. The TV was on most of the time, either showing news programmes or more often DVDs of films or musical concerts. Because the house was an old Victorian house the ceilings were very high and the rooms were large. While the chairs in the lounges were arranged in small circles around coffee tables meaning that residents could see each other's faces, a way of promoting social interaction, the residents often seemed small in the large high ceilinged rooms.

To the right of the front door was a short corridor leading to the dining room and kitchen. The kitchen was locked and only accessible to staff. There were hatches opening from the kitchen to the dining room which may have provided sensory cues

to the residents of the purpose of the dining room. However, recent guidance on the design of care homes suggests that smaller units of 6-12 residents, with a central homelike kitchen accessible to all, are beneficial to residents (Robinson 2010). The dining room had seating for 24 people with 6 tables for 4 people. The tables were set with tablecloths and tableware. Residents who used wheelchairs were normally transferred from these onto dining chairs at mealtimes which is recommended for improving posture and promoting socialisation (Chaudhury et al 2013). Music often played in the dining room. Depending on who was in charge of the shift, the music could be loud or quiet. There is evidence to show that loud music can cause agitation in people with dementia (Chaudhury et al 2013). There was often very little conversation in the dining room and, based on staff comments, there was a sense that some of the staff saw music as creating a cheerful atmosphere.

Beyond the corridor to the dining room a large open staircase swept up to the first floor. Under the staircase was an open area where there were two sofas, a coffee table and a CD player. Residents and visitors would often congregate on these sofas. Beyond the hallway on both the ground floor and upper floor was a long corridor leading to the bedrooms. The activity room on the ground floor was built in an annex off to the left of the main old house.

To the back of the house was a contained wall garden and during my time in the home a sensory garden was being constructed, funded by the City Council Investment Fund. The plan was that this would be a safe outside space for residents to go by themselves. The main gardens to the side of the house sloped downhill making it difficult for residents with mobility difficulties or in wheelchairs to go there by themselves and the open gate onto the busy road at the front was another reason for the locked door.

The hallway at the front door was a hub of activity during the day as residents milled about, passing between sitting rooms, and the dining room. In the hallway a large whiteboard informed everyone of the day and date, which staff were present, and the times of any activities such as a concert or daily devotions. The hallway was furnished with large traditional furniture suitable for the size of the space; for

example, there was a large dresser to the right of the front door and newspapers were left here in the morning. A large Victorian fireplace provided a focal point and a large notice board decorated with artwork changed to reflect the seasons or festivals such as Christmas. It was also a place where photographs of the residents at special events such as the summer garden party were displayed. Around the house on mantelpieces and walls were framed photographs of residents, past and present. This added a homely rather than 'hotel' feeling to the environment.

There were three corridors of bedrooms; rooms 1-12 (annex), rooms 13-25 (bottom corridor), rooms 26-40 (top corridor). The bedroom corridors were quite functional with only occasional pictures, but at intervals there were sitting areas; one was like a 'beach' with bunting and beach pictures, and a small area called the 'library' with a bookcase of books and a few chairs was being developed on the upper corridor while I was there. Their main purpose was to act as orientating signposting for the residents. The name of each resident was on their bedroom door along with their photograph.

All the bedrooms were single rooms. They were about 12 feet square, and each contained a single bed, wardrobe, chest of drawers and chair. Each had an ensuite shower room with a toilet. Making the toilet visible from the bed is recommended as a way of helping people to function independently by providing a visual cue. Most of the bedrooms were not arranged in this way, although this would have been a possibility in some of them. For those residents who required hoisting, manoeuvring from the bed to the wheelchair with the hoist was a heavy and difficult manoeuvre in the relatively confined space. All of the bedrooms were personalised to varying degrees with resident's own curtains, duvet covers, pictures and other personal items. All had elevating electric beds and most had cot sides. Some of the residents had alarmed mats at the side of their beds which alerted the staff if the resident got out of bed independently or fell.

Also on the first floor of the house was a hair dressing salon, a locked staff coffee room, a quiet meeting room, two managers offices and the staff office. The office

spaces were open when they were occupied and some residents who walked around would occasionally enter this space and would sit for a little while with the staff. The staff office was where the handovers took place and housed desks, computers and filing cabinets with resident related paperwork such as care plans.

On the ground floor just beyond the hallway on the corridor leading to the bedrooms was the treatment room where the residents' medications and other 'medical' equipment such as wound dressings and lotions were stored. This room was also used as a consulting room where outside professionals such as the GP or community nurse could see residents, although this would also happen in their bedrooms if residents were less well. The treatment room plus other evidence of illness and frailty such as hoists, wheelchairs, zimmer frames and cupboards filled with incontinence pads were visible reminders of the nature of everyday life in the home and the blurred boundary between a domestic and clinical space. One day towards the end of the study period I saw a delivery of a new hoist and a padded shower cushion arriving, indicators of an increasingly frail group of residents.

4.3 The Residents

Appendix 23 gives a 'moment in time' snapshot of the characteristics of the residents who are included in this study. It is a 'moment in time' snapshot in that characteristics such as functional abilities were not static. In the spirit of the research approach I took, I do not want to reduce the residents to a table of characteristics or abilities they did or did not possess, so below are short pen portraits of each of the residents, written in such a way as to give a sense of their character and what it was like to meet them face to face. It took me time to get to know who was who, and distinguish those residents who were participating from those who were not. I had more contact with some residents than others so there is more detail in some than others. The following pen portraits focus on the 20 residents for whom I had permission from a guardian or welfare attorney to include in my research. All the names are pseudonyms. Their mean age was 89.7 years. Eight of these residents died within a year and a further two within 18 months. I inevitably also got to know the other 20 residents, and others who came to the care home during the fieldwork period

who were not taking part, so the following snapshots only give a partial picture of the many characters living in Primrose Hill.

4.3.1 Catriona

Catriona was popular within the care home among staff and other residents. She was very sociable and if any activity was happening, Catriona would be there. She had a very cheerful and contented personality and was also very affectionate, often hugging and kissing the staff.

Catriona came out of the dining room after her dinner. She told me she was going to visit her grandmother now as this is what she always does at this time of the day. I said to her that it was a cold November night and she said that had put her off going. I invited her to sit with me and few other residents on the settees in the hallway, which she did. (Fieldnote p.54 22/11/12)

During my fieldwork Catriona had a bad fall, from which she recovered quite well. However, she was then diagnosed with metastatic cancer and she died a few months later of what was thought to be a stroke.

4.3.2 Katie

Katie strolled around the hallways, lounges and corridors continually with her hands in her trouser pockets. She did not seek out staff but she would stop and chat if someone chatted to her. We often chatted as she passed where I was sitting observing. She often talked about how useless she felt and no amount of affirmation seemed to help with this. Usually she was asking where she was and why she was here, but at other times she would sing and she loved to dance:

I went into the sitting room and I met Katie walking around. I greeted her– she told me I lookedbut couldn't finish her sentence but was moving her body in an energetic sort of way – I wonder if she was 'feeling my feelings' and knew I was

glad to see her - I took her hands and she started to sing and sway and I asked if she was dancing. She said she couldn't sing but I said she was a very good dancer and she thanked me. We then held hands and danced and swayed and she seemed very happy. Anne passed and said that Katie was really enjoying herself. Quintin gave us a clap. Katie afterwards said that it was nice here but not so nice where she is. This is the first time I have heard her say it was nice. (Fieldnote p.232 31/5/13)

Katie did not change much during my time in the care home, except to be started on nutritional supplements because she was losing weight.

4.3.3 Lillian

Lillian spent her days sitting quietly in the sitting room, appearing to watch the TV. Although she seemed settled and often smiled very brightly with company, she would often cry silently, with tears trickling down her face. She said very few words but occasionally she said something which indicated her awareness of what was happening:

I sat for a few minutes with Lillian when her visitor went away as I feel I don't really know her. She smiles a lot. She smiled at me and looked directly at me and held my gaze. When I eventually got up to go she said 'thank-you'. (Fieldnote p.125 4/2/13)

During my fieldwork it was thought that Lillian was dying several times before her actual death, which was unsettled.

4.3.4 Oswald

Oswald spent his days sitting quietly and contentedly in the sitting room. He had a good sense of humour:

I introduced myself to the lady next to (Oswald) and I was checking that I'd got her name right by saying 'you're Abi – is that right?' – Oswald then made a little joke 'I'm not Abi' and laughed. (Fieldnote p.74 3/12/12)

This also indicates that Oswald's Self 1 as described by Sabat (2001) was enduring as he was using the first person pronoun to identify himself. He died very peacefully two months after I began fieldwork

4.3.5 Sandra

Sandra was known for having a good sense of humour and for being a very pleasant lady. During my time in the care home, however, she became quite unsettled at times, often wailing and nothing seemed to help her. Her mood was low and she seemed distressed about the things she was no longer able to do:

I sat next to (Sandra) for about half an hour. She seemed to be very fed up. She was pointing to the crossword book and novel in the basket on her zimmer and saying she can't do it anymore. She asked repeatedly if I would shoot her as she is no use. (Fieldnote p.279 29/7/13)

Sandra needed full assistance with washing and dressing and used a wheelchair but she changed very little during my time in the care home.

4.3.6 Hilda

Hilda was a tall elegant lady who wore well cut, expensive looking clothes. She could walk with guidance but usually sat in the sitting room and seemed happy and content. She had a very good sense of humour and was very lively with dramatic facial expressions. She changed very little during my time in the care home.

(In the dining room at breakfast time) Hilda came and sat at the table where I was sitting. She talks a lot and uses proper words but they are jumbled. However, as Anne has told me before, she appears to fully understand. As I was saying hello

to her, her name was on the tip of my tongue and I eventually got it out – she seemed to realise that this is what had happened and she laughed and said ‘almost’. She has a very expressive face and smiles a lot and makes knowing nods and winks. (Fieldnote p.184 24/4/13)

4.3.7 Maureen

Maureen was easily recognisable by her one-liners which she repeated frequently out loud to anyone who was around as she sat in the sitting room. The following is a compilation of her often repeated lines, revealing her insight into her situation:

I love you; I love your face, my friend. Still alive, Feeding the baby. I like it here, I love you. Still alive, I’ll be quite happy when it’s all over. I’ll stay with you if you stay with me, my friend, I love you. Poor old Maureen - pushed and pulled. I’m in a hole. (Compilation of fieldnotes)

Maureen changed very little during my time in the care home.

4.3.8 Joanna

Joanna was known as a character with a sharp sense of humour, but also a sharp tongue and an argumentative nature. She was often very unsettled, walking slowly around the rooms and hallways, asking in a loud voice what she should be doing.

...one resident was looking at Joanna as she was settling in her seat and was told angrily to stop being a ‘nosy parker’ by Joanna. Later on in the sitting room Joanna, who continually gets up and down out of her chair saying ‘help, what will I do?’ eventually sat down next to me. When she asked, ‘what will I do?’ I said ‘sit here and keep me company’ and she laughed and said ‘we’ll keep each other company’.
(Fieldnote p.74 3/12/12)

She continued walking around with her zimmer until the day of her death a couple of months into my fieldwork.

4.3.9 Nigel

Nigel was known as a quiet, private man whom the staff knew very little about. I only really became aware of him when I heard about his death, a few months after I began my fieldwork, although I had seen him sitting quietly by himself in the sitting room or at the dining table. He truly was silent and invisible.

4.3.10 Quintin

Quintin was a very smartly dressed gentleman, always wearing a tweed jacket and tie as he sat quietly in the sitting room. He would often mumble to himself and his conversation was limited but his embodied aspects of himself were clear to see, for example, in the way he engaged in social etiquette in conversation in an embodied way:

Barbara and Quintin from across the room looked like they were deep in conversation. Although both of them have very limited language, they were turn taking and laughing and looking at each other. (Fieldnote p.117 27/1/13)

4.3.11 Penny

It took me a while to get to know Penny as she did not speak or initiate any interaction and was chair bound all day. I think because of this it took me a few months to even become aware of her presence. Despite this she was interesting because she was mentioned by several carers as someone they felt they had a good relationship with. I found her difficult to make contact with but when she did eventually make eye contact and smile, it was very rewarding:

Penny doesn't say anything and didn't turn when I called her name but when I held the spoon up to her lips she ate the whole bowl of soup and then we slowly worked our way through a plate of fish and chips. When I asked several times if she was alright she nodded her head very gently and she

did make eye contact a few times and laughed once. She also seemed to be watching the movements of other people around the room. (Fieldnote p.233 3/6/13)

Penny died about eight months after I finished fieldwork.

4.3.12 Annie

Annie was always smart in very pretty dresses and was content to sit in the bay window of the music room, watching the world go by and looking out of the window at the garden. However, she became very angry if anyone took her seat. She enjoyed a chat. Her conversation was very repetitive but she did remember from day to day that I was from the university. She died a couple of months before I finished fieldwork.

4.3.13 Betty

Betty was a sociable lady who enjoyed company and a joke. She was becoming more physically frail and unsteady on her feet which was a source of great frustration for her and created tensions between her and the staff as she tried to assert her independence. She seemed very aware of what was happening:

At 10am Betty was sitting alone at a table in the dining room and when I waved to her she waved back. When she had finished her breakfast she was trying to catch the eye of one of the carers who took a minute or two to notice her – her speech is very poor but she knows what she wants and she knew she was finished breakfast and was ready to go and wanted assistance. (Fieldnote p.181 24/4/13)

Betty at one point became wheelchair bound after a change in her Alzheimer's medication and a chest infection but was back on her feet walking with a zimmer when I finished my fieldwork.

4.3.14 Ingrid

Ingrid was very active and spent a lot of time walking around with two friends. She often thought she had lost things or that she had been robbed. Her paranoia and insight into her forgetfulness were very distressing for her and often led to conflict with the staff. She was one of the few residents who was sociable with other residents and took an interest in them:

At another table I could hear Wanda fretting about her son and Ingrid, who is usually fretting herself about losing things giving her reassurance that her son had been in and he knows that she is here and safe. (Fieldnote p. 115 24/1/13)

Ingrid recovered several times from short illnesses while I was in the care home but died shortly after I left.

4.3.15 Floss

Floss was physically able and spent a lot of time with her many visitors and seemed slightly detached from the life of the home. When she did not have visitors she could be seen sitting by herself reading her newspaper, doing a crossword or at other times playing scrabble with a few other residents. She at times entered into conflict with the staff due to her resistance to washing. She did not initiate any contact with me but I did chat to her a few times and she was able to have a conversation, although her memory was very poor.

4.3.16 Gail

Gail was a slim, fit looking woman and the first few times I saw her I thought she was a visitor rather than a resident. She was mostly very quiet and calm. She struggled with allowing the staff to help her to wash. She walked around the building a lot and often tidied up, puffing up squashed cushions and putting away things that had been left lying around. She seemed very aware of what was being said to her and would nod her head knowingly, although her conversation in response was very limited. She sometimes helped the other residents. She did not change during my time in the care home.

When someone walked past who was a bit wobbly on their feet (Gail) shook her head at me in a knowing sort of way as if to say 'what a shame'. Also later I saw her trying to fix someone's shoe where the Velcro had come undone.

(Fieldnote p.55 22/11/12)

4.3.17 Dot

When Dot was not out with family or in her bedroom she walked around a lot with her wheeled walking frame, occasionally 'gossiping' with other residents about the staff or people she thought might have died.

Dot and Betty were sitting next to each other chatting in the sitting room – I overheard Dot asking Betty if she knew one of the residents had died last week. She had overheard talk about a funeral. Betty knew nothing about it. I later asked a carer if anyone had died – no one has died in the last week. She said Dot has had a lot of funerals lately. As they were chatting a black agency carer was taking people to the toilet. Dot then asked Betty what she thinks of black carers. Betty shrugged as if she didn't mind. (Fieldnote p.81 10/12/12)

4.3.18 Rose

Rose was another person who would fit the category 'silent and invisible'. She was a very quiet and reserved but pleasant lady, spending most of her time sitting quietly by herself in the sitting room. She was not a talkative person, although she still could use words. One evening after her son had just left I chatted to her:

Rose was now in the sitting room with the TV on. It was empty apart from one other lady so I decided to sit with Rose for a bit as she seemed slightly bewildered as to what was happening. I said it was nice to meet her son but she had already forgotten that he had been in. She did say that she

hoped he had behaved himself and laughed at this. (Fieldnote p.127 6/2/13)

Rose died about eight months after I left.

4.3.19 Abi

Abi was very quiet and did not initiate much contact with any of the staff or with me. Although she could walk with a zimmer, she did not tend to get up and walk around of her own volition, but rather just sat in the sitting room and snoozed or watched what was happening. Her family were very vigilant about her care. A lot of negotiation was required with Abi as her usual response to a suggestion was 'no':

... I tried to take Abi to the dining room. I made eye contact and explained that it was dinner time and I would walk with her to the dining room and she could hear me but point blank refused to go and adamantly kept saying 'no'. (Fieldnote p.309 21/8/13)

4.3.20 Emma

Emma was very small and quite stooped so I had to bend down to make eye contact and see her face. She dressed very plainly in trousers and a top. She had a really lovely smile and very gentle eyes. She responded to a smile and she seemed to understand what was being said to her. She tended to walk around looking at the floor and did not initiate contact. She seemed to be in a world of her own. She often cried out in plaintive tones for her sister who was very attentive to her. When she had company she would mumble very quietly and it was difficult to know what she was saying although at times she appeared very lucid:

(Afternoon in the sitting room) Emma...did say clearly among other things 'if there are a lot of people I get perplexed'.(Fieldnote p.76 3/12/12)

Emma died a couple of months after I arrived. One carer described her death as beautiful because it was calm.

4.3.21 Summary of this Section

The short portraits of each resident alongside the table of characteristics (Appendix 23) gives some sense of the unique characters living in Primrose Hill, the diversity in people with dementia in relation to the way that they are affected by dementia and the different levels of dementia. There was not a 'typical' person. This section also begins to point to the complexity of caring for people with such a wide range of needs and different levels of dependency who are living with dementia but also dying with dementia or other illnesses.

4.4 The Staff

The staff group, about three quarters of whom were women, were a diverse group ranging in age from 18 to around 60 and from a variety of ethnic backgrounds. There was a small core of staff from the local area who socialised together outwith work. A number of the permanent staff were of Eastern European or African origin. The majority of the relief staff were African or Philippino. Some staff saw 'caring' as a career, with some planning to do further training in either nursing or social work, and others doing the training provided by the organisation and moving up the internal ladder towards management. Others saw their job as a stopgap, filling time until they found other work or finished their studies. During the time of the study, the care home went through a number of staffing changes, most notably a change in management. At the outset of the study the manager had been there 4 years and deputy manager 20 years indicating some stability in staffing. The manager left and the deputy manager was promoted to manager and a team leader was promoted to deputy manager. A number of the care staff had been there for a number of years, but while I was there 7 people left, 2 went on maternity leave and 9 new people started.

4.4.1 Staffing levels

At the outset there were 47 staff on the staff list, 19 of whom were full-time, with the remainder having various part-time hours. There was a pool of relief care assistants employed by the care home as required and a care agency was also used to provide adequate cover. There were 3 care teams, plus a night team, led by Senior Care Workers who managed a case load of named residents with the support of care

workers who were allocated key workers to named residents, and care assistants who were co-keyworkers.

The early shift ran from 07.30 to 16.00 and always had eight staff on duty, plus the manager and deputy manager Monday to Friday. The late shift ran from 13.00 to 21.30 and always had eight staff and the night shift had 4 staff. Not everyone did full shifts; often the relief and agency staff did shortened shifts which meant there was always sufficient staff but the organisation was not required to pay for breaks. There was rarely a shift when there was not at least one agency staff, and sometimes there could be up to four. Other staff employed by the care home included domestic and kitchen staff, a gardener, a handyman, and an activity co-ordinator. Other staff for whom residents paid privately included the hairdresser and podiatrist.

Primrose Hill was a social care home and therefore did not employ nurses. Both the manager and the deputy manager were trained nurses, but since the home was licensed to provide social care, they were not employed as nurses. Learning and training in social care and dementia care were, however, highly valued by the organisation and all staff undertook some form of training.

4.4.2 Staff Skills

Training was a work in progress in Primrose Hill. All staff were at various levels of the Scottish Vocational Qualification (SVQ) in health and social care for older people. This covered aspects of care such as communication, moving and handling and health and safety and, at level 3, more in-depth training on aspects covered so far in addition to palliative care and care planning. The Senior Care Workers (Team Leaders) were SVQ assessors. Senior Care Workers had to have SVQ Level 3 or a Higher National Certificate in social care. Someone with SVQ level 2 could take charge of a shift (shift team leader). SVQ training, from what people told me and from my own experience of attending moving and handling training, and from what I could glean from the Scottish Qualification Authority website, was not dementia specific. A number of staff, particularly new staff, were doing an online training course on dementia through a vocational college.

In Scotland, the Scottish Social Service Council (SSSC) and NHS Education Scotland (NES) have developed the Promoting Excellence framework in response to the Scottish Dementia Strategy (Scottish Government 2010). It details the knowledge and skills all health and social services staff should aspire to achieve in relation to the role they play in supporting people with a diagnosis of dementia, and their families, or carers. It outlines four incremental levels of practice: informed, skilled, enhanced and expert as shown in Box 2.

Box 2: Promoting Excellence Framework for Dementia (Scottish Government 2011)

The **‘Dementia Informed Practice Level’** provides the baseline knowledge and skills required by all staff working in health and social care settings including a person’s own home.

The **‘Dementia Skilled Practice Level’** describes the knowledge and skills required by all staff that have direct and/or substantial contact with people with dementia and their families and carers.

The **‘Enhanced Dementia Practice Level’** outlines the knowledge and skills required by health and social services staff that have more regular and intense contact with people with dementia, provide specific interventions, and/or direct/manage care and services.

The **‘Expertise in Dementia Practice Level’** outlines the knowledge and skills required for health and social care staff who by virtue of their role and practice setting, play an expert specialist role in the care, treatment and support of people with dementia.

All the staff in Primrose Hill had attended a training day run by the umbrella organisation’s dementia development officer based on the Promoting Excellence framework. This consisted of:

- A DVD from the Scottish Dementia Working Group to help people to see things from the perspective of a person with dementia
- A case scenario of a person with dementia for them to discuss
- The development of an information pack to hand out if someone comes to the care home looking for advice or help about dementia.

The aim was to have all the staff including the domestic staff *informed* (one day training) and all care staff *skilled* (two days training). Two care workers were dementia ambassadors²⁰ and were doing extra training through SSSC. For *enhanced* level training the plan was that staff would choose a special interest aspect of dementia care such as palliative care, activities or continence. Then they would form a group of interested people to lead on that issue in the care home. At the *expertise* level, all managers do specialist dementia training at Stirling University Dementia Development Centre. The organisation would like them all to do a postgraduate qualification but money is limited.

4.5 The Changing Focus of Care

One indicator of the changes in the residents within the care home and the changing nature of the care required was the increasing number of resident deaths over the last few years. In 2009 the care home had 8 deaths (one of which was in hospital), in 2010, 13 deaths in the home, in 2011, 11 deaths in the home and between December 2012 and November 2013, 16 residents died. Some of these deaths were people who had been in the care home for a number of years but three were people who came into the care home during my time there and died shortly afterwards, between three

²⁰ The role of Dementia Ambassador includes:

- Developing confidence using the Promoting Excellence learning framework to improve practice
- Promoting and distributing information about Promoting Excellence learning resources and opportunities within the local area
- Holding awareness sessions, offering peer support and/or signposting to sources of information and support
- Creating sustainability in improving dementia practice built on effective networking and ambassadorial support (SSSC Website 2015)

weeks and five months after moving, all three in hospital. It seemed that within the wider health and social care system the difference between residents who were assessed as requiring a nursing care home and those requiring a social care home were becoming blurred, with the consequence that Primrose Hill was now looking after residents who had more ‘nursing’ needs:

... she's got a lot of needs as well...she was very dependant and almost I think nursing home care, she should maybe...she shouldn't have come to us but we've had to work really hard because she's got a skin disorder and that. (Muriel, Staff Member, Interview, 11/3/13)

Also, becoming a specialist dementia care home had increased the complexity of the care that residents needed:

You know, now it's different of course but I remember when I start my job here it was two years ago it was quiet, we were sitting in the one lounge down the stairs, all the staff and we have three buzzers all night but now you know it's harder really these people they are getting more confused, this dementia progress, you know. (Paul, Staff Member, Interview, 7/8/13)

At one point a senior member of staff said to me ‘we are effectively running a nursing home’ and a number of staff referred to one corridor as the ‘nursing corridor’ because all the residents required hoisting. However, there was also a sense that, despite some staff talking about becoming like a nursing home, others perceived that the needs of the residents were not complex enough to require a nurse on every shift. When I asked one staff member whether she thought it would be good to have a nurse on every shift she did not think this was necessary, indicating a narrow technical view of what ‘nursing’ entails:

Kim (Staff Member) also seemed to think there would not be enough for a nurse to do and they would be bored. In the nursing home she worked in (before) she said that although less people had dementia, the residents were much more dependent with more nursing needs – here she mentioned

*hoists and catheters and diabetics. (Fieldnote p.277
25/7/2013)*

However, issues in the wider health and social care system seemed to be contributing to the changes in the needs of the residents. The managers felt that potential residents were being referred quite late in their illness. The consequence was that, even from the time a referral from a social worker is made and the suitability of the care home for the person is assessed, the person can have deteriorated quite a bit. This creates a problem for the care home in terms of workload and planning. This deterioration before moving could be as a result of a prolonged hospital stay prior to moving. It has significant implications if someone who is able to feed themselves then requires help as this is very slow and labour intensive work. The managers recognised an inequity in the funding arrangements to care homes without nurses as the fieldnote below indicates:

Care homes with nursing get a higher rate which the managers feel is very unfair as they feel they are doing the same job as care homes with nursing. They think the amount of money they get should be based on a needs assessment such as whether a hoist is required, whether help with feeding is required etc, and people who need this level of help should get the higher rate. Also they feel that it is unfair that people with dementia don't get the same level of funding and therefore the same level of care as people with cancer get – they are both a disease they said. (Fieldnote p.150 19/2/13)

Publicly funded rates for social care homes are £480/week and for nursing care homes £565/week (Scottish Care²¹ Personal Communication). The level of funding has implications for the number of staff and the skills mix. Most, but not all, the residents in Primrose Hill were self-funding and were paying £859/week. However, the care home was run by a not-for profit voluntary organisation who were struggling financially and had recently made cut backs in staff pensions, sick pay and paid leave. Any surplus is

²¹ Scottish Care is an umbrella organisation which represents independent health and social care providers

required to meet infrastructure costs. Increasing staffing levels to reflect the level of dependency of the residents did not seem to be an option.

An analysis of the design, or the geography, of the shower rooms serves to illustrate one consequence of the changing needs of residents in the care home in terms of care giving and care receiving.

4.5.1 The Geography of the Shower Room

Twigg et al (2011) suggest that the geography of a building in which hands-on care, or body work is delivered is central to the way that care is delivered. This came into sharp focus when considering the geography of the ensuite shower rooms in Primrose Hill. This section shows how the geography of the shower rooms made washing difficult for both staff and residents.

While shared bathrooms did have electric bath hoists, most residents were washed each day in the ensuite attached to their bedroom. Each ensuite had a toilet, wet room shower, sink and small set of plastic drawers for storing toiletries and wipes. There was no room for a chair in the ensuite so if a resident was unable to stand they would be washed while sitting on the toilet or else showered while sitting on the commode. Also a plastic drawer doubled as a wash basin for those residents who required a bedbath. This lack of space in the bathrooms and lack of equipment such as wash basins seemed to suggest that the care home was planned and designed with mobile residents in mind, perhaps reflecting its previous status as a residential home. This often made hands-on body work awkward for staff and undignified for residents, something of which both were aware. The fieldnote below, written while I was doing participant observation, perhaps indicates resignation or powerlessness on Nita's part:

*Nita (Staff Member) already had Maureen in the bathroom sitting on the toilet and was washing her. I felt slightly awkward about being there and said to Nita I would just leave her as Maureen was on the toilet and she said I should just come in as that is where they wash Maureen as there is no other way to do it with the size of the bathroom.
(Fieldnote p.283 31/7/13)*

The ‘geography’ of the shower room environment did not take account of the bodily effects of ageing and advanced dementia. As a consequence it may have been undermining attempts to provide dignified care and was also undermining the dignity of the care staff as they struggled to give care. While the bathrooms must have met the regulatory requirements in order for Primrose Hill to be registered, care standards which do not fully account for the effects of advanced dementia do not support the provision of dignified care and put front-line staff in the position where they increasingly need to make difficult point-of-care decisions on a day to day basis.

The next section takes a closer look at the cumulative complexity which led the staff to talk about their increased levels of busyness and feeling that people with dementia deserve a higher rate of payment in social care homes.

4.6 Types of Assistance Increasingly Required by the Residents

There were 3 broad types of assistance that it seemed the residents were increasingly requiring: more help to meet their functional needs such as washing, dressing and feeding, more emotional care, care while ill or dying.

4.6.1 Assistance with Functional Needs

During the fieldwork period only one resident would manage to get up and wash and dress independently, 14 would manage to dress but would require prompting or negotiation to wash, and 25 would require almost full assistance with up to six people requiring hoisting. Most people tended to be up and dressed and in communal areas during the day unless they were imminently dying. Only very occasionally did people have a morning or afternoon in bed. Part of the drive to get people up, a senior member of staff told me, was to prevent the residents getting delirium or other complications of being in bed such as chest infections. Consequently a considerable part of the staff’s day was taken up with washing, dressing, feeding, monitoring and documenting bodily functions, taking residents to the toilet, or moving residents around the building. The increasing needs of the residents due to dementia and frailty, the unpredictability of bodily requirements and the impossibility of delay, for example if someone needed help to the toilet, were coming to dominate all aspects of

life in the care home; even the hairdresser had noticed this change over the last few years:

I'm here a lot longer than I used to be...I used to cover the home, the same work in a day and a half, now I'm two full days because I can't work like a hairdressing salon ...these ladies can't have appointment times...I can't work within a certain time ...I can't plan the day, that is impossible because we'll be stopped in the middle for nurses, we'll be stopped in the middle for the chiropodist, em...they need to go to the toilet, they can't go off round to the toilet on their own, I have to stop what I'm doing and I have to get somebody to come and take them to the toilet so an appointment system would be just...it just doesn't happen. (Staff Member, Interview, 30/5/13)

Keeping up with everyone's needs was difficult and at times was a source of tension between staff and families. Una spoke about the challenges of looking after 40 residents and meeting the expectations of families who are paying more than £100 a day for their relative:

...at the end of the day this is our job, but sometimes you're just looking for some understanding that you've got 40 residents here, we've got five or four key clients and you just need to be...I was in a situation that I need to actually explain that I haven't got only your mum which I am looking after I've got the other residents and I can't leave them as well because of your mum so...but that was understand by the person I spoke but you know, sometimes it's difficult, sometimes it's difficult. (Una, Staff Member, Interview, 23/5/13)

The high level of functional needs of the residents sometimes meant that other forms of care such as emotional or spiritual care became side-lined. This was difficult for the staff as well as the residents.

4.6.2 Emotional Care

Coming into the care home was recognised as being the final stages of what might have been an already traumatic journey for the person and their family:

When I spoke about the complex needs that people now have when they come to a care home Elsie (Staff Member) said that as well as this they have been through the whole care system by this point and their care package has failed and they are therefore also exhausted and shell shocked. (Fieldnote p.324 7/10/13)

People with dementia in care homes experience a complex mix of emotional, spiritual as well as behavioural and psychological issues which can be exacerbated by unmet physical needs (Downs & Bowers 2008). When 40 people with dementia are living in one place the needs of individuals can be difficult to meet and can escalate:

.....when you have 40 residents you know, you are one person on the floor for 12 residents. I have one time a problem in the annex when 4 residents was up and everybody was confused. I was myself...you can do nothing, nothing at all, it's very hard. (Paul, Staff Member, Interview, 7/8/13)

The staff felt compromised in their ability to care for the whole person, as the quote below shows:

It's hard like because you're having like people come up to you like Wanda, because she's so confused she's coming up to you every two minutes but you're taking someone to the toilet and you have to sort of, oh Wanda, I can't help you just now, can you go and sit down, and it's just telling the people to sit down over and over again. It feels quite horrible just to be telling people, sit down. But because you're taking someone to the toilet or you're taking someone to bed, you know... (John, Staff Member, Interview, 19/4/13)

What could be described as 'nursing care' also seemed to play a large part in the day to day work of the staff, as shown below.

4.6.3 Nursing Care of Ill and Dying People

The focus of the handover, which all staff got when they came on duty, exemplified the focus on illness and the biological body. The predominant focus was on bodily functions such as bowels and urine infections. Although this was a social care setting

the language used at the handover was clinical. The field note below illustrates this and also some uncertainty about the best way to care for Abi who had distressing skin problems requiring a regime of lotions and creams:

Abi is going to see the dermatologist today. There was some discussion at handover about whether they are doing barrier nursing or not. Abi has MRSA. They have been told to use aprons and gloves in her bedroom but Abi is sitting in the sitting room with other residents and they are not using gloves at these times. Some staff are keeping her in her room and others aren't but the family keep bringing her out of her room. There is confusion and inconsistency about the best approach. (Fieldnote p.242 24/6/13)

The focus on bodily functions in handover was to pick up on subtle changes which may have indicated, for example, a urine infection which could lead to confusion or delirium, which as well as being upsetting for the person, could be very upsetting for everyone else. Keeping on top of brewing infections was important, not only for the well-being of the person affected, but for maintaining a calm atmosphere and social order in the care home. Handovers were also the time when ‘*making the call*’ that someone was now ‘*palliative*’ would be made. This meant they were now dying although they did not use the word ‘dying’. This was usually after a period of decline, or several periods of decline and recovery, where antibiotics were no longer working and it was recognised that the person was not going to recover. The length of time that residents were identified as ‘palliative’ ranged from one hour to three weeks during my time in the care home.

When I started fieldwork both the manager and the deputy manager were trained nurses. However, since the home was licensed to provide social care, they were not employed as nurses. This meant that they were not insured to undertake nursing procedures such as giving pain medication by injection or changing wound dressings. The care staff, however, often sought their advice when a resident was unwell, and the managers also often were the staff who liaised with the primary care team. A manager told me that sometimes carers felt intimidated by doctors and didn't have the confidence to say what they know about the residents. However, the managers

worked 7-4pm Monday to Friday so this clinical expertise was not available within the care home out of hours.

Community nurses visited Primrose Hill frequently, for example, if a resident had been in hospital and returned with a catheter, to renew wound dressings or, if someone was dying, to provide support and advice to staff and families and manage difficult symptoms such as pain or agitation. However, because there was no nurse employed on site, the delivery of nursing care could be disjointed and therefore prolonged and exhausting for both residents and staff. One morning I was helping Kim (Staff Member) as she assisted Catriona with a bed bath. Catriona had recently been discharged from hospital after a fall where she had broken her hip and elbow and dislocated her shoulder. We needed to hoist her from the bed to the wheelchair. We had just completed this manoeuvre when the community nurse arrived to change Catriona's catheter and we had to hoist her back onto her bed which was confusing and uncomfortable for her. The community nurse was not usually around during morning care or if someone needed a soiled sacral dressing changed during toileting, and care staff were not supposed to change dressings. Additionally, while the staff and management in the care home tried their best to deliver good palliative care, there were times when I think they were beyond the limits of their skills. The staff were beginning to recognise the limitations of their abilities to meet the needs of residents approaching the end of their lives:

Wendy (Staff Member) spoke about the Alzheimer Scotland end of life care course she did recently. She was a bit disappointed with it as she felt it didn't address enough of the medical side of palliative care but was too social. The staff struggle when there are more complex symptom issues to deal with. (Fieldnote p.152 19/2/13)

Wendy did say that a lot of the staff have been to a local hospice for placements to learn about palliative care but the problem is that everyone had cancer so what they were seeing was not easily transferable. (Fieldnote p.114 24/1/13)

After these conversations I shared a number of palliative care tools with the senior managers including pain and depression assessment tools, a prognostic indicator guide, and a leaflet on how to care for someone with advanced dementia.

Lillian was seen frequently by the GP and the community nurse when she was dying but I was unsure if she was getting the right palliative care support, even from them:

Spoke to Elsie (Staff Member) who said that Lillian's death wasn't as settled as she had hoped. She felt the family were very stressed and they agitated Lillian....I said to her that I wondered if she would have been better going straight to the syringe driver rather than on to the fentanyl patch (fentanyl patches are only for stable pain) and that I wondered if she had too much morphine on board and that was making her agitated. Elsie felt she started on oromorph too soon. I said it was good she was on midazolam (for agitation). The staff had given the family their end of life policy as a guide to what was happening. I don't think her symptoms were well managed at all but really this is the job of the GP and the district nurse as this is not a nursing home. (Fieldnote p.175 26/3/13)

A few weeks later Muriel (Staff Member) also spoke about Lillian having a difficult death. Lillian's daughter described her mother's death to me as 'prolonged and painful' and three months prior to Lillian's death her daughter told me she felt her mother had no quality of life. At the same time, however, she saw her mother as having received very good care in Primrose Hill.

From the outset of fieldwork I was struck by the complexity of caring for people with dementia all of whom were at different stages and had various co-morbidities. I began to question whether the training for staff working in social care homes matches the complexity of the holistic care required by the residents. Below Vera is describing the intensity of caring for people with dementia:

... I think it's just such a devastating thing to have, I think it's the worst thing...you know and it's hard to deal with because it is very ...ok like physically when they are deteriorating physically but it's very emotionally and mentally straining,

you must know from sitting in here. (Vera, Staff Member, Interview, 26/6/13)

In the literature review I highlighted how the population in care homes, social care homes as well as nursing care homes, is getting older, with the number of people in the 85 plus age group rising. With multimorbidity, this age group has more complex needs and also is more likely to be closer to death (Scottish Care Home Census 2013, Spijker & MacInnes, 2013, Perrels et al 2014, Formiga et al, 2013). Primrose Hill was working through these changes and also the changes that had come about by becoming a specialist dementia care home. The care home had a good relationship with a local GP practice who provided care to many of the residents and a GP visited every Wednesday and at other times. Other residents who were from the local area had kept their own GP, and the staff therefore liaised with a number of practices. There is increasing concern about the sufficiency of external support available to support care homes (Seymour et al 2011, Reid et al 2012, Amador et al 2013). This is particularly pertinent to care homes without nursing and raises questions about the kind of skills which should be available within care homes to care holistically for people with dementia towards the end of their lives.

4.7 Social Care or Nursing Care?

Although on one level the staff could see the increasing frailty of the residents they cared for and the number of deaths and that they were like a nursing home in that respect, at the same time, they saw themselves as a social care home and took pride in that, as the fieldnote below suggests:

Elsie (Staff Member) also talked about the complex needs of people coming in now. I asked why these people don't go to nursing homes – she says people prefer to come to residential homes because in nursing homes people are just put to bed and it is task orientated and all focussed on their illness whereas here people are up and dressed and in company. (Fieldnote p.209 15/5/13)

There seemed to be a disconnect between the rhetoric of what the care home saw itself as doing and what was actually happening. Primrose Hill seems to have tried to move away from the institutional, task orientated model of care which has become

associated with a medical model towards one which is more holistic (McCormack et al 2012). This was evidenced by such things as key working, the provision of entertainment and activities, opportunity to attend Christian worship, emphasis on residents perspectives and experiences, through, for example, resident focus groups, and by trying to develop a sense of community, for example, by hosting a Summer garden party to which all families and staff with their families are invited. Yet day to day the main concern seemed to be to maintain social order and avoid chaos. It seemed that the care home was geared towards wellness and so if someone was ill or dying, which was frequently the case, and simply because of the high level of need of the residents, they were always struggling to avoid chaos descending. This was always a possibility because of the unpredictability of bodies (Cohen 2011), for example, when someone might become ill or reach the end of their life. There was no slack in the system:

A good shift Hilary (Staff Member) told me is when there are no falls or any other incident, nobody is ill, and there are enough staff (Fieldnotes p.42 15/11/12)

Elsie (Staff Member) told me Ursula who hadn't been so well is a bit brighter now and is able to weight bear and no longer requiring the hoist. This is better for them (the staff) she said – when someone is less well it puts a lot of strain on them as there is no slack in the numbers (Fieldnote p.86 14/12/12)

For the organisation 'what worked' was trying to avoid chaos and reduce risk. This lack of slack in the system and striving to maintain order is most graphically illustrated in the way that residents became 'objects of surveillance' in lounges, to protect them from falling. As previously described, there were three large sitting rooms in the care home where most of the residents sat during the day. One member of staff was allocated to stay in each room, primarily to keep people safe. They were also expected to interact with the residents while they did this. There could be up to 18 residents in the room at the time. The following scenario illustrates the dilemma for staff in balancing choice and keeping people safe during these long periods of 'watching over' in the lounges. The staff knew that residents might try to get up and walk because they needed the toilet but couldn't verbalise that. However, in the

scenarios below Betty was a lady who liked to walk around but was unsteady on her feet:

Betty tried to get up. Emily (Staff Member) asked her to sit down again and of course this then made Betty angry. Again she tried to get up and Emily came and sat with her and asked her to stay seated. However Betty was becoming more angry and trying to get up. Emily then decided to go for a walk with her. I think if I hadn't been there in the room this would have been more difficult for her to do as she couldn't have left the room unattended. At the time Emily was watching over about 15 residents in the sitting room, making sure no one came to any harm and also with an expectation that she would engage with them. Later in the other room exactly the same thing happened again – this time I said to the carer that I would go for a walk with Betty. Kim (Staff Member) was getting quite flustered with trying to keep Betty seated. When I offered to take Betty for a walk Kim said it is really hard when there is only one person watching over the room because it means they can't just walk away with someone like Betty. (Fieldnote p.300 14/8/13)

Giving people with dementia the opportunity to engage in meaningful social activity is central to dementia care as boredom can increase agitation (Downs & Bowers 2008). During my time in the care home I observed a number of different types of 'activities' some of which in my view worked better than others. Those which worked best involved music or dancing. The staff were finding that because of the increasing frailty of the residents, it was becoming more difficult to find suitable activities:

Brenda (Staff Member) said to me that crafts are not really working anymore because people are not well enough (Fieldnote p.85 10/12/12)

Despite the SVQ training and training on dementia through the Promoting Excellence Framework, the care staff in the evenings when the activity coordinator had finished for the day often still focussed on 'activities' which did not account for the cognitive effects of dementia. Bingo is an activity often associated with care homes and older people and the staff in this care home were no exception in thinking this might be a nice evening activity for the residents, as one carer said 'to break the monotony'. The

difference between bingo and dancing is that bingo requires cognitive functioning, whereas dancing depends more on embodied action at the pre-reflective level. The following is an extract of fieldnotes taken one evening at a bingo session:

John (Staff Member) came in and began to get organised to play a game of bingo. There were 18 people in the room. Only three said they wanted to play. John gave sheets out to some people who did not reply when he asked them but put the sheet next to them anyway. Several said no or said they had never heard of bingo and had never played it. The numbers were generated on the computer and John called them out – he then went round and ticked off people's numbers. Only two people were able to tick off their own. One lady joined in by helping her neighbour although she had said she wasn't playing – in the room were a retired doctor and a retired lawyer so I'm guessing bingo is something they would not choose to play – I felt it was imposed on them. Muriel (Staff Member) had brought the prizes in which were soap and bubble bath etc. At one point she came into the room and one of the ladies was laughing and said this was the first time in her life she had played bingo – she seemed to enjoy it and Muriel took this to mean that it was a great success. (Fieldnote p.193 30/4/13)

Through the analytical lens of the body, I would suggest that the majority of the residents playing bingo were being positioned as 'body-objects' rather than 'body-subjects' in that they were not really actually playing bingo and neither had they chosen to play it but rather were merely passively present. They were not genuinely engaged in an activity that drew on their abilities. Most of the residents in this 'performance' of bingo, I would suggest, were not being treated as experiencing subjects but as objects who were just there, like biscuits in a tin (Merleau-Ponty 1962). This sounds very critical and I do think there is something to be said for the staff's efforts at creating a sense of community by being inclusive. However, there is a difference between this and creating an appearance of life which is more of a performance than real (Komaromy 2010).

From my observations and from talking to the staff it seemed to me that the changing resident population had thrown the care home into a state of uncertainty about its role

and purpose, and its ability to fulfil that role. This raises fundamental questions about what ‘care’ entails for people with advanced dementia as they approach the end of their lives and the nature of the care-giving/care-receiving relationship.

4.8 Conclusion

This chapter has set the scene for the next three results chapters. It has given a description of the care setting, the people involved and also some of the organisational challenges which are shaping the care-giving/care-receiving relationship. These illustrate that, due to increasing numbers of people with dementia in the population and changes in health and social care which means that the population of care homes is becoming older and frailer, Primrose Hill is in a state of flux.

Analytically this brings to the surface questions about what ‘palliative care’ entails for the oldest old with advanced dementia in care homes in the last years, months and weeks of their lives. The next three chapters seek to analyse and articulate the complexities of ‘palliative care’ and the caring relationship more closely by focussing on three themes which emerged as important aspects of care-giving and care-receiving: body work, recognising and supporting selfhood and witnessing and responding to suffering. The way that people with dementia are positioned within what emerged as constituent parts of care-giving and care-receiving is examined.

5 Body Work

5.1 Introduction

General daily life revolves around the maintenance and care of our bodies; the rhythms of the body and its care provide an existential foundation for day-to day existence (Twigg 2000). When 40 people, most of whom require some assistance with bodily care are all living in one place it therefore seems inevitable that body work is a key focus of the day for the staff and residents in a care home. Body work is work that focuses directly on the bodies of others: assessing, diagnosing, handling, treating, manipulating, and monitoring (Twigg et al 2011).

My fieldwork observations confirmed the above; body work was one of the main points of contact between staff and residents and, therefore, a key component of their relationship. Body work, as mentioned previously, is regarded as unskilled and therefore low status work. Consequently, little analytical attention has been paid to body work in dementia care and the experience of people with dementia as they relate to their carers in this way. As Twigg (2000) suggests, the task, say washing, can be accomplished but it is in the fine texture of the exchange that the essence of care lies. I am interested in how the fine texture of the exchange during body work can illuminate the essence of care for people living and dying with dementia.

The aim in this chapter is to analyse the body work which took place in Primrose Hill from the perspective of both people with dementia and the staff caring for them. Since body work is a core part of 'palliative care' and much of the caring relationship revolves around giving and receiving bodily care, a deeper analysis of body work in this chapter will help develop a better understanding of what 'palliative care' entails in the context of advancing dementia. I begin by giving a description of the daily routine in Primrose Hill in order to demonstrate the centrality of body work and confirm its importance as an analytical focus. I then go on to describe some of the tensions and complexities involved.

5.2 A Typical Daily Staff Routine

Although there was flexibility in the routines of the residents, such as the time they got up, there was an observable rhythm to each day. This description focuses on the visible, predictable and non-negotiable work the care staff do each day, meeting basic needs such as washing and feeding people. It does not include specific illnesses or dying which could occur in the course of a shift, nor does it include the hidden work which took place in private spaces and face to face with the residents. The hidden and 'unpredictable' work, and indeed the daily lives of the residents will become more visible as this and subsequent chapters progress.

After morning handover from the night staff, the day staff went to their allocated corridors at 7.30am to check which residents were awake and to decide who they were going to help to get up. Once the resident was washed and dressed the carer would bring them to the dining room, get them seated and bring them their fruit. Two members of staff served breakfast in the dining room while the team leader dispensed medication to the residents with their breakfast. The medication could take up to 2 hours to dispense. This process of getting people up and into the dining room and fed could take up to 10.30am. Some people were in the dining room for over an hour as they slowly fed themselves, were prompted to feed themselves or were given assistance. Some residents were able to get up when they were finished and walk back to the lounges, but over half of them required assistance both to walk and find the lounge.

The activity coordinator started at 9am and would begin by walking people who had finished breakfast back to the lounge, where she then spent some time doing a group activity such as exercises. The activity coordinator then took those who wanted to go to the activity room. This tended to be those who were more cognitively able or more sociable. There were usually about 11 people out of 40. They chatted, looked at newspapers and did a quiz and then had coffee and biscuits. They had their own special china and there was a sense of it being something special. The remaining 29 residents were now dispersed between the three lounges, mainly the music lounge and the TV lounge.

At 10.30am the tea trolley came round. There was usually one member of staff watching over each lounge while the rest of the staff began to take people to the toilet. The person watching over the lounge sat with residents or gave handcare, or repaired residents' clothes (each staff member was a 'key worker' for specific residents and was responsible for their clothes and toiletries). Some staff did their 'key chats' with the residents for whom they were key worker. A 'key chat' was one-to-one time and was an opportunity for the resident to raise any issues or concerns with their keyworker or to do something they enjoyed such as look at photographs.

During this time the hairdresser, podiatrist, GP or community nurse or other outside professionals might also be seeing residents and the staff would usually be required to facilitate this.

By 11.30am residents would be back from the activity room and the activity coordinator would do one-to-one work with residents she had not yet spent time with, such as going out for a walk or handcare. Occasionally there would be a trip out in the morning. Individual residents might also have friends or family come or take them out for lunch. One resident had a befriender.

By 12.00 midday there was a move back to the dining room for lunch which usually took until 1.30pm to complete. Throughout lunch the team leader dispensed medication. During this time staff had their own lunch breaks, wrote up documentation, made phone calls such as to the GP practice or pharmacy, or emailed families. The late shift staff started to come on at 1.30pm although often there were staggered start times which meant the team leader giving a number of handover reports throughout the afternoon.

In the early afternoon the activity coordinator might organise a small group to play scrabble or there might be a church service or a concert with musicians coming from outside. Staff again did key chats with their key clients or sorted out laundry. The watching over the lounges and sorting out laundry or tidying rooms continued, as did the regular toileting and care of anyone who was ill or dying and their families. Staff might be given protected time to do care planning or SVQ work. Sometimes there were training sessions, for example, on caring for people with sensory impairment.

Sometimes up to two or three families visited in the afternoon. For many residents the afternoon seemed to be quite long and was spent snoozing.

At 3pm the tea trolley came round. Sometimes the care staff would organise carpet bowls or something similar. Around 4.45pm mobile residents began to gather outside the dining room for dinner. Dinner lasted until 6-6.30pm and again throughout the meal the team leader dispensed medication.

The time between 6pm and 9pm often felt quite fraught with many residents being agitated and wanting attention. Depending on which team leader was working, the routine could be quite different. One team leader thought the residents were tired by now and her approach was to get people to wind down, bringing calmness and getting organised for bed. Some people might go straight to bed after dinner and others might come back to the lounge in their dressing gowns for a hot drink and a biscuit at 7.30pm. Another team leader felt that people were bored at this time and she liked to organise some activity such as bingo or a film night as she felt this gave people a better quality of life. This meant that getting people ready for bed did not happen until later. As usual the regular toileting continued.

A 9pm check was done of anyone in bed to make sure they were safe and anyone who had bedrails, a crash mat etc. had what they needed and this got marked off on a sheet. The day staff did their documentation and reported any issues to the team leader.

At 9pm the night team leader arrived for an update of the day. The other three night staff came on duty at 9.30pm and received a quick update from the night team leader before going to their allocated corridor of bedrooms.

The night team leader then began giving out the medication, a process which again took a couple of hours. The three care staff then got whoever was still up and about to their rooms for bed, one by one. Sometimes if there were quite a few people still up they would bring the tea trolley to the sitting room at this time.

Once everyone was in bed, the staff then checked those who were already in bed when they came on duty. This included checking people were in their beds and had

not fallen out, checking incontinence pads or taking people to the toilet and giving drinks.

After the midnight round, the staff did their cleaning duties, wiping down surfaces in the sitting rooms and generally tidying up. Breathing checks were then done two hourly overnight unless the resident had requested not to be disturbed in this way. Only one resident had requested not to be disturbed and had a form signed in her notes saying this. Some people also had their pads checked if they were known to be incontinent overnight. For a lot of people the check involved the staff going in quietly and checking breathing without disturbing the resident.

In between checks the staff did various jobs, for example, sewing name bands on new clothes and answering buzzers. Each member of staff sat alone on the corridor they were covering. It depended on how the residents were, whether there was someone dying and/or there was family sitting with them whether this was a busy time or not.

If it had been a settled night residents generally seemed to begin to stir around 5-5.30am. At this time the staff also did a round where they changed people who wore pads. This waking meant that some residents then got up at this time while others went back to sleep. The staff also emptied rubbish bags and updated fluid and bowel charts. The TV went on in the sitting room around 5.30am for any resident getting up. The domestic supervisor arrived at 5.30am and began vacuuming the communal areas. The kitchen assistant arrived at 6am. If any resident was up they were given tea and biscuits. One resident liked his shower at 6am. The manager arrived at 6.30am. The team leader would dispense any necessary medication such as pain killers before people got up. The night staff gave quick updates to the night team leader about how people on their corridor had been overnight and they wrote their notes. The early shift team leader was given a handover from the night team leader between 7am and 7.15am before the day shift began with the handover at 7.30am.

The predominant focus of the daily routine of the staff, due to the high level of dependency of the residents, was on body work. During fieldwork I had the

opportunity to assist with body work and the complexities of such work were evident.

5.3 Body Work - A Task or an Opportunity to Build a Relationship?

Kontos & Martin (2013) suggest that the personhood movement has inadvertently privileged the social over the corporeal with its focus on interactionist conceptions of self. A potential consequence of the privileging of the social over the corporeal within social care homes is that it could relegate body work to a task rather than seeing it as part of the care of the whole person. The following quotes seem to affirm this suggesting that body work has become equated as a routine task:

The books say, you know, all the leaflets you hand out from (Voluntary Organisation) say that we work in a person centred way. The reality is we get so caught up in the very basics of feeding people, toileting people and, um, putting them to bed that we sometimes miss the person centeredness. (Muriel, Staff Member, Interview, 11/3/13)

The high levels of dependency of the residents meant that attending to functional needs was somewhat relentless and it was easy to see how the staff came to see themselves as ‘caught up in the very basics’. In some ways the staff had become slaves to ‘the routine’ in an uncritical way, or at least did not feel able to question it. This was best shown during the night where residents would be disturbed every two hours so their pads could be routinely checked without considering whether the impact of disturbed sleep could be avoided for at least some residents. A distinction was made between quality of care and quality of life:

But we’re trying to improve, not the quality of care...there’s nothing wrong with the quality of care, we’re trying to improve and make life a bit more interesting and we feel that’s important. (Muriel, Staff Member, Interview, 11/3/13)

The above quote also seems to suggest that the social aspect of care is more important in terms of quality of life than care of the body. Staff were concerned that the amount of time taken up with body work meant that often residents were sitting for long periods in the morning, afternoon, and evening with very little interaction

with staff outwith the time they were receiving bodily care. The care home managers and staff, including the activity coordinator, tried to address the residents' need for meaningful engagement as best they could.

Kontos (2003, 2004), as described in the literature review, highlights how the body is a constituent of selfhood; that if we fail to pay attention to the embodied nature of human existence as a fundamental aspect of our humanity, then we ignore a vital aspect of personhood that persists for those with dementia. If the body and mind are not taken together as the whole person, it can lead to bodily care being delivered in a perfunctory manner. Equally, if care staff are forced into situations where they are rushing care, for example rushing to get people up in the morning because they know three other people are also waiting to get up and have breakfast, it can lead to perfunctory care. It undermines selfhood and overlooks the importance of bodily care and comfort which older people have identified as increasingly important as they become frailer (Bower et al 2001). From the outset of this study I was interested in the ways that the staff related to residents during body work.

It was clear that some staff saw giving hands-on care as an opportunity to connect with the residents and not merely a task to be performed:

I still make a point of it's not just a task at hand, it's, this is time where you are interacting one-to-one and it's good for them because they can have a chat with one person one-to-one and even if they are not really talking, it's still that one-to-one time that they are getting... (Edith, Staff Member, Interview, 11/3/13)

Even taking someone to the toilet was often used as an opportunity for a chat:

Vera (Staff Member) came in and went over to Annie. Annie was admiring Vera's jumper which was long and had a picture knitted into the front of it. Annie always wears nice dresses so maybe she likes clothes. Vera chatted to her about where she got her jumper...she then asked quietly if Annie would like to go to the toilet and off they went. A few minutes later they walked back in. Annie was smiling and looked happy. The sun was shining through the windows and the room was brightly lit up and Annie said 'Oh I'll go back to my nice little cosy corner' - she always sits in the same seat

in the window where it gets the sun. It seemed that this was an interaction that was centred around an act of physical care but which was done in a way which made Annie feel happy - there was a bit of initial chat about something she liked, she was respected and her dignity remained intact – she was a person first and the fact that she was a resident who needed help was secondary. (Fieldnote p.139 11/2/13).

Being in the person's room and surrounded by their own familiar things, part of what made up their identity also seemed to help make a connection:

So I think it is a time, you know, that you are in their rooms and you've got all the objects around you that are familiar to them, so it's so easy to like make a conversation about that, you know, and to just get their attention maybe. (Zoe, Staff Member, Interview, 7/3/13)

While Anne and I were washing and dressing Lillian one morning, Anne made every effort to engage Lillian, always making eye contact and smiling and telling me about Lillian and her life. Lillian required help with everything and used a hoist. Lillian had virtually no verbal communication. Lillian seemed to trust Anne and was smiling back and seemed to be engaged with us. Afterwards Anne said:

.... sometimes there is pressure to work faster but I think you need to spend the time, this is the only time I get to spend with Lillian. (Anne, Staff Member, Interview, 7/3/13)

The increased time required for more hands on care which comes with increasing physical frailty, the 'slow work of gentleness' (Robinson 2004 p.220), may mean that there are more opportunities for relationships to be built up *if* the emphasis shifts from the task of care to the building of relationship (Ronch 2004). If the emphasis in these caring encounters is refocused from the task of care to the building of relationship, this could have great potential for culture change within the care home setting (Ronch 2004). This means a shift from the 'what' of care to the 'how' of care and directs attention towards the relationship between care provider and care recipient and how each are affected by it (Bowker 1992 cited in Ronch 2004).

The above quotes describe care-as-relating (Bowers et al 2001) which Moser (2011) suggests is a way of holding people with dementia in relation and helping them to participate in and connect with the collective life of the home and the rhythms of sleeping and waking, and mealtimes. There was a recognition that within this interaction there was still a task to be performed. If the carer does not know the resident well or does not often perform body work, the task dominates the interaction:

Because I don't do it that much I've got to check what pad number it is and sometimes I'll talk my way through it... But once a task is done maybe if I've put someone in bed I'll not just shut the door and walk out, I'll maybe sit on the edge of the bed and have a wee chat, um... I'll take the opportunity then but while I'm doing it I feel that I've got to focus on the task that I'm doing. (Muriel, Staff Member, Interview, 11/3/13)

If staff do not know the residents well, then body work is in danger of becoming a task and not an opportunity for an interaction. This is perhaps most obvious with agency staff. The following fieldnote taken on a night shift seems to suggest that the relationship of agency staff with the residents was pragmatic or instrumental:

The agency carer was responsible for 10 people he had never met before. I felt sorry for him - he looked nervous. He was writing down lots of notes about pads and who could stand and who should have a crash mat etc. It is a huge responsibility. (Fieldnote p.211 16/5/13)

I did not have much opportunity to observe the work of agency staff due to ethical constraints but on one occasion I worked with an agency carer who was in the care home regularly and had given her consent. The following is a reflective fieldnote recorded after observing her washing Maureen:

The whole interaction between Maureen and the carer was focused on getting Maureen up, superficially washed and dressed with as little delay as possible. Although the carer was not rough and did speak to Maureen in a gentle way, the focus was on physical care. There was no banter and the carer did not tell me anything about Maureen in the way that

other carers have done with residents which indicated to me that the only thing she knew about Maureen was how to get her up and what needed to be done to achieve this. It seemed that this is what she was there to do. It is too harsh to say that it was perfunctory. I think the carer was taking some care to make sure Maureen was alright but I would not say that there was any meaningful connection between them during this interaction. (Fieldnote p.136 11/2/13)

Perhaps the agency carer's gentleness is evidence that she was compassionate and able to reflect on Maureen's vulnerability, but her approach seems to suggest an understanding that she is being paid to get Maureen up and dressed rather than to build a caring relationship with her which supports her selfhood. In the circumstances I think agency carers are very limited in the possibilities there are for them to do this and thus focus on what they can do.

The care home tried to get regular agency staff who did get to know more about the residents from the regular carers but this was not always the case. Kelly (2013) suggests that 'in the absence of any 'quick fix' solutions to organisational and structural constraints in dementia care and in an attempt to move person-centred theorising beyond intangible, uncertain and problematic ideals' (Kelly 2013 p.1085) care workers without a knowledge of the person can still, through empathic reflection, engage sensitively with people by recognising aspects of selfhood that they share in common.

The regular staff were able to reflect empathically on what it might be like for the residents to be dependent on them and a sense of their shared humanity:

Because there for the grace of God go any of us, you know. We could all be in the same situation, therefore we should have an understanding of what it's like, to actually...and to be so in other people's care and so dependent on other people, I think that's...you know, would be a very difficult thing...situation. (Anne, Staff Member, Interview, 7/3/13)

I am man you know, it is very hard when I have to change somebody pad, especially a woman, ok what this man doing ...I would be feeling exactly...not comfortable you know if

*somebody came to my room to check what I have in my
breeks²² you know? (Paul, Staff Member, Interview, 7/8/13)*

The care staff recognised that it might be embarrassing to need help with a wash and they tried to support the dignity of the residents:

I try and make them feel as comfortable as possible. I try and make it like it's no big deal, you know it's just like 'O come on we're getting ready' you know you're just trying to keep their dignity and you're just...because they are fully aware they are naked and, oh that must be horrible so I just try and act like, I just act normal and I don't, I still talk to them, I don't keep in silence because I think that's bad and if there's a radio I have the radio on and we just, just to distract them a little from what's going on. (Vera, Staff Member, Interview, 26/6/13)

People in the later stages of dementia, as Vera recognises, are fully aware of their vulnerability:

I sat in the sitting room and chatted to one lady – she was saying her legs weren't right and were wobbly. She asked me how my legs were and told me to look after my legs because if your legs don't work then you are at the mercy of somebody else. (Fieldnote p.211 16/513)

The variability in the residents' functional abilities day to day also often led to washing and dressing being dominated by the task rather than an opportunity to build relationship. Quintin was a very tall well-built man and although he could physically stand, he often found it difficult to understand what was being asked of him. He also had painful arthritis in his knees and ankles for which he had ibuprofen gel prescribed. One morning I was helping Izzy assist Quintin to get up, washed and dressed. After spending some time trying to explain to him that we would like him to stand, he could not follow what we were asking him to do and we eventually had to use the hoist to move him from the bed to the commode. We gave him a shower but

²² Scottish word for pants

he had been faecally incontinent and we again asked him to try to stand so we could wash his legs properly:

By some miracle (at least that is what it felt like) Quintin suddenly did manage to stand with his zimmer and he stood for ages while we got him cleaned up. I think the secret was that we weren't hauling him or pushing or pulling him and without this he got it – that's what puts some of the residents off – it's as if they do know what to do but rushing them or over explaining or trying to help is counterproductive and just leads to confusion – maybe it is an overload of information – at least on this occasion it was – he is so variable. (Fieldnote p.306 15/8/13)

Wangblad et al (2009) suggest cognitive decline and communication difficulties increase physical strain on care staff and that flexibility and specialised training in transferring skills is required in dementia care. No doubt pain associated with conditions such as arthritis also plays a part. Perhaps Quintin did not want to get up and we were so focussed on the morning 'routine' that we did not consider this is what he was communicating.

An overarching observation of my fieldwork is that body work is more complicated when dementia is layered on top of an already frail body, often becoming an area of ethical uncertainty.

5.4 The Complexity of Body Work and Ethical Conflicts

From my observations and participation in care I could see that when dementia is layered on top of a physical need, meeting that need is much more complex and time consuming. The example below shows how having a blocked catheter removed and a new catheter inserted by the community nurse was distressing for Catriona who was struggling to make sense of what was happening:

It was necessary for Catriona to position her legs in a way that allowed the nurse access to her urethra but Catriona found it very difficult to do this. She was bewildered and upset by what was going on and the catheter was obviously quite sore as she was wincing a lot and screwing up her face. (Fieldwork p.275 25/7/13)

The community nurse had not met Catriona before and so was relying on the carer to help keep Catriona calm. As I came to see, body work was not straightforward but was imbued with ethical dilemmas. Thus seemingly simple tasks, carried out by care staff, who were not professionally trained, were a constant balancing act between giving the residents choice on one hand and avoiding potential harm on the other. This requires reconciliation of two basic principles of ethics:

- The universal duty of good clinical care – the use of expertise to protect life and health of the people to an acceptable standard
- The universal duty to respect the autonomy of people (Clarke et al 2011)

I will focus below on three aspects of body work, namely washing and dressing, mealtimes and palliative care, and use them to explore these ethical issues through the analytical lens of the body. Using the body as an analytical lens opens up consideration of whether residents are perceived as body objects or experiencing body-subjects, the ways they enact their subjectivity and how this is attended to by the staff.

5.4.1 Washing and Dressing

Maureen was a lady who was completely dependent on the staff for help with washing and dressing. When up and dressed and in the sitting room she appeared content and happy and would smile and laugh and say ‘*I love you*’ or ‘*I like it here*’. While she was being assisted with care however she would often appear disgruntled, not smiling and very stern faced. She would use phrases such as ‘*Poor old Maureen, being pushed and pulled*’ or ‘*I’m in a hole*’ as she sat being washed on the toilet and could also direct her distress towards the staff:

Anne (Staff Member) showered Maureen while she was sitting on the toilet as Maureen has difficulty standing. The whole time Anne was kneeling in a puddle of water – I asked was she not getting soaked and she said she is always wet when she is at work. A few times Maureen looked directly into her face and told her she was ugly at which Anne just laughed. (Fieldnote p.188 26/4/13)

Tensions often arose between staff and some residents in the area of washing and dressing, particularly with those residents who were more physically able:

Elsie (Staff Member) also got on to the topic of Floss who doesn't like to get up in the morning. Her family want her to be up and the Care Inspectorate don't like to know that people are lying in bed but they don't see the whole picture and that Floss doesn't want to get up and they can't force her. (Fieldnote p315 22/8/13)

...they might not feel comfortable with you giving them a shower, or anyone giving them a shower...but, like, you've got to give them a shower, you know, you've got to help them in that way. (John, Staff Member, Interview, 19/4/13)

The staff struggled on the one hand to meet what is seen to be a good standard of care by the Care Inspectorate and, on the other hand, support residents' right to choice and control. This negotiation in day to day practice was demanding and time consuming for the staff. Even in the hairdressers, hair washing could be a struggle and the staff were aware of the ethical dilemmas:

I find that the carers must find it very difficult because where does...what would be the right word...where does abuse start and where does it end because would it not be...it would be abusive to let somebody be covered in faeces because they are not going to cooperate to get washed or have hair that's filthy dirty and they won't agree to have it washed. (Catherine, Staff Member, Interview, 30/5/13)

An examination of reports from the regulatory body, the Care Inspectorate, show that soiled food on clothes is identified as an indicator of poor quality care. It may be that the regulatory system is operating on the assumption that care is unproblematic, but care is not a simple 'thing' (Twigg 2000). Using the body as an analytical lens it is clear that people with dementia are not passive objects of care but rather experiencing body-subjects with agency and intentionality, struggling to make sense of their world and come to terms with receiving help. The emotional demands placed

on the care staff is illustrated in the quote below where Harry resents the fact that he needs help and directs his resentment at those trying to help him:

Well I mean like Harry today. But I happened to go in when he was actually standing up in the toilet when I got there, because of his dementia he's getting frustrated. I can understand where he's coming from, he wants to be independent and do things himself, but he can't manage to do his buttons any longer and he doesn't want you to do it and he just doesn't want anything to do with you or any one, because he can't and he's losing face. And to deal with somebody like that, you're thinking, I know I've got to cope with this, how am I going to deal with it? (Anne, Staff Member, Interview, 7/3/13)

Twigg et al (2011) suggest the interpersonal and emotional work undertaken by care staff is often to get residents to willingly participate, for example, in a wash. The interaction has an 'instrumental' character designed to produce a compliant patient or resident. However 'getting people to do things' was more nuanced than producing a compliant resident because it is tied up with the duty to provide good care and expectations of the Care Inspectorate and the family. The complexities of care and the challenges of supporting families through this are highlighted below:

...sometimes family is very like in, like in shock of dealing with this whole situation. Having mum is this stage when she doesn't recognise me or who is incontinent and she was always the head of the family, so I think we have to try to understand and support family and that's why it's just like very, the caring process is complex. We care for family and for residents, sometimes more for family and, er, that's why we, and I think most, most of them they will accept everything if you tell them in the right time and the way how you tell them, er, because sometimes they are coming upstairs with complaints, very unhappy to see mum, er, I don't know, with long nails or dirty nails but we could avoid that to tell them in the beginning that mum was difficult these days, we couldn't help her. We can't force her. We can't drag her and do her nails, for example. So information and communication is very, is very important for families because they are coming here, they expect, expect mum, to see mum or dad, er, in dignity, in respectful, er, clothes, er, and it is, I think for

most of us it would be very hard to see mum or dad in this stage. (Angela, Staff Member, Interview, 26/3/13)

There is a high incidence of depression among people with dementia (Banerjee et al 2011) and the staff have noticed that over the last few years more people are coming to the care home with antidepressants prescribed. Depression may also be a contributory factor in the lack of motivation to get up or get washed that some residents display as recognised by this carer:

*...I suppose like cause (Harry) had his depression and stuff, like in the morning it was always a big thing, obviously people with depression want to stay in their bed, it's their safe place and it was a big thing trying to get him out, like up and out of his bed at the start of the day and it was just trying to get used to, like what would make him motivate to get out of bed and to do stuff during the day and things...he'd want to do things if you motiv...like cheered him on to do it.
(Debra, Staff Member, Interview, 9/5/13)*

Here I think what Debra is trying to do is more complex than producing a compliant patient. Perhaps her interest in Harry makes him feel valued by her and this motivates him to get up. On the other hand, Harry, as I heard from the staff, died only four months after coming into the home so perhaps his not wanting to get up was because he did not feel well. People like Harry, and others I will refer to later, did not meet the prognostic indicators for the end of life for people with dementia (<http://www.goldstandardsframework.org.uk/home> 2014) in that he was still mobile, he could still feed himself and he could still have a conversation. He died *with* dementia, rather than *of* dementia. However, the presence of dementia did have an effect on the quality of the last months of his life and the complexity of caring for him. We must ensure that a diagnosis of dementia which is in the earlier or middle stages does not obscure other conditions and prevent those people from accessing appropriate care. Identifying those in need of palliative care and adopting a palliative care approach for people with dementia in care homes must take account of co-morbidities at all stages of dementia; all the stages impact on quality of life and the experience of receiving care in the last months of life. The complex and time

consuming nature of what is seen as basic and ‘unskilled’ care also needs to be considered in staff training and staffing levels.

5.4.2 Mealtimes

Mealtimes took up a considerable chunk of the day because residents were not rushed but encouraged to go at their own pace. The care home were concerned that residents should have a positive dining experience and tried to achieve this in a number of ways as the following pledge which was up on the dining room wall illustrates (Box 3):

Box 3: Mealtime pledge at Primrose Hill

M – Make sure I’m comfortable, in a good position and I am not in pain
E – Everybody is different – find out what I like
A – Appetising smells and presentation will help me enjoy my food
L – Let me feed myself if possible but help me if I need it

T – Tell me what I am eating and go at my pace
I – I like a calm environment without clutter, clatter or chatter
M – Modify the consistencies to suit me
E – Eat with me when you can

The dining room was a bright room with tables set for 4 with tablecloths. Just after I completed my fieldwork, a new catering manager was introducing a new initiative called ‘Come Dine with Me’ where several families were invited to Sunday dinner with their family member. It was proving very popular. Using the body as an analytical lens all of this, I would suggest, shows that food was seen as more than the biological requirement of a material body and feeding more than a task to be achieved for the smooth running of the organisation. Attention to how food was served and social interaction positions the residents as experiencing body-subjects at mealtimes.

At one staff meeting it was raised that there are not enough staff to cope at mealtimes and the care staff asked if volunteers could be brought in to help. Unfortunately, since they have become a specialist dementia care home they no longer have any

volunteers. There was some discussion at this meeting about using adapted cutlery and plates to help people eat independently and keep food warm but it did not materialise while I was there.

Mealtimes were very busy and very messy for the staff with residents dropping plates of food on their laps, spilling drinks, seemingly confused about what to do with their food; for example, putting their cup or their hands into their bowl of porridge or lining up orange segments on the tablecloth. Often people who were mobile would get up and walk away and would be brought back by the staff.

The majority of residents needed guidance or assistance to get to the dining room and then leave again when they finished. Some residents could feed themselves independently but quite a number required constant prompting and reminding that they were in the dining room, that their food was in front of them, and how to use their cutlery to feed themselves. The amount of help someone needed often varied from day to day and needed to be reassessed at each meal. Other residents needed full assistance to be fed. I often helped to feed someone at mealtimes and the experience of doing this revealed to me an ethical dilemma.

(Maureen) ate her fruit quite happily. She then got porridge with cream and sugar. She spat out the first spoonful onto the tablecloth. She was saying no and she was not smiling but had a closed stern look on her face and was looking away and not making eye contact, but again I felt the heavy expectation that the residents should be fed and this requires persistence as this is what the other staff do. I waited for a bit and then I tried again and she did eat most of the bowl of porridge. Then I moved to the cup of tea. It was very weak looking tea. Again she did not seem to want it and was saying no and turning her nose up. (Fieldnote – Maureen p.36 15/11/12)

Maureen was known to like porridge and tea and had them regularly. It could be that initially the porridge and tea were too hot for Maureen despite being allowed to cool, but these scenarios where residents would turn their face away or refuse to open their mouths were common. Using the analytical lens of the body, I think that what is revealed here is the way

that Maureen is using her body, as well as saying ‘no’, to demonstrate intentionality and agency; it seemed that she did not want the food she was being offered. For me as her ‘carer’ at this point however, this creates a dilemma; do I keep trying to persuade Maureen to eat and drink because that is good for her and that would be good care and because she may have lost the cognitive capacity to recognise that; or do I take her bodily communication seriously and let the decision be hers?

The National Care Standard on eating well, against which care homes in Scotland are monitored by the Care Inspectorate states that:

You can be confident that the provider is aware of your nutritional state and will, with your agreement, arrange for this to be regularly assessed and reviewed. This assessment will take account of any changes in your health. (Scottish Government National Care Standard 2007)

In practice, this meant that residents were on food and fluid charts, and monthly weight charts and if there was weight loss they would be seen by the GP and usually started on high calorie drinks. The Care Inspectorate judged that this standard was fulfilled by inspecting the charts, seeing a detailed plan of care and any actions recorded. McCormack et al (2012) suggest that the inspection and regulation of care quality in long term care is dominated by clinical markers without corresponding markers for how these translate into person-centred practices. I would add that they do not recognise the relational dynamics of care nor include how people with dementia express agency, for example, expressing a view on whether to eat or not in non-verbal ways. A number of residents were on build-up drinks as they had been losing weight. The amount of documentation required was time-consuming and staff talked about how it took them away from spending one-to-one time with the residents. It also created a culture where good care was seen as the resident eating well and not losing weight. The tensions this created for the staff is illustrated in the quote below:

... you don't force somebody if they don't want to eat and they are making that clear to you whether it's pushing your hands away or spitting food out you've got to respect that, so that's tough from our point of view because you want them to get their nutrition, you want them to have fluids but at the same time you have to respect their wishes... (Hilary, Staff Member, Group Discussion, 18/1/13).

It also creates tensions around decision-making and setting goals of care: is refusing food a one off occurrence because the food is not nice? Is refusing food a sign of illness which needs to be treated? Or is the refusal of food a sign the person is approaching the end of their life or dying?

5.4.3 Palliative and End of Life Care

The number of deaths in the care home was increasing and caring for people who were deteriorating and dying was an increasing part of the day to day body work. The care home did have an end of life care policy and the GP was responsible, through the Care Home Anticipatory Care Locally Enhanced Service, for discussing an anticipatory care plan and 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) with families. This discussion was mandatory and was updated yearly. The aim was to complete the palliative and end of life care protocol with families within the first 6 weeks after moving in. This documentation meant that inappropriate hospital admissions and attempts at CPR could be avoided, which is one vital aspect of respecting dignity in dying and setting appropriate goals of care as part of a palliative care approach. Having such documentation in place meant that most deaths did occur in the care home rather than, inappropriately, in an acute hospital.

The end of life care policy and palliative care plans used suggested that the parent organisation and the care home recognised that their population of residents had a progressive illness and required palliative care and ultimately end of life care. There was an understanding of what this might entail, such as: good symptom management; regular liaison with the GP and community nurses around appropriate prescribing; support of families including facilities to stay; and, open visiting. However, while some people talked about all the residents being for palliative care, in reality there was

a blurred transition between care as per the usual generic plan and palliative care for which they had a specific care plan. The following extract is from a generic care plan:

Normal routine: When people are ill they deserve a lot of pampering and consideration. We will encourage you to take things easily and your routine will change if you wish. It is always a good idea to get extra rest if you are off colour (Care Plan Extract, Fieldnote p.263 10/7/13)

The realities of recognising dying presented challenges to this aspiration. My palliative care background meant that during fieldwork I often found myself ‘assessing’ residents, looking for signs of decline and those people who were less well drew my attention. On a number of occasions when I was in the care home, residents became unwell and there was an uncertain period where it was not clear whether the person would recover or whether they were actually dying. The GP would prescribe antibiotics and there would be a period of time when the staff and family would wait to see if they worked. If the antibiotics did not work and the person continued to deteriorate they would be classified as ‘palliative’.

Weight loss and reduced oral intake in someone who has advanced disease and is frail are a natural part of the dying process (<http://www.goldstandardsframework.org.uk/home>). During the waiting period, the staff tended to continue to bring the person to the dining room and try to feed them. A number of times I was surprised to see that the person did recover. However, there were also occasions where the person did not recover and I felt that these residents would have been more comfortably cared for in their beds sooner. The following fieldnotes are an example of this in the life of Annie, a 97 year old resident:

Annie is not well at the moment. She is on liquid antibiotics as she is having trouble swallowing her medication. She is dehydrated. She is on a fluid balance chart and Ensure (Build-Up) drinks and at times she is breathless and panicky. She was dressed and in the dining room. She had a bowl of rice crispies in front of her but she seemed too weary to lift up the spoon although she had it in her hand. When I spoke to her she just looked wearily in front of her, not making eye contact and sighed but managed to eat the rice crispies when

she was helped. She looked quite flushed. She eventually managed her medication and was walked back to the sitting room. She is normally quite alert and when she is spoken to directly she smiles and engages in conversation, but not today. (Fieldnote p.181 24/4/13)

Two days later....

Three people described as 'failing' at handover – one of them was Annie. Annie also is reported as having very poor mobility, refusing fluids, having a temperature and her grandson had been informed and he had come to visit last night but she told him to go home. She also was in the dining room for over two hours (this morning at breakfast). Throughout this time Edith (Staff Member), watched closely by Betty (another resident) who was at the same table, spent a lot of time with her trying to encourage her to open her mouth and swallow an Ensure drink and her medication. Annie seemed very reluctant to take any fluids into her mouth or swallow. Edith persevered and I heard her say to the team leader after 10am that (Annie) had managed some fluids. Annie barely had her eyes open and looked worn out - she really looked like she would have been better in bed (Fieldnote p.185 26/4/13)

Four days later Annie was classified as 'palliative' which meant that there was now agreement that she would not get better and was going to die soon. However, she was still up and dressed and on a recliner chair in the sitting room as the staff felt this would help her breathing, as the fieldnote below indicates. She had been seen again by the GP and the community nurse. Her antibiotics were finished and she was not being prescribed any more:

I was surprised to see Annie up in the sitting room on the blue chair – she looked like she should be in bed – very weary...I did go and say hello to Annie and she smiled at me but was unable to say anything and just closed her eyes again...Later Annie was being given her medicine for her bowels – a long slow process. Annie was in the TV room where she never sits as she always chooses to sit in the window in the other room. She is now 'palliative' and probably not able to say (where she wants to sit as she did previously) – these little things matter however and are about knowing the person. (Fieldnote p.190/191 30/4/2013)

Three days later Annie was being cared for in bed in her bedroom as the note taken at handover shows:

Annie is in bed and is 'palliative'. She has been a bit unsettled and has been refusing drinks. The DN came in early around 8am to see her. Her bowels have not moved – she is still impacted and has overflow. Her family were in this morning. One of the carers was asking how to use the mouth sponges – not experienced in palliative care. (Fieldnote p.196 3/5/13)

Annie did seem to settle and she died 10 days later. Her death was described by the staff as peaceful and her daughter and two members of staff were with her.

Annie had spent some time as a contested being, neither fully living nor fully dying. She was also in a contested space in that, for a time, she continued to be brought to the communal living areas, rather than, from what her facial expressions of discomfort communicated, the more comfortable space of her bedroom, as she made her final transition through the borderland between living and dying (Froggatt 2001a, Froggatt et al 2011).

The uncertainty and unpredictability of the length of the dying phase in dementia is perhaps part of this protracted decision making process. The fieldnote below gives some indication of the thinking behind getting people up:

Asked Wendy (Staff Member) about delirium in people with dementia... she spoke about how they prevent delirium by pushing fluids and always being quick to test to see if someone has a UTI or other infection. She spoke about how this is why they really try to get people up out of bed and not to allow them to languish in bed as this is when they begin to get delirium – but also she talked about how it is difficult to know sometimes when it has become the dying phase – often it is when people just let food or fluids fall out of their mouths. (Fieldnote p.196 3/5/13)

The emphasis on cure and maintenance of function of the 'material' body object in Annie's case was pursued at the expense of maximising comfort of the experiencing body-subject. The staff gave what they felt to be the best care they could but were,

perhaps, inadvertently postponing death and prolonging suffering, although it is not possible to say this with any certainty.

Occasionally residents did have meals in their rooms but the norm was to be up and dressed and in the dining room. Focussing on food and using the body as an analytical lens perhaps highlights that it was almost as if, for a period of time, the autonomy of the person was overlooked in favour of the drive, influenced by the regulatory context, to provide adequate nutritional support. However, once a certain point had been reached where it was clear that the person was not going to recover, but was actually dying, the remnants of their autonomy in relation to food, now inscribed in bodily form (Hughes 2013a), was reinstated. Once a resident was classified as ‘palliative’, the staff would continue to offer food and fluid, if the person could swallow. However, they would not *push* food and fluids, as in the scenarios above, but would be led by the resident themselves. The quote below shows that Oswald was able to communicate verbally that he was ready to die, but he also put up his hand in a gesture which means ‘stop’:

Oswald who literally just two days before he died said ‘please don’t give me anymore’, cause I was trying to get him to have Horlicks and he put his hand up and said ‘please don’t try any more’ and then later on he said to me and he said to Edith as well ‘I just want to go’, so we knew there was this desire in him, he was finished here and that was, he was in bed two days I think....(Muriel, Staff Member, Interview, 11/3/13)

Knowing the ‘body’ of the residents through building consistent relationships was important for the staff in decision making as shown below:

...if you got better relationship with some of them, you can see things, er, which are missed by other people because you know them better like, for example...Penny... I know she had some moments when she’s, er, chesty. She sounds chesty but it doesn’t mean she’s got a chest infection because I know she can’t lie flat when she’s in bed. She has to be a little bit...or she’s got episodes of being sick but it doesn’t mean nothing major. I’m not saying I’m ignoring symptoms but it’s just I see that it can happen, you don’t have to panic when she’s sick... (Angela, Staff Member, Interview, 26/3/13)

This practice knowledge of the body in the context of relational care needs to be brought more to the fore and recognised as important in decisions about care.

Lillian had a somewhat unsettled death and there was a general view that her pain was not well controlled. The extended fieldnote below was taken when she was labelled as 'palliative', 12 days before she died. When a resident was labelled as 'palliative' it meant their deterioration was irreversible and progressive and they were expected to die in the near future. The fieldnote highlights some inexperience in the fine texture of palliative care, such as eye care and mouth care. It also illustrates the visible ways that Lillian continued to communicate that she was fully present and also uncomfortable, either due to pain or fear or both:

Popped back up this morning to see Lillian. Angela (Staff Member) was giving out drugs in the dining room and she told me Lillian had had a good night and had slept well but was now on oromorph. She is still swallowing and also drinking and still able to say thank you so they think that she has a bit of time to go...She was staying in bed today. Kathy(Staff Member) was (in Lillian's room) with an agency carer. Kathy thought Lillian was sore because she was moaning a little and her face looked quite tense. They thought it was her left leg that was sore. I asked if she had had pain killers and Kathy didn't know. Kathy thought it was just oromorph as required and not regularly. They got her settled on her left side with a pillow at her back and put her head up a little. Kathy is very gentle but they weren't really talking to Lillian; they didn't say when they were moving the bed back into place. Lillian looked like she was beginning to relax. I said to Kathy that maybe she was just sore on movement and she agreed. I asked if she was planning to mention the pain to Angela the teamleader and she said she would. I spoke to Lillian. She was wide awake and I felt like she was looking to trying to see who I was. She seemed to have a question in her eyes. I asked her to squeeze my hand if she was sore but she didn't but she moaned slightly as if she was trying to say something. I stroked her head. Her skin felt quite clammy. Kathy asked if I thought she was too hot. I didn't think she was too hot although she was a bit clammy and quite pink in her cheeks. Her eye was a bit sticky and I don't think they had cleaned her mouth as it looked a bit sticky. (Later on they got mouth sponges and were cleaning her mouth). I asked Kathy if Lillian had had a drink and she

said yes she was drinking a lot. I sat for a bit stroking Lillian's head. She was looking at me but there was no flicker of a smile and she normally smiles a lot. I thought she looked a little frightened but she was not restless. Kathy opened the curtains and the sun poured in and I said to Lillian that it was a lovely sunny day. She continued to just look at me. The family had gone home about teatime yesterday. Kathy put some hymns on the CD player. Lillian seemed to be relaxing and began to close her eyes. Kathy was leaving the room... I did feel that Lillian seemed quite isolated being left in a room with the door closed at the end of a corridor. A few minutes later I met Brenda in the hallway. She had just taken the local minister who is chaplain to the home up into Lillian's room and left her to sit with her. Lillian's daughter had arranged for this to happen. (Fieldnote p.171 12/3/13)

In the above fieldnote, I felt that Kathy, although gentle and kind, was inexperienced in providing basic palliative care such as mouth and eye care. Also she was identifying pain but perhaps not anxiety. This raises the question of what competencies are required to ensure care staff are competent to deliver the level of care required by the increasingly frail population in care homes.

The fieldnote below involving another resident, Penny, who at this point was not dying, demonstrates that when staff knew the residents well, they were able to identify the subtle but visible changes in demeanour which indicated uncontrolled pain:

...she's got quite bad arthritis in her knees, um, and a few months ago, she was not on any painkillers for it, you know, because she was transferring with a Zimmer frame, and we started noticing that she was rubbing, you know, her knee, so when I was sitting with her, I noticed that she was, you know, just rubbing her knee all the time. And sometimes, you know, that's where it gets sore, and she wouldn't say to me, yes, you know, well she'd, you know, just like...just look at me, so, you know, she...she...her face, you know, even pain, you know, when she's not...because she's always is smiling, she's quite...and the family says that she was always like that, she was very...a content lady, you know, she was always happy, quite...you know, but you can see, like if there is pain in her...you know, in her...I don't...I...it is hard to explain how you can read that there is pain in her face, you know, but the fact that she was rubbing and she didn't look as happy as

usual, then she's not...we...we got the doctor to see her and she actually has quite, you know, bad knees and I try to say, they will, you know, be swollen and things so she's on like regular pain killers now (Zoe, Staff Member, Interview, 7/3/2013)

In the very final stages of life when a person is immobile and being cared for in bed, indicators of pain and distress, as in Lillian's case, become even more subtle and more confined to the face. Understanding facial expressions is of paramount importance in recognising and alleviating suffering when a person with dementia is dying.

Dekkers (2010) suggests that bodily autonomy, or the wisdom of the body, may be used as a guide when difficult moral and ethical end of life decisions are to be made with and for those who are deemed to have lost the capacity to make rational decisions. For example, he suggests that bodily actions such as pushing away a spoon, spitting out medication or pulling out a feeding tube, alongside facial expressions or bodily defensive movements should be taken seriously when treatment decisions are to be made. I would suggest that paying more attention to the bodily communications of people with dementia, positioning them as body-subjects with bodily agency, instead of passive recipients of care could indeed be helpful. It would be useful in the context of difficult end of life decision making and in providing good care which promotes comfort. This comes with the caution that it is a complex area of care which requires expertise, a relational context, teamwork and open and honest communication with families to avoid abuse.

5.5 Conclusion

There is a paradox at the heart of this analysis of the care home context. On the one hand, body work dominates the way care home staff relate to residents, shaping the caring relationship in a very particular way. The downside of this is that, when a resident is not having hands on care of some form, they can be left sitting with little human contact for prolonged periods as the staff attend to the other 39 residents. The effects of this are discussed further in Chapter Eight.

On the other hand, human beings are embodied beings; our body is part of our self. In the context of dementia, increasing cognitive losses, and the physical frailty of advancing age and dying, engaging with the person in a bodily way becomes increasingly important. Body work is not simply caring for a body-object but an experiencing body-subject, or the 'self'. Body work can be an opportunity to support the selfhood of a person with dementia and provide comfort. Thus body work is more than meeting basic physiological needs, such as the need for food and water but can also be a means of supporting a sense of self and self-esteem. Recognising the agency inherent in bodily movements and actions also acts as a counter to social death, ensuring that people with dementia remain engaged in their relationships and in decision-making about their care at the end of life. The next chapter focuses on the idea of recognising and supporting selfhood.

6 Recognising and Supporting Selfhood

6.1 Introduction

The previous chapter focused on body work as a way of gaining a deeper understanding of one of the main points of contact within a care-giving/care-receiving relationship in the context of advancing dementia. This chapter focuses on the ways that selfhood is expressed by residents and how the staff attempted to see the person behind the dementia within the caring relationship. It explores the ways the notion of ‘selfhood’, including embodied selfhood is understood and operationalised in the care-giving/care-receiving relationship. I focus particularly on those people with advanced dementia who have virtually no verbal ability remaining and, while they may be mobile, have high levels of dependency.

As a participant observer for 10 months in Primrose Hill I had the privilege of spending time with some of the residents. I was able to draw on my own interactions with the residents to gain insights into how they expressed their selfhood. During the first days and weeks it was those who walked around who I got to know first as they came to see me as I sat in the front hallway watching what was happening. Initially I felt unsure of how to respond in certain situations, such as when someone was talking but I couldn’t make sense of what they were saying, or they were asking why the front door was locked or were upset about something.

I often found myself ‘watching over’ the sitting rooms, making sure no one fell, while the care staff came in and out taking residents to the toilet. The time moved very slowly as I did this in the first few weeks. There would often be silence in the room, except for the music, as there was very little interaction between residents. It was difficult to converse with any of the residents for more than a few minutes because of the limitations in their verbal abilities and memory loss.

Over the months, however, as I got to know the residents, their characters began to emerge in small ways such as a wink, or a squeeze of the hand; the more I looked the

more I saw of the 'person'. I came to know the person not from what I heard in handover or saw staff doing but from face to face encounters, or intercorporeally.

As I became more comfortable and less awkward in my position as an observer, I began to take more notice of the capacities which remained, as described by Sabat (2001 See Section 2.6.1), and paid attention to the embodied aspects of selfhood as described in the literature review (Kontos 2003, 2004). I drew on my own interactions with the residents as a way of understanding them and as a way of exploring the staff's experience of care-giving.

6.2 Looking for the Person – Continuity of the Self

In this first section I explore the ways that the staff engaged with residents and how they seek to support selfhood. I particularly focus on the ways that the staff identify with the residents as fellow human beings and how they experience them as fully present. I also consider how the residents responded.

6.2.1 There's more than 'Just the Penny I Know'

When residents first came into the care home it took some time for the staff to get to know them. They had to learn about the residents in two interrelated ways. Firstly, they had to learn about their care needs and how to practically care for them, such as how to get them up in the morning and what kind of approach was required to enable this. Secondly, in order to help with this, the staff had to learn things about the person, such as knowing about their life and what kind of person they were. There did seem to be a recognition that the person in front of them who was very forgetful, whose words were jumbled or very few, who required a lot of assistance to do basic things such as wash and dress, had not always been like this. The care staff recognised that there was more to them than this and that their past life was important to their present situation, and within the care-giving/care-receiving relationship:

*...when I came, this was my first...the first place I worked
that it was just for people with dementia, and, you
know, ...it's quite hard to see the individual there, because*

sometimes they are not able to talk to you, you know, and you just see them like they are now, and you forget that they had a life before, you know, that they did like...some of them did amazing things, you know, in their...in their past...and I think that knowing a little bit about what they did makes you just...I don't know, you just don't look at them as just, okay, that's one of the residents, you look at them, that's Penny, you know, that's what she did (talks about all the things Penny did) ...so it helps you to, you know, to identify, to just care for...(Zoe, Staff Member, Interview, 7/3/13)

Zoe seems to be hinting at how knowing about Penny's past helps her to identify with Penny in the present as a person rather than simply 'a resident', perhaps pointing to the idea of solidarity as human beings standing together in the world (Hughes 2011). Kelly (2013) applies the notion of 'differentness' to dementia care and describes how if others are perceived as different from us in some way, then understanding and empathy can be impaired. However, if other's experiences are psychologically similar to ours, some degree of understanding can be achieved. By knowing that Penny, like Zoe, had children and went to church, Zoe was better able to identify with her as a person. Zoe recounted how hearing a talk given by members of the Scottish Dementia Working Group helped her to realise that there is much more to Penny than '*just the Penny that I know*':

And when...when they were introducing themselves as like, oh, I'm an engineer and I was diagnosed with dementia five years ago, and, you know, and people think that I've lost all my abilities just because I was diagnosed with dementia, and I think there – that day – I started to realise that there is more than just like...the people that...just the Penny that I know... there is much more, and I think that made me curious, you know, to go and find out what she did or what each one of them did. (Zoe, Staff Member, Interview, 7/3/13)

Below Anne seems to be referring to what is described by Sabat (2001) as Hilda's Self 2; Hilda was a well-educated person with a knowledge of literature, something of which persists even in advanced dementia. Anne is using her knowledge of Hilda's Self 2 as she gives hands on personal care. Such knowledge transforms a task performed on a material body to an interaction with a person:

...I mean like Hilda, I have the most wonderful jokes with her in the morning when we're doing personal care because she likes to play on words and although she talks a load of nonsense, she...she'll come up with a word and I'll come up with something similar and because...I mean she's been a very well educated person. She...she...she remembers the patterns of thinking of things, you know, like if you mention something from Shakespeare or something like that, or a quotation, do you know what I mean, she'll...she'll...she'll recognise it. (Anne, Staff Member, Interview, 7/3/13)

Anne described knowing things about a person's life story as 'handles to hold onto' which gave her a way of connecting to a resident:

So as she goes down hill I...I find sometimes...I can actually bring recognition back to her just that moment of understanding, erm, when she'll talk about something like that with me, you know. Er, well not talk, but she'll listen to you and her face lights up. (Anne, Staff Member, Interview, 7/3/13)

Anne was from the local area and often the 'handles to hold onto' were aspects of culture and history she shared with residents, for example, Scottish songs. This suggests it may be more difficult for care staff from other countries to make these connections.

Hughes (2011) introduces the idea of narrative unity giving coherence and shape to a life. Knowing about the residents' past lives helped the staff maintain narrative unity as shown in the quote below from an interview:

Researcher- And how do you use that – kind of 'what she was like before' – how do you use that day to day?

Debra - So the family said to me she always used to be out when she was younger, always outside so because of that she's always by the door so I like to go out with her because I know she used to enjoy that when she was younger so it's I suppose it's just if you've got the time to take her out one to one for a wee walk and get fresh air. (Staff Member, 9/5/13)

It wasn't just facts about a person's life that the staff tried to discover but personal attributes or aspects of their personality:

I...sort of understanding that although everyone in here has got dementia that even with the dementia they've all still got their wee quirks and like, you know, sort of ways that ...sort of what they like doing and you can still get a wee understanding of, or get clues as to what they like doing and things like that... (Izzy, Staff Member, Interview, 26/6/13)

It seemed that 'experiencing' the residents was as important as knowing their story or knowing about dementia. This indicates that embodied knowing is as important for care staff as cognitive knowing in the building of relationships with residents, as shown in the interview extract below:

Vera- Em...I've learnt more...I think I know as much as anyone else here but em I've done courses and things but I've learned through doing and experiencing them, like if you were to read all the information about them and then come in...it's not the same, although the information is right...

Researcher- In their care plan or whatever?

Vera-In their care plans, or courses or whatever, you come in and you're just woahh!... this is a lot more intense than I think things like courses and books make it out to be. (Staff Member, 26/6/13)

This could be described as the phenomenology of caring which is rooted in ordinary lived experience and active involvement in a two way interaction between the staff and the residents.

There was a sense of a building of relationship between staff and residents over time. The personhood of the resident was not always immediately obvious but slowly emerged so that they became seen by the staff as a fully present person.

6.2.2 The Emergence of the Fully Present Person

The care staff spoke about how residents communicated with them in various ways. Below Brenda is hoping that by paying attention to what people say she will find

meaning in what they are communicating, thus positioning the residents as people who were trying to communicate effectively:

...and sometimes, it might be foolish I don't know but especially with the ones with dysphasia ...I try to listen very careful because in my heart there is a hope that one day, and it happened before, you could see one word here then maybe ten words, fifteen words doesn't make sense but there's something else there that you could bring together and make sense. (Brenda, Staff Member, Interview, 31/1/13)

Zoe below describes the subtle ways she connected with residents and the importance of 'catching a look':

...it's just trying to catch like one look, you know, because you know sometimes they are just looking at the...at the room but then it's simple things like that, trying to catch her attention and then she looks at you or she smiles at you, and then I think, yeah...you know? (Zoe, Staff Member, Interview, 7/3/13)

Above it is Zoe who is taking the initiative and she has to persevere in order to catch Penny's attention, pointing to what Zeiler (2013) describes as the asymmetry in their relationship. However, Penny eventually does pay attention to Zoe's signs of attention to her.

As part of their approach to caring for the residents the staff intuitively drew on aspects of embodied selfhood (Kontos (2003, 2004). As the quote below shows, Anne is recommending I tap into Hilda's bodily know-how which is an aspect of her embodied selfhood:

As I was walking to the activity room with Hilda, Anne (Staff Member) stopped me and suggested I walk with her in a different way. I was walking with my right arm around her back and holding her hand at the front in my left hand – the way we are taught in moving and handling so that if people fall it is possible to control their fall so they don't get hurt or break your thumb by grabbing it. Anne suggested I walk with my right arm holding Hilda's right arm 'like doing the Gay Gordon'²³ as this seems to help her to keep going forwards

²³ The Gay Gordon is a Scottish country dance

and go in the right direction. This is using her embodied knowledge to know what is expected of her I think. (Fieldnote p.198 3/5/13)

Anne's advice was very effective and created a 'shared space of dynamic intercorporeal engagement' (Zeiler 2013 p136) between myself and Hilda to achieve movement and reach our destination. I felt it was safe as Hilda was steady on her feet. The quote below shows how a combination of knowing the residents' biography and recognising the memories inscribed in his body, which were part of his selfhood, helped in encouraging walking:

I watched another carer try to guide a resident out of the dining room. He was having trouble knowing what to do with his zimmer and couldn't seem to get moving. Eventually she told him to march – left, right, and he was able to do this – she explained to me that had been in the army. (Fieldnote p.56 22/11/12)

The next quote I would suggest refers to what Kontos (2004) talks about as culture-specific conditions of primary socialisation which function below the level of cognition at a pre-reflective level and which also form part of embodied selfhood. Gemma is recognising and respecting class habitus, displayed in habitual manners:

I think it's very important with dementia to get to know the people first, to know what kind of things they like, what kind of things they don't like, as in are they someone who would respond more to a sort of formal level of conversation or if somebody likes a bit of banter, that kind of thing... (Gemma, Staff Member, Interview, 3/6/13)

The residents themselves often adhered to the rules of social etiquette, with some going to the kitchen hatch after lunch to thank the chef, even if they did not remember where they were, wanting to do the right thing:

I was standing in the hallway with Catriona, who was ready for bed, when she heard music from 'The Sound of Music' coming from the sitting room and she wanted to go and hear it. I walked through with her. As we passed the team leader Catriona said very politely to her 'good evening' – then she

*whispered to me 'was that the right thing?' (Fieldnote p.68
28/11/12)*

*It was mid afternoon and I was observing in the sitting room
and the kitchen assistant was there giving out the afternoon
tea. Katie ...was very perturbed that I didn't have a piece of
cake and tried very hard to give me half of hers. Later I
heard her ask another resident 'Are you lost? I don't know
where I am, no I don't, I definitely don't.' (Fieldnote p.74
3/12/12)*

Even as dementia advanced and there was minimal verbal interaction, it seemed that the staff still recognised the residents as fully present. Penny was a person with very advanced dementia. She had virtually no verbal communication and she required full assistance with everything including feeding. A number of staff spoke about how getting any response from Penny, perhaps an indicator that she was fully present, was very rewarding:

*'I think it's really hard, I mean Penny, that's heart breaking
isn't it because I'd love for her to be able to talk to me and
tell me all the cool stuff that she used to do, it's hard. But it's
really rewarding, like the other night I put her to bed and
said 'goodnight Penny, God Bless' and she said 'good night'
back and I was like 'oh we've just had a conversation' and
that was really really cool....that made me smile
lots....(Debra, Staff Member, Interview, 9/5/13)*

I would suggest that Debra's encounter with Penny above, where each is attending to each other's signs of attention is a 'pre-reflective process of social attunement through which they can experience themselves as "we" (Zeiler 2013 p.138); Penny 'knows' how to interact despite losing many of her cognitive abilities. These subtle connections between the carer and the cared for are rewarding for both and as Jenkins (2013) suggests can help dissolve the distinctions between the carer and the cared-for, creating a 'we'. Even without Penny's response, the way in which Debra is speaking to Penny is a way of affirming her residual self-consciousness which Post (2006) suggests is more than symbolic but morally crucial. Debra also seemed to draw on this idea of 'we' when she was helping Betty get washed:

I sat outside the bathroom but I could hear the dialogue between Debra (Staff Member) and Betty. Debra said she was taking Betty's nightie off and then said she was putting a towel over her to keep her covered up – she kept saying 'we'll take your nightie off', we'll put a towel over you' - maybe this gives a sense of them doing it together – Betty likes to continue to do the things she can do and this approach seemed to work well with her as she did not become agitated at any point. (Fieldnote p.288 5/8/13)

This again draws on Zeiler's (2013) notion of incorporeality; Betty would not have been able to wash and dress independently but her remaining capabilities 'spring forth in joint activity', the practical activity of getting dressed.

The ways that residents use their bodies to communicate is used in practice but it is not made explicit in care plans. Below is an extract from the communication section of Sandra's care plan:

I have no problem with communicating. I enjoy company and meeting with people especially during mealtimes. I can sometimes be a little low in mood and at times I need a lot of encouragement from staff to communicate and make decisions. I no longer find it easy to attend activities and the group work and am better with a one to one from staff. Due to my dementia my memory is poor and I need a lot of guidance. I can become quite agitated at times and can shout out and make humming sounds which I am unaware I am doing. At these times I need a lot of reassurance from staff. (Care Plan Extract, Fieldnotes p.262 10/7/2013)

This extract indicates that Sandra has no problem communicating but also that she needs encouragement from the staff to communicate. In reality, the interview quote below illustrates the myriad ways Sandra communicates with the staff:

Gemma - ... (Sandra's) got very good body language, if you speak to Sandra, sometimes she'll smile and she'll be light hearted, other times you get the shoulders... (Demonstrates shrugging)....you know the shrugging...you know you speak to her and say 'What's wrong today Sandra, how are you, nice to see you' ...she just goes (Shrugs) ...and you think right, she's not in the mood today

Researcher- So she is communicating how she is with her body....

Gemma - Oh yes definitely she communicates, you can see she shrugs, the shoulders go up, the whole body just (slumps) and she shakes her head and ...other times she'll...look up and she'll smile and things like, as I say you get to know her, because she is my key resident (Staff Member, 3/6/13)

Embodied aspects of selfhood and continued ways of communicating could be made more explicit by articulating them in care plans. If discovering and supporting embodied aspects of selfhood and capitalising on them were core to the work of care homes, it would provide a greater therapeutic direction for care staff and help develop the theoretical basis of relationship-centred palliative care for people with advanced dementia.

6.2.3 Reconstituting the Self

'Doing things together' was important for some of the residents as shown by the fieldnote below:

Catriona was agitated and trying to get up out of the big blue chair she was in. I sat with her for a bit. She was really bright. She wanted company and she also wanted to be doing something – she said to me 'let's do things together'. (Fieldnote p.299 14/8/13)

Catriona had fallen and broken her hip and was confined to a chair at this point. She was very cognitively impaired, for example she had no short term memory whatsoever, but was very sociable and enjoyed being in company. The quote below shows the approach John took to enabling Catriona to do things with other people, despite her cognitive losses:

Like when we play scrabble, they ask to play scrabble or dominoes sometimes, there's maybe like four residents that can play scrabble quite okay and Catriona is there with us. Catriona can't play at all so you just sort of, you're on their team, kind of thing, you know. (John, Staff Member, Interview, 19/4/13)

Many times I saw Catriona sitting in on sessions like this and, when she was mobile, seeking out these situations and happily sitting alongside others who were doing a quiz or playing a word game. It may be that the staff had found a way to support or ‘reconstitute’ (Lawton 2000) Catriona’s sense of herself as a social person who liked to do things with other people, despite her cognitive losses and she experienced this in a positive way. A further example is given below:

Penny just sits and surveys us all and then all of a sudden she’ll start laughing and we’ll say ‘what are you laughing at Penny?’ and she’ll say ‘Ha Ha Ha!’ and then the rest all start to laugh so it’s like she just joins in in her own wee way ...but you don’t really, you can’t really have any sort of conversation with Penny back, you can talk to her and I think she takes a lot in ...so really again I just talk to her the same as the rest and I’ll say ‘What do you think about that Penny?’ even though she’s not going to answer me, it’s joining them together and bringing them into the conversation is important I think (Catherine, Staff Member, Interview, 30/5/2013)

The ‘joining them together’ seems to be a key part of what is working in these interactions; the sociable personality that both Catriona and Penny retain, rather than being fixed is reconstituted in a new way which allows them to feel included in a way that is affirming (Jenkins 2013). This shows how the theory of intercorporeal personhood can be operationalised in practice with people with advanced dementia outwith body work.

6.2.4 Clothing as an Aspect of Personhood

Dressing people as they would like to be dressed was important to the staff and tied to preserving the identity of the person as shown below:

Because sometimes if, you know...you...I don’t want to dress them the way I want them to look like, you know, you just want to go with like the clothes that they brought with them when they...they came here, and then there is a little bit of their personality, you know? Like Penny has quite...like her red and purple, nice colours, bright colours, because I think she was that kind of bubbly personality, you know? And then you’ve got other people like Rose, she wears more like white and brown and...and black and she was a little bit more

reserved I think, you know, so... (Zoe, Staff Member, Interview, 3/7/2013)

The extended interview extract below shows why one carer thought clothes were important:

Vera –...like there's some people that have been here and you find out that they have been very particular about certain things, things like they only wear this or they only wear that and then we didn't know that, you feel really quite bad because we would be dressing them just with what they've got and you think 'right ok that looks nice but it's not what they would have worn in their time' ...so

Researcher- And why do you think that is important to the person themselves?

Vera - Aw because it's as important as...I know they've got dementia but they are still aware, like they can still see, you know imagine if you looked down ...and they can't, might not be able to tell us 'well what is this, I don't like this?' ...like say if Iona was wearing something, she would just be like ...I remember when I first cameI had Iona and she used to walk around all the time and I'd put on like 5 different things because she kept telling me she didn't like it so I was like 'Oh my God' so... I think it's very important like if someone did something to me I'd be like 'Oh my God I look hideous, you know!' I think it's important, they need to feel good

Researcher- Yeah... it's about them being the person that they always have been and what's important to them

Vera- Of course ...I know things change because of deterioration and there might be things...you just need to do what you can at the time but as much as possible you should, like if they liked to wear lipstick put lipstick on them, if they like to wear earrings put earrings in...I know it's very silly and materialistic but what else have they really got, you know, to start their day, they can't do it themselves? (Staff Member, 26/6/2013)

Here Vera seems to be drawing her ideas about the importance of clothes from a number of sources. Firstly, from her intuitive recognition of the importance of

biographical continuity and embodied selfhood. Vera knows how Iona liked to present herself to the world and wants to uphold this part of the narrative of Iona's life. Secondly, from what Vera herself would feel like if she was wearing clothes she didn't like, drawing on her own embodied experience as a site of tacit knowledge (Kontos & Naglie 2009). Thirdly, based on Vera's knowledge of the resident over a prolonged period and what she was like when she was able to express opinions verbally and fourthly, on the basis of continued awareness of the resident. Vera is acknowledging the effects of time and that it may become more problematic in the face of deteriorating health and bodily changes, but that there are still small things that might help as the care-giving/care-receiving relationship evolves. Interestingly, despite this, Vera is referring to the residents as 'they' which may indicate that she sees them as different to herself, using this turn of phrase to create social distance between herself and the residents (Lyman 1993). However, the research context and asking about relationships may inadvertently create this distinction.

'Appearance work' provides an opportunity for engagement, interaction, communication, and connection but the following authors stress that it is not the end point of appearance alone that is of importance but also the process that is used (Twigg & Buse 2013, Ward & Campbell 2013, Downs 2013). How much dress matters to people with advanced dementia perhaps remains an unknown but it may be that care staff focus on dress as a strategy to find meaning and satisfaction in their work. The quote above suggests that Vera saw the small act of putting lipstick on somebody who had always worn lipstick as something she could do which might help, when there often seemed to be very little else to do that would help. This provides her with a way to cope with caring for people with very advanced dementia and find meaning in the face of suffering. Ultimately valuing and finding dignity in care work might encourage care workers to stay in this type of work. Balancing the needs of care-givers, in what is undervalued work, and care-receivers, is an ongoing challenge for dementia care.

This section has illustrated that care staff knew there was more to the residents than how they appeared in the present, and therefore were not defining them by their

dementia but looking for the person behind the dementia. Recognising and supporting the selfhood of the residents and creating opportunities for its expression were important aspects of the caring relationship and there was evidence the care staff perceived the residents as fully present. However, there were challenges to supporting selfhood and there were times when it was undermined, mostly inadvertently, and these are now explored.

6.3 Challenges to Supporting Selfhood

6.3.1 Lack of Biographical Detail

There were several challenges within the care-giving/care-receiving relationship in supporting the residents' selfhood. The care staff depended a lot on families in order to get to know the story of the person's life. In the absence of involved family, this created challenges for the staff:

..at the time when they've come in, they've not got a lot of information, the only information they've got is from a doctor or a social worker and that's quite difficult because it's hard to get a background of what type of person they were so with that its just genuinely playing off what you see, um, what type of person they are, um, because Nigel, we didn't know anything about him and it wasn't until, um, Elsie and Wendy when they went to his funeral they found out such a lot about him that we never, ever knew and we never got to find out, um, but it's just trying to judge them on appearances and doing what you can. (Edith, Staff Member, Interview, 11/3/13)

Nigel died without the staff ever knowing much about him. The quote below shows that this made a qualitative difference to the relationship they had with him compared to Stanley who they knew much more about and who had a more extrovert character. They just accepted Nigel's death but were upset by Stanley's death. This quote came from a group discussion which took place after a number of deaths in the care home:

Vera (Staff Member): Well we all loved Stanley, you know ...

Chris (Staff Member): He was a nice man

Vera (Staff Member): He was so nice and funny and things, so it was harder...cause, compared to Nigel, Nigel was very quiet and you didn't really get much out of him, even though you still cared for him and stuff, Stanley was such a character in his own way. (Group Discussion 21/1/13)

There is a sense that they cared for Nigel in a more detached way than they did Stanley, whom they 'loved'. While the visible embodied selfhood of the person is important, in the absence of biographical detail, it is not sufficient and this has implications for the caring relationship. A distinction has been made between 'caring about' someone which is defined in feeling terms and 'caring for' someone which is defined as task orientated and more closely defined as 'work' (Ungerson 2005). The lack of biographical background the staff had on Nigel may have been a critical factor in the staff not having such a strong sense of his selfhood and feeling a weaker bond with him. Being quiet may also have been a factor. However, there were a number of residents who rarely spoke yet the staff did still have a strong sense of them as a person, for example Penny in the previous section, so I do not think this in itself was the issue.

I would suggest it was much more difficult for agency staff to connect with the whole person in the absence of background biographical information which they usually were not given in handovers. During 'body work' it was often the small details about a person, often unknown to an agency carer, which made the difference to the smoothness of an encounter. It is the importance of knowing the 'silly wee things' that is explored in the next section.

6.3.2 Knowing the 'Silly Wee Things'

I participated or was outside the door a number of times as Maureen was assisted with washing and every time she was very disgruntled, her mood contrasting with how she was when she was in the sitting room, except on one occasion when Izzy showered her as described below:

Izzy (Staff Member) gave Maureen a shower and I stayed outside the door. She had Maureen's shower cap on which I thought was nice – no one else has done this but the fact that she has one maybe shows that she'd normally wear one if she

was showering herself. Izzy was talking to Maureen but not in a patronising or rushing way and Maureen seemed to be in quite a good mood and even at one point said she was very happy here– she was not saying ‘poor old Maureen’ nor that she was being pushed and pulled. She maybe liked Izzy’s quiet manner and that she was not bossy. (Fieldnote p.319 26/8/13)

I am not oblivious to the fact that my own presence during Maureen’s washing at other times may have been having a negative effect on her. I only undertook participant observation focussed around washing and dressing in bedrooms after I had been in the care home a number of months. I had spent quite a bit of time with Maureen by this point and had always connected well with her, with her frequently telling me she loved me. On balance I therefore reasoned that it was not unethical for me to be there helping the staff with the written consent of her family.

Maureen was often unsteady on her feet and needed two carers. Being disgruntled during washing seemed to be usual for her. Perhaps on this occasion with Izzy Maureen did feel something as simple as wearing her shower cap, as she had perhaps done her whole life, helped her to feel more herself. Other staff observed that sometimes knowing these seemingly very small details about a person helped stop residents getting upset when they were receiving hands on care:

And it stops them getting upset as well and arguing and getting worked up as well. Because, like, if Annie doesn’t have her socks, like, if you take her stockings off and you’ve not got her (bed)socks ready to put on then she’ll.....kick off. (Kathy, Staff Member, Interview, 21/3/2013)

These ‘*silly wee things*’ were shared between frontline care staff by word of mouth and they tried to pass these details on to agency staff too so that care giving would run more smoothly. They also thought these details should be written in care plans:

...those silly wee things should be in the care plan, like, I like to wear bed socks. Okay. That seems stupid to everybody else but it’s what you’ve done all your life so why should you not be allowed to do it now that you’re not able to care for yourself anymore. You know, but you should still be... (Nita, Staff Member, Interview, 21/3/2013)

This echoes the findings of Ryan & McKenna (2015) in a study of families' experiences of rural nursing homes. From the perspective of families, as the quality of life of their relative declined, 'little things' about their relative, such as whether they liked gravy on their dinner took on greater significance.

In my study, however, sometimes families became quite focussed on seemingly small things, even when they seemed to have become less important to the person themselves, which could become a source of tension with the staff as shown in the fieldnote below:

Nita (Staff Member) gave Hilda a glass of apple juice at one point – Nita says Hilda's daughter insists she has it because she thinks her mum loves it but that Hilda doesn't actually drink it. They seek to please the families – there seems to be this friction between them and families a lot of the time. Later I saw Hilda with her glass of apple juice untouched inside her bowl of rice crispies and she was eating the rice crispies from around the outside of the glass. (Fieldnote p.312 22/8/13)

It raises the question of who the apple juice is actually for and is it meeting the needs of the resident or her family. When 'little things' are neglected by care staff, it is a source of both annoyance and distress for families (Ryan & McKenna 2015). Harnett & Jonson (2010) suggest that the challenge for care givers in care homes is to understand the intention of family members to preserve the sacred self of their loved one and that this might be driven by fear, grief and desperation among family members. Some conflicts between family members and staff may then be understood and avoided.

I would suggest that the evidence presented here shows that staff recognise the selfhood of residents and seek to support it. It may be that communicating this 'project' more explicitly as a central tenet of their work and with families may be helpful. Discovering the small but important details when the person is not able to tell the staff is part of the challenge. People with dementia are dependent on families and staff to take the initiative which supports the social interactionist position that personhood at

least partly emerges in the social context although embodied selfhood has an important role to play.

6.4 Agency and Selfhood

Some of the residents in my study were experiencing a loss of agency, defined as the ability to ‘do’ and ‘act’ for oneself (Lawton 2000), less in relation to bodily weakness and fatigue, but more because of restrictions imposed on them by the organisational context. The physical layout of the care home impacted on the way that life in the care home was organised and shaped the caring relationship in particular ways; the layout of the building, with long hallways and bedrooms on two floors at a distance from the central area, meant that staff tried to keep all except the most mobile residents in the central area of the hallway and sitting rooms, which at times was a source of conflict when residents wanted to walk around more freely.

Betty was unsteady on her feet and had already had a fall and been to hospital. Although she often wanted to get up and walk around independently, the staff were worried she would fall and spent a lot of time asking her to stay seated, unless one of them was free to walk with her. There was a tension for the staff between keeping people safe and supporting agency. In the early evenings after dinner when residents were being helped to bed, there were not enough staff to watch over the three lounges and get people to bed, so the usual plan was to bring all the residents, unfortunately labelled by some staff as ‘the vulnerable’, into one lounge to free up staff. I observed one occasion where this resulted in a flare up of temper from Betty who did not want to move rooms.

Nita (Staff Member) came in and asked Muriel if they should bring the ‘vulnerable’ people from the other sitting room all into the one room – it is a way of freeing up another member of staff so that there are more available to get people to bed without someone having to be in the other room watching people. It was at this point that trouble began. I came out into the hallway and Nita was trying to get Betty to walk along to the other sitting room but Betty was being very resistant and shouting and pulling her zimmer away very roughly and at one point she hit out at Nita. (Fieldnote p.194 30/4/13)

In an ethnographic study, McGolgan (2005) showed that ‘sitting’ is one of the few activities people with dementia do in care homes and is used as a way to create private space and a sense of home. If choice about where to sit is undermined, people with dementia employ resistance strategies as shown by Betty in this scenario. If Lawton (2000) is right and selfhood is tied to the ability to do and act for oneself, Betty’s selfhood is being undermined in this scenario by the organisational context. Betty had dementia and was also increasingly unsteady on her feet after being unwell several times. Her dementia, age and other co-morbidities were a factor in her bodily abilities being restricted but she could still walk. Her selfhood is being undermined, I would suggest, not because of bodily weakness but because of the restrictions put on Betty because she lived in a context which did not have the resources to enable her to use the embodied skills she still possessed, which was very frustrating for her. What on the face of it could be interpreted as ‘irrational hostility’ is really ‘righteous indignation’ (Sabat 2001) created by a malignant social environment.

On one occasion I saw two carers lift Betty bodily from a wheelchair to an armchair. There was no need for them to do this as she could move by herself but it took longer with a lot of negotiation and close supervision. In the fieldnote below Betty is showing agency; her ability to do and act for herself in going to the activity room. This scenario highlights her abilities and personality rather than her walking problems.

I met Betty coming down the corridor with her zimmer on her own. One of the carers, Anne, saw Betty and me in the corridor and was a bit alarmed to see us – she said Betty is not supposed to get up as she has had some falls. I said I’d found her in the corridor and again Anne was surprised and told another carer this as she was passing. Betty seemed very determined to keep going with her walk so I kept walking behind her. We passed some chairs and I asked if she would like to sit down as I was worried that her legs might be a bit wobbly but she determinedly kept going. I suggested we go to the activity room for some coffee with Brenda and some other residents and she agreed. She managed to walk the whole way. We opened the door and Betty said ‘can we come in?’ Brenda offered her some coffee and there was some joking about bribery and corruption and this being the bad girls club. Betty admired some flowers on a table and asked

*Brenda if she had stolen them and again there was laughter.
(Fieldnote p.181 24/4/13)*

Another example of where agency was lost, not because of bodily weakness, was because of lack of freedom to go outside. There was an acute awareness among some of the staff of how shut in the residents felt, not being able to go outside when and where they wanted because the doors were locked.

And I...I'm...and being able to understand what it's like for them, that they're shut in you know, for the rest of their life, they're never going to get out again and they do feel that a lot of the time, you know, unless they go out with somebody. (Anne, Staff Member, Interview, 7/3/2013)

This too could be a barrier to supporting selfhood. The staff understood the importance for the residents of getting outside and took the opportunity to go out with them when they could. While I was there a safe outside garden was being developed. The staff were constrained by the other responsibilities they had within the house in the amount of time they had to take people outside and there was a sense of resignation or powerlessness to do anything about this. Many of the residents were not mobile enough to go for a walk outside independently and the duty to provide a safe environment, ensuring residents did not fall or go missing led to the locked doors. One resident did 'escape' one winter evening while I was there and was brought back by a stranger who found him.

There is no easy answer to considering how to care safely for 40 people with dementia living together. Regulators have perhaps inadvertently imposed a risk averse culture in care homes by enforcing 'protection' which undermines 'care' and fails to pay attention to the silent harms this can cause (Clarke et al 2011, Tronto 1993). Recognising the link between agency and selfhood and that a loss of agency may cause distress due to the undermining of selfhood may further help understand the distress that residents often express. Making the support of selfhood, including embodied selfhood, a core concern in palliative dementia care and accounting for this in deciding staff numbers, organisational and environmental planning and

consideration of acceptable levels of risk may help to avoid situations where selfhood is inadvertently undermined as restrictions are put on agency.

6.5 Dependency and Selfhood

During my time in the care home as I was assisting the care staff with hands on care of the residents, I was trying to understand what worked well for the residents. Betty who featured in the scenario above was a lady who did require help to wash and dress, particularly in terms of being reminded what to do, but still had the bodily ability to do a lot for herself. The reflective fieldnote below was written after observing John help Betty get up one morning:

John (Staff Member) told Betty he was pulling the (bed) covers back and then did so. He said he was going to swing her legs around which he did and then got her sitting up. He asked her to sit forward onto the edge of the bed which she did. He then got her to push herself up to standing with the zimmer and we then together walked to the bathroom. John was very much letting Betty do things herself rather than rushing her or trying to speed her along. He got her sitting on the toilet. She was smiling and 'chatting' but they were not real words. John gave Betty a cloth and asked if she wanted to wash her face herself which she did well.....(Later in the corridor) John says that Betty knows she can't do things – she has insight and this makes her very frustrated and if the things she can still do are taken away from her or if she is just 'done to', she gets very upset and angry. Between us we decided that actually it is quicker to allow Betty to do things for herself even though she is slow as to try to speed her up or do it for her can end in her fighting back. John said other residents are more passive and just let the staff do the care for them. (Fieldnote p.271/272 25/7/13)

John was letting Betty do the things she could still do herself and there were no temper flare up as sometimes happened if she was rushed or bossed about. It may be that she was being enabled to do and act for herself which in turn supported her selfhood, including her embodied selfhood at the prereflective level. She was being enabled to be an active agent in her relationship with her carer, John, which countered any perception of her as socially dead.

I began to pay more attention to where the staff let people do things for themselves and also where this did not happen. The following reflective fieldnote was taken as I was helping Anne clean Sandra up after she had been incontinent:

Sandra was in the large blue reclining chair (in the sitting room). She had been yelling out for help to get cleaned up. Anne (Staff Member) wheeled her down the corridor. At one point she stopped and said to Sandra she was moving her foot in so it didn't hit the door post. Later I thought that perhaps Sandra could have done this herself. Sometimes I think staff do things for people because it is quicker and residents have become passive. (Fieldnote p.202 9/5/13)

Hakanson & Ohlen (2014) in a study exploring the experiential outcomes of bodily care in a specialist palliative care context found that sometimes staff were described as 'over-caring' by patients which led to a withdrawal of bodily capability from the individual. The withdrawal of bodily ability from an individual amounts to an imposed loss of agency and undermining of embodied selfhood (Kontos 2004, Lawton 2000), which contributes to social death. Anne in the above scenario continued to do things for Sandra which I knew from other times when I assisted with her care that she could do herself, such as take off her glasses and her watch. As we were finishing cleaning Sandra, the following happened:

I asked Sandra if she would like a wet cloth for her hands which she took from Anne and washed her hands with. I then gave her a dry one. Initially she seemed bemused but then did dry her hands with it. Anne was surprised as she seemed to think Sandra wouldn't know what to do with it. Anne said 'it's amazing how old habits remain'. (Fieldnote p.202 9/5/2013)

These scenarios perhaps highlight an assumption that because many cognitive abilities are lost, embodied abilities may also be lost and the body is seen as passive. The fieldnote below shows another example of such an assumption being made by an agency carer:

An agency carer was going around taking people to the toilet. She couldn't get Hilda to stand up. John (Staff Member) went to help her. Hilda was resisting and saying no.

They were trying to encourage her to stand by taking her arms under the shoulders. Eventually John just asked her to stand up and she did it and said something like 'I can do it'. (Fieldnote p.237 5/6/2013)

Perhaps the effects of over caring by staff in the ways described above, which is well intentioned, needs to be highlighted more. There were however, other occasions as described below when help was acceptable:

I chatted to Betty in the sitting room. Her mouth was dirty from her lunch. I went and got her a cloth and gave it to her saying it was to wipe her mouth. She wiped it a little bit but then gave the cloth back to me. I asked if she wanted me to wipe her mouth and she nodded and let me do it. (Fieldnote p.204 14/5/2013)

Hakanson & Ohlen (2014) also found that there were times when cancer patients, especially when they were more poorly, found relief in handing over responsibility for their bodily care; they found it dignifying for someone to comfort them by caring for their body. This suggests that dependency in itself does not undermine personhood. There are times in all our lives when we will be dependent on others for care and all humans have needs that others must help them meet (Lloyd 2004). Dependency is part and parcel of personhood; it does not make us less human but fully human.

In the examples above I would suggest that Sandra's selfhood may have been supported by giving her the opportunity to dry her own hands, tapping into an embodied skill that was part of her selfhood and in this way she may have been empowered. However, Betty's selfhood and her dignity was also supported as her embodied selfhood was respected, as was her need for help which she chose to accept. The goal of independence and rehabilitation is enshrined in dementia care standards (Scottish Government 2011). However, in dementia care practice in care homes, within a relational palliative care approach, I would suggest a more appropriate therapeutic direction would be to support selfhood, acknowledging that dependency is not a failing but part of the human condition.

With the exception of people who die unexpected sudden deaths in the midst of life, the majority of us will be dependent on care in very old age and as we are dying and it is to consideration of selfhood and dying that I now turn.

6.6 Selfhood in End Stage Dementia and in the Dying Phase

People with advanced dementia and those who are dying are on the conceptual boundary between being viewed as a body object and an experiencing body-subject (Cohen 2011), which has implications for their experience of relationships and how others relate to them. This section presents data which seeks to understand how the care staff perceived residents who were dying and whether they saw them as objects of care or fully present body-subjects. There were times when I observed residents being treated as ‘objects’ of care, such as the example below, but these were uncommon:

Cindy doesn't look well (she died 9 days later). She is in the recliner chair. At one point two carers came from behind and began pulling her chair backwards without telling her and she screamed. (Fieldnote p.300 14/8/2013)

At a conceptual level it seemed that mostly the care staff did not question the personhood of residents, even those who were close to death as indicated by the following response from John in an interview:

Researcher: Well, I suppose towards the end of life as they are maybe in bed and maybe in the last week of life or the last days of life, how do you find...I suppose, do you still see them as a person and how do you still treat them as a person right until the very end.

John: Because they are still a person, you know. (Staff Member, 19/4/2013)

And also Gemma:

I mean in a way you hear so many people say things like, when the person has died, it's almost like a relief because they've already done their grieving because the person is not the person they knew so...in a way the grief isn't the same as it would be if somebody died unexpectedly and they didn't

have a long term dementia condition em....so it's hard but I always try ...I wouldn't say I think of them as 'already gone' I don't think I would ever do that I always think they are still here and while they are still there it is our em...it's our responsibility to give them the best that they deserve so I always try and still talk to them and still just chat away as I would normally...(Gemma, Staff Member, Interview, 3/6/2013)

The staff employed a number of methods to show the person who had very advanced dementia or who was dying that they understood they were still there, for example:

...I think sometimes I use physical touch a bit too, you know that actually touching someone on the arm, or giving them a kiss you know, or a little hug, I do, I think that's really necessary for people when things are, you know... and not talking over them. Very often when people are in their last stages, it's very easy to talk over them to the other person, and you've actually got to talk to them still, you know, because that person's still there, you know, erm...(Anne, Staff Member, Interview, 7/3/2013)

Calvin below talks about his approach to Lillian when she was dying, indicating that he still saw her as fully present:

I felt I was a lot quieter, and I wasn't, like I was, I was still speaking to her and telling her what we were doing, but it was a lot quieter and a lot slower. Erm, and you know you weren't, obviously you weren't getting a reply, but I still kept speaking to her, just to let her know... you know, it's ...she was, she was lying there, so I felt it was right for her to know what was happening. (Calvin, Staff Member, Interview, 19/4/2013)

Awareness, even in those who were dying with advanced dementia, was an indicator to the staff that a resident was still fully present and not imminently dying in the next few hours. The fieldnote below refers to Lillian who was classified as 'palliative' by the staff and was being cared for in bed:

I asked Elsie (Staff Member) how she knew that Lillian was not dying last week – she said she just knew from experience – I pushed her to try to unpick how she knew – it seems that she was well perfused (no peripheral shutdown) and she was

still following what was going on and was alert. At the same time they knew she needed to be in bed as she had a weariness about her. (Fieldnote p.173 21/3/2013)

The above fieldnote shows that objectively reading the material body was important for communicating to the family the stage of dying that had been reached. Lillian's level of awareness, or presence, was also important. At the handover the staff spoke about how they knew Lillian was still aware as she was following people's movements around the room with her eyes. This continuing recognition of the person is not based on a philosophical argument about what a person is but comes from direct experience: *just by talking to the person, you do get a reaction (Anne)*. Hughes (2011) suggests that in thinking about the application of philosophy to dementia conclusions must square with practice and the phenomenology of care and also the experience of the human encounter. The staff do not question that the fully present person remains because in their experience, they do.

There was a recognition that the relationship between the staff and residents changed as they were dying. However, there were still small signs, as described in the interview extract below, that the person was present:

Hilary: ...that particular lady that I'm talking about, when she started to deteriorate and she was in her bed all the time I would go in and maybe spend 20 minutes with her and I'd look through the favourite book or I'd talk about her boy.. and you would, you'd get a wee movement out of her or she'd open her eyes for a few seconds and then close them again, so I certainly think it's still there even though maybe it's not a two way thing any more

Researcher: Aha... What do you mean it's not a two way thing anymore?

Hilary: Maybe the resident is not able to verbalise the same comedy or the same wit that she used to but there's still the recognition there

Researcher: And how do you know there's that recognition, what makes you think that

Hilary: You almost feel it ...you maybe sense a change in the person's breathing, they come more relaxed or calm or the eyes open, they look directly at you, close again, just wee things (Staff Member, 29/1/2013)

I would suggest that the above, and Lillian's following movements around the room with her eyes, are indicators of embodied selfhood and a fully present and experiencing body-subject, even when very close to death. Hilary speaks about 'feeling' or 'sensing' the resident's recognition and presence. Hilary 'feels' intuitively that she is being perceived while at the same time being the perceiver because intercorporeality is the basic form of human-being-in-the world as described in earlier chapters (Crossley 1995); there is an embodied reciprocal interchange which she then describes in words when asked. The staff tap into this as they give care and make decisions about what stage of dying has been reached.

In contrast, the fieldnote below seems to suggest that the 'living body' is being seen as passive and a mere container for the self, which here is perceived as being 'gone', rather than a constituent of the self.

I sat with Lillian's daughter this morning and her mum, well we don't know, it's an unknown (how long it would be until death – Lillian died 13 days later) and she was getting emotional and I felt I could squeeze her hand and say, you know, I've been here and I know...she says I feel bad I just want this over with now. I've been there and even with my own dad it's like...but you've already done your grieving it's a shell, it's not really your mum, your mum was the person that brought you up and had conversations and taught you to bake and things like that, this is, you know, this is the sad final stages. (Muriel, Staff Member, Interview, 11/3/2013)

I have no doubt that Muriel was trying to comfort Lillian's family. However Lillian's family were upset because she was unsettled as she was dying. Their upset seems to suggest that they did not see her as a 'shell' or an 'object' but as a fully present experiencing body-subject who was agitated and/or in pain as described in previous chapters. This underlines the importance of good symptom assessment and symptom control at the end of life. Also as Lesser (2006) points out, the present situation does

not invalidate the past: Lillian *is* the person who taught her daughter to bake and this was why the present situation was so painful.

Other staff too spoke about how important they felt it was for a resident not to be alone as they died, again suggesting they did not see the person as an ‘object’ but that their personhood was inherent and that at some level they were fully present:

I think if they are not alone then that's fine, I think that's a nice way... (Vera, Staff Member, Group Discussion 21/1/2013)

Also the fact that they see it as important that the residents die in the care home rather than being transferred to hospital to be cared for by strangers seems to suggest a continuing connection with the resident as a person and not as an object of care:

'... personally I look at it as a privilege, it's something that nobody else gets to do and we know the person whereas if they were in a hospital it would be a nurse who'd maybe known them for a week'. (Hilary, Staff Member, Interview, 29/1/2013)

The staff talked about how they continued to see the resident as a person, and continued to interact with them as a way of coping:

Louise (Staff Member): We keep them clean, we just make them comfortable we talk to them as well even though they are not answering....

Gemma (Staff Member): The hearing is obviously the last part to go...

Louise (Staff Member): We laugh....we talk about the things they used to do, maybe sing the songs they used to sing, maybe that helps...

Angela (Staff Member): Even when we are doing the body...

Louise (Staff Member): We are still talking to a dead body ...come on Stanley

(All laughing)

Gemma (Staff Member): It's just a way of coping with it all isn't it...it's just how you do it (Group Discussion 4/2/2013)

Gemma's comment here on finding ways of coping points to the emotive nature of the work in care homes. The suffering and the often difficult realities of advancing dementia and dying the staff bear witness to is explored in the next chapter.

6.7 Conclusion

How people with dementia are perceived by carers is crucial to how care is given and received and the way people with dementia are positioned in the caring relationship at the end of life. This chapter has explored the ways that selfhood is expressed, recognised and supported in people with dementia towards the end of life including the last weeks and days. Drawing on practice examples it develops thinking on how the theory on embodied selfhood and intercorporeality can be articulated and more fully harnessed in the caring relationship. This could help avoid objectifying people with dementia, ensuring they are recognised as fully present until the end of their lives. It has also drawn attention to factors within the local and wider organisational context which can undermine selfhood and perpetuate suffering.

The next chapter examines another important aspect of palliative care for people with dementia which emerged: witnessing and responding to suffering. The causes and expression of distress are examined and the staff response, with a particular emphasis on the interdependency of the feelings of staff and residents and how this relates to boundaries in relationship-centred palliative dementia care.

7 Witnessing and Responding to Suffering

7.1 Introduction

The previous chapter explored the different ways that selfhood was expressed and supported in Primrose Hill and began to consider some of the ways in which supporting selfhood could become more explicit as one of the core aims of relationship-centred palliative dementia care in relieving suffering. As discussed in Chapter 2, the concept of suffering and the relief of suffering is core to the definition and purpose of a palliative care approach. Suffering is defined as ‘the bearing or undergoing of pain or distress or tribulation’ (Oxford English Dictionary 2014). This chapter focuses on the concept of suffering and how this impacted on the care-giving/care-receiving relationship. The chapter is in two sections: the first section describes how residents expressed suffering and how the care staff identified and responded to it; the second section explores emotions experienced by the staff in response to the residents’ suffering, how these emotions were dealt with at an individual and organisational level, and implications for relationship-centred palliative dementia care.

7.2 Expressions of Suffering

While I was doing fieldwork I observed distressed behaviour which was not relieved despite ongoing efforts from the staff and the wider multidisciplinary team that included: the Behavioural Support Team²⁴, the GP, community nurses, and an Art Therapist²⁵. I often witnessed various visible forms of agitation, such as unsettledness with people getting up and down out of their chairs, or calling out for help but not being able to verbalise the problem.

²⁴ An NHS psychological service which supports care homes with residents who have behaviour which challenge the staff

²⁵ The Art Therapist was recommended by the Behavioural Support Team as part of a treatment plan for a resident

Merleau-Ponty (1962 cited in Kontos 2004) argues that speech is a gestural system and that even when speech has no linguistic meaning, a person can communicate through the expressive dimensions of the gestural body which is fundamental to human communication. The quote below shows how John, a staff member, is able to tell that Barbara is upset in the absence of coherent speech because of the body's inherent ability to apprehend and convey meaning (Merleau-Ponty cited in Kontos 2004).

Barbara, for example, what she says, you can understand the words, it's just the sentences, the words within the sentences are all mixed up and they're all just random words. But if she's not happy about something, she's sort of...her arms are crossed and she has sort of like blunt movements and just her tone of voice, but if she's just talking to you about something she'll just...I don't know, she'll be really loose and free with her arm movements, because she uses her arms a lot. (John, Staff Member, Interview, 19/4/13)

John is able to deduce from facial expressions, bodily movements and tone of voice when Barbara is unhappy because he shares the same world as Barbara where bodily signs of unhappiness are a shared pattern of communal practice (Hughes et al 2006). Barbara's unhappiness is *visible* to John; he can see and sense it with his body (Zeiler 2013). Her behaviour and reactions can be interpreted in the light of human practices (Hughes 2011), although, from this he does not necessarily know what she is upset about.

Getting to know and understand the residents' emotional state was inter-embodied, with the residents getting to know the 'face' of the staff and the staff learning to read the bodies of the residents:

...most of the time, you just watch her...their body language, you know, most of them have problems with communication, you know, even though they might be able to speak, their speech might be a little bit, you know...we can't understand really what they were trying to say. So I try to spend time with her in that way. And it's just so that she gets familiar to my face as well, you know, like because I'm there trying to

chat with her, um, and then you know how they are usually, you know? How...what is their normal, you know, so if maybe one day she was more agitated or...she's very, very active, so if maybe one day she was too quiet (Zoe, Staff Member, Interview, 7/3/13)

Brenda below talks about 'paying attention' to the resident's feelings which again points to intercorporeality; an embodied expression as well as an embodied understanding of how the residents are feeling:

I have almost this urgency to kind of try to pay attention to them because ...it must be a terrifying thing to be in that position, you can't say how you feel (Brenda, Staff Member, Interview, 31/1/13)

Often the staff would go through a process of trial and error to try to get to the source of suffering.

7.3 Identifying Sources of Suffering

Behavioural and psychological symptoms, such as mood disorders and depression, agitation, or aggression are common in dementia and affect 90% of people at some point in the course of their illness (Sampson 2010). They may be indicators of unmet need such as under-detected or under-treated pain, delirium or infection, but distress does not always have a physical basis and psychosocial approaches to alleviating this form of suffering are also necessary (Hughes 2014, Jordan et al 2011). In the advanced stages of dementia over half of people with dementia remain agitated and distressed (Sampson 2010, Mitchell et al 2010).

If a resident was distressed, the staff would firstly try to identify if there was a physical cause behind it:

Sometimes when they are frustrated they have got things that you have to look at – either they are tired, or they are hungry or they need the toilet or they just want a change of environment, to move from where they are, maybe it is noisy, it is crowded, the light is too bright - so try and pick up what

is the best for her because they know what they want to tell you but because they have got dementia or they have got Parkinson's and they can't communicate they can't tell you 'I'm wet, I need the toilet' but you just see by them standing up, very often walking about, that they are looking for the toilet, they need the toilet but they can't tell you, or maybe they are hungry but they can't tell you. (Ida, Staff Member, Interview, 23/5/13)

At times this approach would be successful and calmness would be restored. However, often the staff struggled to relieve the distress the residents were expressing. There was a recognition by staff that distress went beyond physical suffering to other kinds rooted in emotional or existential distress due to the many losses that dementia brings:

...sometimes you see some of them crying, yesterday there was a lady crying and I was thinking 'why is she crying?' and part of me thought is it to do with physical pain or is it more to do maybe the way she was feeling herself because I mean you have to be taken to the toilet and that could be a male or a female, do you know, you don't have it your way, like me I love at least two showers a day ...do you know, you don't have that, it doesn't matter how much money you pay it's still, the staff are so pushed for time ...and I think gosh... her daughter was with her yesterday and I wonder if it is the way she is feeling herself...my daughter is here and I'd love so much to be different, I don't know (Brenda, Staff Member, Interview, 31/1/13)

7.3.1 'I like it here but you can't help thinking about home'

The quote above was recorded in a fieldnote after chatting with Katie, one of the residents. The very fact of being in a care home rather than in their own home was a source of unhappiness for some residents, although certainly not all, as the quote below shows.

But there are people, you could divide people who are coming here, and they are just willing to be here... there is the staff, there is somebody to look after (them)... and there are people like Joanna; from the first she came here she just was opposite, you know, everything for her was negative, she didn't want to be here, she was very rude to her daughter,

she was very rude to the staff, she was very rude to the residents, so everything, when she look at everything here, it was absolutely wrong, absolutely bad, she was constantly saying she hate the place ...certain who are here and they don't wish to be here, they don't like it, they'd rather stay at home... (Una, Staff Member, Interview, 23/5/13)

The above quote shows that there was variation in how well people settled in the care home. Differences in physical problems undoubtedly play a part in untangling the complex factors which contribute to distress but this aside, I myself did wonder at how some people could seem so content yet others so discontent within the same environment. In my own encounters with the residents I experienced a sense of feeling helpless in the face of the loss of home:

I went and sat in the hallway for a bit with Katie. She is always talking about how useless she feels and no amount of affirmation seems to help with this....She then asked me what this place was called and when I told her it seemed to just dawn on her that she was in a care home. She was devastated and wanted to know who had done this to her. She was sitting with her head in her hands in disbelief. She couldn't believe it. She went very quiet. At one point I asked her if she was crying and she said 'a little'. (Fieldnotes p.214 16/5/13)

Katie had a supportive family who visited regularly. She was physically very active, walking around a lot and sometimes dancing or joining in with activities, but still there was this sense of loss at being in a care home and that she could not stop thinking about home.

The quote below gives a carer's observation that being in a care home is associated with a loss of selfhood and an eventual giving up on life.

I think really they give up after ...they've got that fighting spirit and 'maybe if I talk more about it' ...they try to go out the door... 'I might be able to go' ...but then...it does affect themselves as well I think it does affect the way they view life after that ...cause that sense of abandonment as human beings, even animals ...it kills animals because you miss the company of the people that you are used to, you miss the

*company of the people who understand you as you are....
(Fred, Staff Member, Interview, 23/5/13)*

This insight from Fred underlines the importance of building in the support of selfhood as described in the previous chapter as a strategy to alleviate suffering and as a core tenet of palliative care for people with dementia.

7.3.2 Fear of Being in a Strange Place

Fear, as the staff told me, was often recognised and indeed verbalised by the residents:

*'Like XXX 'I feel so frightened' but she's able to say 'I'm frightened' because she recognises what she is feeling
(Brenda, Staff Member, Interview, 31/1/13)*

This fear seemed to be linked with the resident being surrounded by a lot of people she did not know: There was a sense of helplessness from the staff:

...I think she would benefit more in a smaller group of people, I think it's too many people, too big a place and I think that gets her a bit more agitated I think...I think she just needs...even when you try and give her something else to do it doesn't last for very long...I don't know, we have tried so many things... (Vera, Staff Member, Interview, 26/6/13)

Vera's idea of a smaller place with less people is indeed what the literature on the physical environment would suggest is most beneficial for people with dementia in terms of person-centred care (Chaudhury et al 2011). A sense of being with another person one to one often did seem to bring a sense of comfort and security, even if only for the short period that this was possible in the busyness of the day:

(Mid-morning in the sitting room) One of the residents was sitting on the edge of her seat looking very perplexed. It is a very big room and she looked very alone in it. The TV was very loud. I went over to her and sat next to her. I held her hand and asked if she was OK. She doesn't say very much and she just continued to look perplexed. I asked what I could do to help and she shrugged and shook her head. Then she said 'just be with me'. I said that I would and I held her hand

and she held my hand sandwiched between her two hands....She continued to hold my hand between her two hands and twice she lifted my hand up to her mouth and kissed it. Eventually she fell asleep. (Fieldnote p.244 24/6/13)

At times the staff spoke about how, when a resident was difficult or unsettled, they would tell themselves it was the ‘illness’ and not really the person. Bury (1982) describes how objectifying the disease in this way provides a socially legitimate basis for difficult behaviour and also clinical intervention, perhaps in the form of sedative drugs. It might help care staff to retain a positive regard for the person despite difficult behaviour. However, it has two consequences. Firstly, it can overlook the impact the illness has on personhood. Secondly, it points to a limited view of what causes difficult behaviour in people with dementia and a lack of recognition of the factors in the environment which might be contributing to distress or agitation, leading to a sense of helplessness on the part of front line staff.

The physical environment of the care home is known to have an impact on symptoms such as agitation and mood (Chaudhury et al 2011, Garre-Olmo et al 2012). A sense of being in a large empty space is known to be distressing for people with dementia. However, some aspects of the environment such as the high ceilings of a Victorian building are somewhat fixed. Other aspects of the micro-environment, such as noise levels, are not fixed. There were occasions when I asked residents if they liked the music that was playing and often it seemed they did not actually notice it. However, there is a hint in the fieldnote below that the constant music may have been over stimulating and a source of agitation for Emma:

I sat with Emma in the hallway on the settee under the stairs. Yesterday at handover they spoke about Emma as being agitated and on the move all the time... She held my hand and when I looked into her face she smiled. She was talking quite a lot but although she was saying words they didn't make sense to me and I couldn't hear her very well. She did say 'long' at one point and 'forget' and I did get the sense that she was trying to communicate something. She also said 'noisy' at one point and actually it was quite noisy – there was music playing beside us which was just 'on' and music in another room which was just 'on'. I sat with her for about 10

*minutes and she was starting to dose off. (Fieldnote p.19
26/10/12)*

A phenomenological perspective highlights that people with dementia perceive their environments, as do we all, in an embodied way which does not depend on having cognitive ability. If the environment is noisy or chaotic, we will experience it as such. People with advanced dementia may not have the cognitive ability to make sense of it, therefore, become fearful or agitated. If the atmosphere is calm this is also 'felt' and may calm fears and bring peace.

Several care staff spoke about how they liked taking the residents out for trips, either one to one or as a group, as the person seemed to blossom when they were out of the care home environment. On these occasions the staff saw the person in a new light, not simply as a 'resident'; the person often surprised the staff by, for example, eating well without requiring prompting, or behaving in a more 'appropriate' way. There seemed to be something within the environment of the care home which obscured the real person; the busyness or the noise, or simply the number of people. This is a concern for people towards the end of life who are much more limited in their ability to go out for trips.

7.3.3 Fear caused by an Awareness of Dying

A couple of weeks before she died, Emma who was still fully mobile and was up and dressed told me she was frightened:

*I went to the sitting room and found a lady I know well
(Emma) – asked how she was and she said 'I find myself
frightened'. I asked what she was frightened of and she said
'things'. (Fieldnote p.92 14/12/12)*

Emma was often heard calling out for her sister. With hindsight, it may be that an awareness of impending death was contributing to her sense of fear and her cries for her sister. Although understanding of screaming in people with dementia is poorly understood, there is some evidence which suggests it might be an indicator that the end of life is approaching (Bourbonnais & Ducharme 2008).

Joanna also frequently shouted for help. The care staff did recognise that residents were at times frightened because they were aware of their impending death, as the quote below shows:

Muriel: One of our key clients was Joanna, who I think we were all quite fond of, she was quite a character, but her last, what five weeks, was quite draining on her as well, she didn't know whether she was coming or going, she was almost frightened in her eyes...big eyes...and not taking medicine and just constantly demanding attention. I felt at the end she was actually...I think she knew she was dying and she was frightened

Researcher: Right, do you?

Muriel: I think she was frightened to be alone because one day she had slid off the chair under the stairs and I had done the checking that she hadn't damaged anything and she held onto my hand and said 'don't leave me', you know, 'I don't want to be left alone down here', and there was loads of other people but I just think she was really frightened of being left on her own. And I know that she was using the buzzer a lot through the night as well just to have people to talk to as well, so I think there was an element of fear involved with her. (Staff Member, Interview, 11/3/13)

Joanna was recognised to be 'declining' by the staff. She was still mobile with her zimmer until the day before she died so accurate prognostication was difficult. Examining medication charts was not an objective of this study but, from conversations with the staff, drugs such as midazolam²⁶ were rarely used in the care home and it tended to be only oromorph²⁷ for pain which was prescribed on an 'as required' basis in anticipation of difficult end of life symptoms with s/c

²⁶ An injection used to treat anxiety, recommended in 'just in case' boxes in anticipation of anxiety in the dying phase when the swallowing reflex is lost (Scottish Palliative Care Guidelines 2014)

²⁷ A liquid medicine used for severe pain (Scottish Palliative Care Palliative Guidelines 2014)

diamorphine²⁸ occasionally used if the dying process was longer and the swallowing reflex was lost.

In the context of dementia, as it is beginning to emerge, current symptom management based on general palliative care guidelines may be suboptimal for people with dementia (Hendricks et al 2014). It may be that short acting anxiolytics such as lorazepam²⁹ which are not currently included in general palliative care guidelines may be appropriate for people with dementia, not as a substitute for providing company but in addition, to alleviate this kind of suffering. While much attention has rightly been paid to the misuse of psychotropic medication for people with dementia (Banerjee 2009), failing to provide appropriate symptom management as part of a palliative care approach may prolong suffering. We must challenge situations where people with dementia get less adequate palliative care than those without dementia. However, the sources of suffering for people with dementia are complex and multifactorial and a broad approach which also addresses environmental and relational factors is essential.

7.4 A Case Study of Distressed Behaviour – Sandra

Sandra was a lady who was particularly unsettled during the last few months I spent in the care home, and she could often be heard wailing. Physical reasons for her distress had been considered. She was regularly seen by the GP and it was felt her pain was under control. She herself said she did not have pain, although she had a small sacral pressure sore which occasionally broke down and then healed up again. She was also being seen by the Behavioural Support Team and she was on an ABC³⁰ chart.

²⁸ An injection used for severe pain recommended in ‘just in case’ boxes in anticipation of severe pain in the dying phase when the swallowing reflex is lost (Scottish Palliative Care Guidelines 2014)

²⁹ A short acting rapid release tablet for anxiety

³⁰ This is a chart which the staff use to document the Antecedents of behaviour, the Behavioural disturbance, and the Consequences of the behaviour in order to reveal patterns and triggers for particular problems (Sampson 2010)

Sandra had been in the care home for seven years. She and her supportive family were well known to many of the staff. She had vascular dementia which was thought to be progressing because of frequent trans-ischaemic attacks. Her verbal ability and comprehension in the moment was good and it was possible to have a conversation with her, although her short term memory was very poor. She could stand, but used a wheelchair to move around. She could feed herself and ate well, enjoying her food.

Often the staff tried to cheer up residents who were sad or distressed. In the past this had worked well with Sandra who enjoyed a joke, but now it had got to the point where this was more difficult:

I've always had a good relationship with her because I know exactly how to cheer her up ...like she's always saying, now she'll say things like, she's done it for a while, 'oh I'm fed up, just get a gun, can you not shoot me, em ...and I know with her how to respond and I just say 'oh I forgot my gun, I'll bring it tomorrow, I'll meet you at 2 O' clock out the back' and she just laughs and you can get her straight out of that mood and brighten her up and I kind of deal with a lot of stuff with Sandra in that manner. Now it doesn't always work quite as well because sometimes she's very down at times and she's so confused and agitated at times that sometimes it doesn't matter what you do it doesn't always work...(Gemma, Staff Member, Interview, 3/6/13)

Gemma who was Sandra's key worker recognised that Sandra was no longer able to do the things that gave her pleasure and meaningful occupation was difficult for her:

...that was her big thing was crosswords and reading ...and she's just not able and I think she knows within herself she's not able to concentrate and she can't do the crosswords and things now so I think a lot of it is boredom and attention but I think it's more attention as in 'I'm bored senseless so I want somebody with me to talk to or do something with because I'm not able to do it myself. (Gemma, Staff Member, 3/6/13)

...I think a lot of the time it's a definite attention seeking thing as well because she doesn't want to be on her own...she hates being on her own ...(Gemma, Staff Member, Interview, 3/6/13)

However, the ability of the staff to meet the need for company that Sandra craved was impossible to fulfil with 39 other people to look after:

I thought 'I'll get her into her nightdress' because she was wanting the toilet anyway so I took her to her room to use the commode and when I was talking to her she was fine, she was great no problem and I was chatting away and she was light hearted and everything and I says 'come on up you get lazy bones' and stuff like that and she just laughs and she stands up, what have you, ...and then the second I went into her bathroom to clean her teeth she started groaning and I said 'Sandra, why are you making this noise, it's a terrible noise, what's all this about Sandra? ... 'you went away and left...I didn't want you to go away and leave me' ... 'but Sandra I have to, I'm only in the bathroom cleaning your teeth but there's other people that need my attention as well...I will come back and see you'. (Gemma, Staff Member, Interview, 3/6/13)

Sandra's wailing was upsetting for the other residents to hear and there was a conflict for the staff in deciding whether to keep Sandra in the sitting room with everyone else, or to take her to her bedroom. Sometimes she settled in her room and seemed to be comfortable on top of her bed but other times she wasn't and would try to climb out over the bed rails. The fieldnote below was taken one morning after breakfast when there was disagreement among the staff about how to 'manage' Sandra:

In the sitting room Sandra continued with her wailing. The male agency carer... then appeared with a wheelchair. Debra (Staff Member) asked him who it was for and he said that he'd been told to put Sandra back to bed. Debra objected to this and said that Sandra had just got up and she didn't think she should be in bed – she just continues to wail and to climb over the bedrails and she has been in bed all week and it's not good for her just to be left in bed all the time. She said she thinks she wails because she is bored and she would be too if she was in her position. (Fieldnote p.223 30/5/13)

Sandra was then asked by the team leader if she wanted to go to bed and she said 'no'. Debra got Sandra knitting and this did settle her for about an hour. Although this small breakthrough was not recorded in her continuation notes, it was passed on at handover. However, the next day when they tried the knitting again it didn't work.

The two approaches at work here were to treat Sandra as a body object and remove her from the room as she was causing distress to other residents, or to treat her as a body-subject and try to break into her suffering and connect with her, taking a relational approach as described by Moser (2011). The deeper problem behind Sandra's wailing is perhaps the existential angst her son felt she was experiencing in that she had had enough of life but for some reason was not able to die:

..he just keeps saying you know mum's problem is that she's lived too long, she doesn't want to be here anymore, she's had enough, she's just fed up and I think he's right, she's just decided she's had enough... (Gemma, Staff Member, Interview, 3/6/13)

However, in the midst of the wailing there were times when Sandra seemed to be finding some pleasure in life as the fieldnote below shows:

(Later) Sandra was also in the dining room. When she had finished eating what was in front of her she began wailing. Twice I gave her toast and chocolate spread and then somebody else gave her some as well. She smiled at me when I offered her this – even in her wailing she has a twinkle in her eye... (Fieldnote p.318 26/8/13)

Sandra was not imminently dying at the time of writing when these fieldnotes were taken but lived for another eight months. Whether it is ever possible for the staff to restore meaning to life in this living/dying interval is a difficult question to answer. What is clear is that caring for people with advanced dementia towards the end of their life exposes the care staff to a maelstrom of emotion which in turn raises a complex mix of emotions in the care staff.

7.5 Emotions Experienced by the Staff in Care Work

This section firstly looks at the emotional rewards of working in the care home. The emotional costs of bearing witness to suffering, especially when there was a sense of not being able to alleviate it, are then considered alongside the dilemmas this raises in relationship-centred palliative dementia care.

7.5.1 Emotional Rewards for Care Staff

A number of the care staff talked about the satisfaction and happiness that spring directly from their interactions with the residents. The fact that it was a challenge for the residents to express any appreciation for the care they received meant that when the care staff did get such feedback, it was more meaningful:

I think it does make you happy making that difference, knowing that people like, with Penny, when, you know, a lot of the time she's quiet and just quite... but then when you do say something to her and you get that laugh out of her, it makes it that much more special. (Calvin, Staff Member, Interview, 19/4/13)

This shows that people with advanced dementia can continue to make a significant contribution within their relationships which is rewarding for care staff; the significance of a smile was not lost on them:

Iona today who's obviously very ill and not eating and not drinking, but it's the smile, it's just the way it lights up on people's faces, they must be, they must feel something, you know, erm, some form of happiness, despite everything, you know. (Anne, Staff Member, Interview, 7/3/13)

Twigg (2000) in a study of bathing in community care describes how the neediness of clients creates strong bonds in caregiving and promotes self-esteem in care workers and there was a sense among the carers in this study that they were doing something valuable:

...the nicest thing anybody can ever say to you before they go to bed is, like, basically, like, thank you....that is lovely ...it's, it is such a nice, nice, nice thing to have someone just thank you... and you know that they are so sincere because they can't do it for themselves. (Nita, Staff Member, Interview, 21/3/13)

The effects of dementia on memory meant that the rewards of the work had to be appreciated in the moment because the next moment something very different could be happening:

... what for me matters is the moment being together because with dementia you can't say...you can't always say this was an amazing day of work...they understood it, they remembered it, because maybe two minutes later they will forget about everything you did but I know that moment we enjoyed together and we were doing things ... (Brenda, Staff Member, Interview, 31/1/13)

7.5.2 Special Relationships

During interviews I asked care staff to tell me about relationships with residents they felt were good. A number spoke about residents they key worked. It seems that these consistent relationships were significant to the residents as these particular carers, whose faces they came to recognise, could often provide them with better emotional care than other carers who knew them less well. This consistent relationship where the residents 'recognised' the carer at some level, even though they did not necessarily know their name was important towards the end of life when people could become more agitated or fearful. This, in turn, is rewarding for the care staff but also creates a greater sense of loss when that person dies. Edith below is talking about her relationship with Joanna.

...it was so important to me because she always recognised me. Even though she didn't know who I was, um, she couldn't remember my name or anything but she always knew she knew my face, she didn't know how, um, and I always seemed to brighten her day. So if I came in and she was in an awful mood and she had been shouting at everybody, I'd come in and she'd go, oh Bunty, and she always used to call me Bunty. And I was coming to sit beside her and it was just being able to see that change in someone because they've seen you. So I think I do, I do miss that, I miss, um, knowing that you've made that much of a difference to someone's day, um, because with dementia obviously it's hard because it's hard to get through to people to try and reassure them and help them. (Edith, Staff Member, Interview, 11/3/13)

This indicates that one carer cannot simply be substituted by another and that 'care' is not something that can be separated from the person performing it (Chatterji 1998). Nursing staff in care homes have identified longitudinal relationships and

emotional attachment to residents as improving the quality of end of life care (Hanson et al 2002). 'She knew my face' was significant for a number of the staff and was also my own experience with some of the residents, pointing to the importance of the inter-embodied nature of relationships, not relying on cognition, such as remembering names. The sound of a familiar voice was also important:

...the normal way to have a relationship is I talk and you talk, you know, and we, together, you know, build something, but I never thought that like simple things like that, you know, or a...just a look maybe when they are busy with something else and they recognise your voice because you've said, hello. They just look at you and, you know, it's just very, very rewarding. (Zoe, Staff Member, Interview, 7/3/13)

Below John seems to recognise this blurring of the distinction between the carer and the cared for as they build a relationship together:

...it's not just a job. You come in, you're seeing these people every day, they are part of your life as much as you're part of their life, if you know what I mean. (John, Staff Member, Interview, 19/4/13)

The fact that the residents do become part of the lives of the staff means that the care staff experience a sense of loss when residents die:

And you are losing, as I said before, you are losing people that are part of your life and have been part of your life for a while ...so there's a great big gap (Derek, Staff Member, Group Discussion 18/1/13)

7.5.3 The Effects of Witnessing Unrelieved Suffering and Dying

The reverse side of emotional rewards for their work was when the staff felt unable to alleviate the distress of the residents. Sometimes this was related to the natural and irreversible progression of the disease:

It is difficult, you see them progressing... I mean I think most staff here could tell the moment something happens and they go down, because you know they go down and they never go

back it's always like, they could get stable but it's never the same (Brenda, Staff Member, Interview, 31/1/13)

There were times when residents experienced acute episodes of confusion which were very distressing for all involved as the following fieldnote shows:

Ingrid has had a very acute episode of paranoia this morning. She was discovered smashing up plant pots in the herb garden ...She thought she was being gassed and was worried about her children. (A member of staff) tried to distract her by taking her for a walk but Ingrid then became very suspicious of her saying she was 'one of them' and grabbed her by the neck. The staff member ended up on her knees with Ingrid's hands around her neck, unable to free herself until the domestic supervisor realised something was wrong and came to her assistance. (Fieldnote p.296 6/8/13)

A number of residents were constantly demanding the attention of the staff and only settled when there was someone sitting with them. This was draining for the staff who were not in a position to sit for as long as the resident would like:

I think (Joanna) just wanted to talk and have people around her. And it was draining on the team, I'll not pretend it wasn't...but we never ignored her, we always...well she was one of our key clients, we always gave her attention. (Muriel, Staff Member, Interview, 11/3/13)

Knowing that they did not have enough time to just sit with residents who needed them felt horrible for the staff:

For the time that you could do it, for those like ten minutes, I think she got like reassurance that she was with someone and, you know, she didn't have to really worry about where she was kind of thing. But the horrible thing about this job is you can't sit all day with one resident, like we have forty people, so it's harder that way. (John, Staff Member, Interview, 19/4/13)

At other times it was difficult for the residents to express what was troubling them and their agitation persisted;

...sometimes when she has a problem she can't actually tell you what it is..so say if she's had like an accident or

something she can't tell you she'll just ...she'll talk about something else, so you'll have to try to do some problem solving and that makes her more agitated because you are trying to do different things and I guess she feels like she's not getting listened to so... (Vera, Staff Member, Interview, 26/6/13)

Bearing witness to residents' distress and being unable to help, either due to a lack of time or not getting to the root of the problem was difficult:

...whereas I said before like, XXX I find it very difficult to be beside her and don't like, I like her but I don't like (being) beside her when she's (distressed)...which is hard when she's my key client (Vera, Staff Member, Interview, 26/6/13)

Some staff recognised that they were burnt out and actually left shortly after this:

XXX sees me and hones in on me and at times I'm just burnt out with it. (Muriel, Staff Member, Interview, 11/3/13)

Prolonged dying was particularly difficult for the staff to witness, as was supporting families through this. Lillian was in bed and dying for three weeks and some of that time she was quite unsettled. It was particularly difficult for the staff to continue to provide emotional support to her family:

Eleven days. Ten hours at a time. Just staring at the bed and we try our best to change the bed covers, something different to look at but it's not taking away from the fact that she's slowly watching her mum die and... but it's now got to the point where we don't know how to support her anymore. (Nita, Staff Member, Interview, 21/3/13)

Death and dying raised up particular negative emotions for the staff, such as fear. Below Vera is talking about her fear of going into the bedroom of someone who is dying in case she finds them dead and how the staff support each other:

I'd never go in by myself...not brave enough...I mean together, if you're working you support each other, you talk about it all the time...so that really helps when you talk about it with people who know what you are talking about...(Vera, Staff Member, Interview, 26/6/13)

The actual physical appearance of some residents when they were dying could also be upsetting:

*And for me also...some residents ...they look like angels...they still have...their skin is...I don't know what to say...they look like, they look like when they were alive...but Tom, they were like (pointing to cheeks), so skinny and sunken ...there was nothing there just skin and bone.
(Angela, Staff Member, Interview, 26/3/13)*

The cumulative effect of a number of deaths also affected the staff and their sense of loss was clear:

Angela (Staff Member): It's emotionally draining ...I feel like no matter how many years of experience you have got, if it happens week by week

Louise (Staff Member): It's too much

Angela (Staff Member): It's too much. You come to work and oh no...who is next because you can see your colleagues' facial expression ...and it's just the waiting, the length of time...Stanley ...He was a person, he was everywhere and you miss him, you see him in the corner he's dancing, he's singing...(Group Discussion 4/2/13)

In the experience of some of the staff, the residents appeared to be highly attuned to the feelings of the care staff:

...and they feel as well, if you are nervous they know that...I walked in one day, I was just walking in and Ingrid said to me 'oh, is there anything wrong?' and I thought no, I didn't say anything and what was it, I can't even remember what it was, something quite simple but she actually picked up so much and then I think that's quite odd so....they are very perceptive and they feel your feelings, you know, again they are very experienced people...(Brenda, Staff Member, Interview, 29/1/13)

This 'feeling your feelings' has important implications for relationship-centred palliative dementia care. When people with dementia are experiencing distress which

is difficult to relieve, or they are dying, this has an emotional impact on the staff caring for them which can in turn have a reciprocal effect on the person with dementia. Each plays an active part in the life of the other, indicating that residents, even in the late stages of dementia, are not socially dead. The high level of emotions circulating between staff and residents due to the effects of dementia, dependency, loss, illness and dying and the limitations imposed by the organisational context has implications for relationship-centred palliative dementia care.

7.6 'Feeling your Feelings' – Implications for Care-Giving/Care-Receiving Relationships

The parent organisation of Primrose Hill discouraged care staff from having favourite residents to ensure everyone received the same standard of care in the service they were providing:

... (The parent organisation) always tell you don't get attached to the residents, you are here to provide a service. (Hilary, Staff Member, Interview, 29/1/13)

Also there was a view among some of the staff that they were not there to be the resident's friends:

...you're not there to be people's friends but you're there in a support mechanism to almost empower them to live as much a quality of life as they can. (Muriel, Staff Member, Interview, 11/3/13)

At the same time, however, there is an expectation that care staff are empathetic:

...managers have to have some skills, er, interpersonal skills, er, to listen (to) people and see who, who have some empathy and who could build up the emotional relationship with the person, who would be, er, open to another person and who could care for those who are in need because I can't see in this kind of job someone who is very, how do you call it, very institutional, I mean don't show their human being side. I think we all have to understand and feel how it is in

someone's shoes, how do you call that? Empathy. (Angela, Staff Member, Interview, 26/3/13)

Front-line staff recognised that because residents could 'feel their feelings', superficial or distant relationships were counterproductive:

...I mean you are professional but you can't get away from the fact that you have to have emotions involved or you couldn't, you could never ever do your job, do you know what I mean it would be just superficial. (Brenda, Staff Member, Interview, 31/1/13)

Ungerson (2005) highlights the ambiguities in the use of the word 'care' and the difficulty of distinguishing between care as 'feeling' and care as 'work'. Again Brenda below is pointing to how residents could pick up on the difference:

I think they like to know that you want to spend time with them ...because one of the ladies here she always says 'thank you so much for using your time to take me for a walk' or whatever but it's my job, but they don't see it that way, they see 'you' taking your time and spending with them ... (Brenda, Staff Member, Interview, 31/1/13)

Brenda is making a distinction between doing something for a resident because that is what you get paid for as opposed to doing it because you are a human being, hinting at Hughes (2011) notion of solidarity, connecting person to person rather than paid worker and care recipient. This created a conflict for some staff; on one hand they knew that not to relate to people on an emotional level led to superficial and less good care, yet at the same time there was an expectation that they would retain a professional distance from the residents and not become emotionally involved.

7.6.1 Knowing Where Professional Boundaries Lie

Working with the emotions of the residents, the intimate nature of body work which means emotions are at play, the emotional effects of care on the care staff either positive or negative, and the longitudinal nature of the caring relationship meant that care staff did become emotionally attached to residents, even to the extent of providing mutual support:

you can't come in every day and you are happy happy you know, there's days where you are just like ... I'm feeling rubbish or whatever and I like to go and sit beside Penny and you just...you cuddle in or whatever, that gives something for each of you, she ...I think she likes it too because sometimes she puts her hand on yours or she'll play with your hair or ...and it's quite nice, I feel quite calm sitting beside her ... (Vera, Staff Member, Interview, 26/6/13)

Vera below is acknowledging that there is a two way emotional interchange between her and the residents, which might be somewhat at odds with her expected role to be giving but not receiving 'care':

I'm there for them, they're not here for me although they are, even though they don't know it (laughing). (Vera, Staff Member, Interview, 26/6/13)

My own experience with some of the residents is that they often communicated through touch in a way that I have not experienced when caring for people who do not have dementia, for example Catriona below:

At handover Catriona was reported as not so well and they were asked to push fluids with her. She is also on a bruise chart. She is still walking around and later when I was walking beside her she said 'do you mind if I give you a kiss?' (Fieldnote p.218 20/5/13)

Catriona then kissed my cheek, something she often did as a way of expressing thanks. Below is another example of Catriona's affection:

Later I went to Catriona's bedroom with Ida who was doing her bedtime checks. She tucked Catriona in. A few seconds later Catriona came back out of her room after being in bed saying she hadn't had a hug and she wanted one. Ida gave her a big warm hug. (Fieldnote p.68 28/11/2012)

It is difficult not to build up a bond of affection with someone like this and to refuse to allow these expressions of thanks also seems questionable. However, the expectation of not getting attached to residents created tensions for the staff:

... sometimes you have to know your professional boundary and you have to think how close is too close and, I mean, we're, we all hug our residents and we're very close with our residents but at the same time you have to know that they do have, they still have families and they still have people who are going to need you to be more professional and not break down and cry when they're passing away or when they're, you know, when they've died. You just have to remain really professional and then take it home with you but it is really hard to know that professional boundary... (Nita, Staff Member, Interview, 21/3/13)

Particularly in the face of death, it was difficult for the staff to contain their emotions in a way that was expected of them:

Annie died yesterday – they said it was peaceful and her daughter was with her. Muriel was there when Annie died along with John. The family had called them as they thought Annie had died so she and John went in. However she had not quite died – they could see a pulse in her neck but she died a few minutes later. Both Muriel and John had started to cry. Elsie told Muriel to pull herself together as it is her job to support the family. Later Elsie apologised for this and said that she had had a little cry herself. (Fieldnote p.210 16/5/13)

Being professional and not expressing emotion in front of the family when their relative died to the point where they were unable to support the family was seen as important by senior staff. However, the quote below seems to suggest that families do not see staff emotion as a sign of being unprofessional but of being human, and appreciated it:

...cause last time Sandra, she didn't die but we thought she was going to die a year or two back and her daughter was in and she was really upset and she started crying and, totally unprofessional, I started crying as well (Laughing)...I just felt so sorry for her, and we just sort of gave each other a hug and she thanked me afterwards and she said 'that just made me feel like you were human and not just a carer' kind of thing ...but I sort of tend to put on my professional hat for want of a better term and just get on with it... (Gemma, Staff Member, Interview, 3/6/13)

This idea of ‘putting on a professional hat’ and remembering that this is a job was often used:

I think we all have to remember that we've got our own life ...that's our job, we do it best as we can. (Angela, Staff Member, Interview, 26/3/13)

However, putting on a professional hat was easier said than done and required the staff to contain their emotions in various ways.

7.6.2 Containing Emotion

The care staff employed a number of strategies to contain difficult emotions in ways that enabled them to do their job including: talking about it with colleagues, rationalising dying as the end of suffering and doing a good job, and emotional distancing.

7.6.2.1 Talking and Receiving Support within the Team

A number of the staff talked about how the team leaders and also fellow care workers supported each other with the emotional aspects of the job:

... having ...friendships with people you are working with I think is a big thing, um, in somewhere like this because it's...you can talk about things if you are having a stressful time, then there is someone there to talk to.(Edith, Staff Member, Interview, 11/3/13)

Some people recognised that it was important to express emotions at work rather than taking them home, although there is an element of containing emotions so that residents' families do not see them:

It's still Ok to have the emotions, you know because sometimes that will help you, you never know what might happen at home, you might have nightmares or something so...just bring it out but at least not in front of the family or something. (Louise, Staff Member, Group Discussion 4/2/13)

However, for more senior staff, giving support to others required control of their own emotions, the effort of which was costly:

I'm not a, how do you call (it), stone cold person. I do show expression and emotions but for me I, I don't have to tell my staff how sad I am. I mean they will see I am upset. I will go home. And I will... luckily I walk home so I've got this half an hour to think about and calm down and don't take my problems from work to home... but it costs me sometimes a lot. (Angela, Staff Member, Interview, 26/3/13)

7.6.2.2 The Relief of Dying

Some staff recognised the long journey with dementia that some of the residents had travelled and saw death as a natural end to this:

...when it actually happens, it's just...you know, they're actually rested, you know, that some...some of them have been on this journey for such a long time and maybe they were just tired and I think...like knowing that you gave to them what you could in the last few days or weeks, um, and you were just there for them really... (Zoe, Staff Member, Interview, 7/3/13)

When a resident had gone through a difficult time leading up to their death and their suffering was difficult to relieve, a number of staff talked about how death was a relief for both the residents and themselves as carers and it helped them to know that the resident was now at peace and no longer suffering:

Emma, I mean Emma was like a poor demented soul for ages, eh, she had no life, going about shouting... and trying to pick things off the carpet, that's no life for anybody, so you feel, although you are sad, you feel, well she's not suffering that state that she was in (Derek, Staff Member, Group Discussion 18/1/13)

...as soon as it's happened you go 'oh yeah, it's better for them because they are either going to get worse or they are already in the worst place'.... it's not a life. (Vera, Staff Member, Interview, 26/6/13)

For others, accepting death as part of the job and knowing that they had helped the last stage of someone's life to be more bearable, helped them to deal with the pain of losing them. This was the approach taken by more senior staff when comforting junior staff after a death:

I went in and had a chat with them and kind of just said... it's a privilege, look what you have done, she looks beautiful, very respectable, family are grateful, is there anything we could have done better?... And all the staff said no we done everything we could so...it's kind of looking at the positive side of it – but it's hard going'. (Hilary, Staff Member, Interview, 29/1/13)

Others prepared themselves for the residents dying by recognising the various steps in the dying trajectory:

...it's just the deterioration, people are coming here and people are on the stage they are quite fit and then you can see... they are just going down...and obviously you know it won't be better, it will be worse, that's what you're expecting. Some of them they are going to the hospital, for example, an accident or a broken hip and then they manage to recover after spending some time in the hospital, and then they are coming back here and eventually die here. (Una, Staff Member, Interview, 23/5/13)

However, the view among some of the staff about palliative care only being for when someone was dying seems to indicate that there was some distancing among the staff from emotions associated with residents dying.

7.6.2.3 Emotional Distancing

The following quote shows how this member of staff did not want to think that all the residents were for palliative care because it brought a 'dark cloud' on the care:

Researcher: ...so what do you think...the way you are saying 'palliative care' there Edith you mean like for the last few days, the very end of life, do you see palliative care as for...I mean some people might say everybody in a care home is for

palliative care...palliative in that they are not going to get better, what do you think of that?

Edith, Staff Member: I don't see it as that because personally I find that brings a bit of a dark cloud on the care if you are constantly thinking these 40 residents are all on palliative care, it kind of brings a bit of a damper...so I prefer to more think of 'care' and then the end stages are 'palliative care' and the end stages to me is when they are in bed, on turning charts, when you know that it is, kind of they are not going to come back round. (Group Discussion 21/1/13)

Adopting a palliative care approach early in an illness trajectory has been shown to improve quality of life and even prolong survival in lung cancer patients (Jackson et al 2013). Early identification of those who would benefit from a palliative care approach is seen as a prerequisite for good end of life care; it prompts a review of appropriate goals of care and helps to anticipate problems, preparing for them rather than reacting to crises. Tools such as the Supportive and Palliative Care Indicators Tool (SPICT) are under development to help with early identification (Highet et al 2013) and policy and clinical directives in the UK advocate early identification of people who would benefit from a palliative care approach. The World Health Assembly (2014) recommend that palliative care should be integrated throughout the course of advanced illness. Yet in practice, as is shown here, palliative care continues to be associated with imminent dying and indeed often those with palliative care needs are not identified at all in primary care (Boyd and Murray 2014, Harrison et al 2012). In the data presented here, it is the emotional 'dark cloud' associated with palliative care which prevents staff thinking about it earlier. The senior staff in Primrose Hill recognised that many of the staff did not want to think that palliative care was an appropriate approach for care homes to adopt and they were in the process of introducing a palliative care policy as a way of addressing this and preparing the staff for residents dying:

Researcher: ...You know how you said your mindset kind of shifted from (palliative care) just being for the last few days to being from when they (the residents) come in, do you think people have got that mindset now?

Hilary: Some of the younger staff I think find it difficult to grasp it and don't want to grasp it because they don't want to think that the person is here to die but you are trying to keep them in the real world as well, for their own development and for their own feelings and to prepare themselves for it, cause it is difficult when it just kind of springs on staff (Staff Member, Interview, 29/1/13)

However, Hilary is still in the above quote associating palliative care with imminent dying rather than an approach which affirms life while regarding dying as a natural process, neither hastening nor postponing death (WHO 2002). This suggests that care homes require more education on what a palliative care approach actually entails. Indeed, it also raises the question of whether alternative terminology, such as supportive care, would be more likely to ensure that people living and dying with dementia in care homes would have their needs met in a timely way (Hughes et al 2010).

The staff used other ways of coping with the loss of residents, such as humour, which may also have led to emotional distancing:

I make a wee joke of it ...I'll go 'ken Frankie was awfully quiet the now eh?' Because you've got to because if you dinnae, if you sit and think about it, you would walk out that door in the morning and you wouldn't come back... (Queenie, Staff Member, Interview, 7/3/13)

Busyness also diverts the staff from attending to their emotions:

And I think it helps in here because it's so busy, ...sometimes you just get on, you know, you've got no time to kind of stop and think about it and have a bad moment or whatever, you're just so busy that life goes on, the job goes on...you're so busy doing other things (Gemma, Staff Member, Interview, 3/6/13)

One consequence is burnout which can lead to detachment from the emotional pain of the residents.

I sometimes think I must be getting very hard... Maybe it just depends what you're like, I seem to be getting very detached to it. (Anne, Staff Member, Interview, 7/3/13)

While I was doing fieldwork Anne left the home saying the work was becoming too heavy and her patience was wearing thin.

Ungerson (2005) describes 'cool' relationships in the context of paid care as those where both sides understand and agree upon the boundaries of the relationship and understand that it is service orientated and empty of strong feeling. There were times, especially in the dining room when this seemed to be the nature of the relationship between staff and some residents:

There is a different relationship perhaps at mealtimes, certainly with some residents, perhaps those who are more able – they do behave more like customers expecting a good service in a restaurant and I think a lot of the residents here have led very comfortable lives and so may have a lot of experience of how to behave in a restaurant and an expectation of service. (Fieldnote p.141 14/2/13)

Some residents would catch the eye of the staff and point to their empty plate as a way of getting the next course. In these situations some staff did behave like waitresses rather than carers, focussing on giving out plates of food and clearing tables with little interaction with the residents beyond the task of serving food.

However, it may be that people in the later stages of dementia will be unable to play their part in this type of caring relationship, but instead expect a two way flow of emotion which Ungerson (2005) describes as a 'warm' relationship. The following fieldnote illustrates the way two carers responded in different ways to the emotional needs of a resident who was crying. One paid attention to the resident's emotions but did not take responsibility to engage at an emotional level. The other paid attention to the emotion and also took responsibility to engage with it:

Catriona was sitting in the back of the lounge and she was crying. The carer went to her and asked gently what was wrong. Catriona said she didn't know and the carer asked

her would she like a cup of tea and then went and brought her one. She gave it to her and then she went off again. I went over to Catriona who was still weeping and sat next to her. She put her head on my shoulder and I put my arm round her and she then hugged me. I asked what the matter was and she didn't know. I asked if she was worried which she was but she didn't know what about. I asked if she was feeling sad and she said yes and I tried to reassure her that everything was alright and she was safe. She said repeatedly 'I'm so stupid' and 'I'm sorry'. The music on the TV was so loud at times that it was making her jump and her eyesight is very poor so she couldn't see where the noise was coming from. She also had a very bad cold and her nose was very runny. Angela (Staff Member) came in and saw her weeping and she was very concerned for her. She sat down in front of her and held both her hands. She told her that her son had been in today and they had a lovely time together eating a box of chocolates. Catriona said 'was he' and lit up and was pleased to hear this. Angela told her what a lovely family she has and their pictures are all up in her room and again this seemed to please Catriona to hear this and she was smiling. Angela seemed very compassionate and willing to enter into how Catriona was feeling and acknowledge her feelings and also knew how to reassure her. (Fieldnote p.109 17/1/13)

On a number of occasions I observed residents crying or upset in some way and staff, often agency staff, seemingly oblivious to it. There was a hint in the comment below that sometimes the staff switch off or become immune to the cries of the residents if they feel helpless in the face of their emotional pain and it is ongoing. This carer noticed it because she had been off for a while and had come back; she noticed the crying out before it faded into background noise or before she distanced herself from it or it became normalised for that person:

Angela (Staff Member): That's what she was ...she was always saying that, 'God help me, God take me'

Gemma (Staff Member): I never heard her say that

Kathy (Staff Member): I never heard her say that

All talking over each other

Angela (Staff Member): No I heard that from her... Maybe because I was back (from being off for a while) and I just ...because when you were with her in one room... you just sometimes switch off your ears... because you can't hear always the same noise (Group discussion 4/2/13

Undoubtedly the staff are busy and also need to find ways of coping with the emotional aspects of the job so they can continue to function day to day. While senior staff did their best to provide support after a death, it seemed there was a culture within the care home where the right approach to dealing with emotion was to contain it and that being professional was equated with not getting too close to residents. Paying inadequate attention to the emotional effects of caring for people living and dying with dementia or a culture which does not take these emotions as seriously as it might has consequences for relationship-centred palliative dementia care; if people with dementia are able to 'feel the feelings' of those caring for them, emotional detachment or 'switching off' by carers as a way of coping will be felt by residents, increasing their sense of isolation and contributing to their social deaths, and their suffering.

7.7 Conclusion

This chapter has shown that when a person has dementia they might be unable to verbalise how they are feeling. Consequently their suffering is often communicated in an embodied way. As human beings we have a shared pattern of communal practice which enables us to interpret the feelings of another to some degree, even in the absence of words. If a care worker does not pay attention to how they are feeling in the face of the suffering of people with dementia, either because this is seen as unprofessional, or because they cope by distancing themselves from their feelings, they not only can objectify the person with dementia, but they themselves can become immune to the suffering of another. This is counterproductive in the caring relationship and undermines the humanity of both care givers and care receivers; both are fully experiencing body-subjects, not body objects passively receiving care, nor machines passively delivering care. The local and wider organisational context, which can support or undermine holistic relationship-centred palliative care of people with advanced dementia, needs to take account of the environmental and

organisational issues which may exacerbate distress. Crucially it also needs to recognise the interdependency between staff and residents so that the emotional needs of both are supported.

This is the final results chapter. The next chapter draws together the findings from the last four chapters and uses Ethic of Care theory (Tronto 1993) as an interpretive framework.

8 Caring with Integrity - Discussion, Recommendations, Reflections

8.1 Introduction

In this final chapter I draw on Tronto's (1993) Ethic of Care as an interpretative framework. I use the four levels of care described by Tronto (1993): caring about; taking care of; care-giving; and care-receiving, to examine my findings in Chapters Four, Five, Six and Seven. I also use the four ethical elements of care described by Tronto (1993): attentiveness, responsibility, competence and responsiveness, as interpretative lenses at each level of care. I embed the discussion in Kontos' theory on embodied selfhood (Kontos 2003, 2004, 2005, 2006, 2012) and that of intercorporeal personhood (Jenkins 2013, Zeiler 2013).

This thesis brings new understanding to relationship-centred care of people living and dying with dementia in care homes. My overarching argument is that people with advanced dementia continue to experience and respond to the world, and those around them, and continue to be active agents in their relationships, until they die. This must be taken seriously at all levels of the caring process if we are to challenge social death and care for people with advanced dementia in care homes with integrity. I demonstrate how my empirical findings support this argument and the implications for caring at each level described by Tronto (1993). The chapter ends with some critical reflections on the methodology and suggestions for future research. The questions below, first posed in Chapter Three, guide the discussion:

1. How does the practice context of a care home shape relationship-centred care and the way selfhood is supported or undermined?
2. How is embodied selfhood and intercorporeal personhood enacted in day to day life in a care home and in the context of body work?
3. What is the role of embodied selfhood and intercorporeal personhood in ensuring people with advanced dementia remain active agents in their relationships until the end of life?

4. What role does embodied selfhood and intercorporeal personhood play in relationship-centred palliative and end of life care and how can this be developed?
5. How can the theory of embodied selfhood and intercorporeal personhood inform a methodology to understand relationship-centred care from the perspective of people with advanced dementia towards the end of life and their carers in a care home?

8.2 Levels of Care – Tronto's (1993) Ethic of Care

The main focus of this thesis is on the care-giving/care-receiving relationship but this relationship does not occur in a vacuum. In this chapter I use Tronto's (1993) four levels of care and ethical principles, first expounded in Chapter Two of this thesis, as an interpretative framework to explore the integrity of the caring relationship. The four levels of care are:

1. Caring about – this is noticing the existence of a need and making an assessment that this need should be met. This could be at the face to face level but also refers to the political level³¹.
2. Taking care of – this assumes some responsibility for the identified need and determines how to respond to it. A belief that action is possible is required. Again this could be at the face to face, or at the political level.
3. Care-giving – this involves the direct meeting of needs of care, the actual work of care that needs to be done that usually requires face to face contact.
4. Care-receiving – this is the response of that which is cared for to the care (in the case of this thesis, a person with dementia). This is useful in dementia care as it challenges the notion that people with advanced dementia are passive recipients of care but, rather, recognises their responsiveness.

³¹ Political level – by this I mean how care is organised and administered at a state level which would include policy directives.

Recognising these four levels of care allows a shift from thinking of caring as a disposition, and thus sentimentalising it, to caring as a practice. Barnes (2012) suggests that ‘care’ has become qualified in various ways, relating to who is responsible for delivering it: medical care, health care, nursing care, community care, social care, family care. The Ethic of Care however, as Barnes (2012) highlights, is an ethic which derives from everyday lives and provides a shared language for conversations between different disciplines, service users, friends and family, making it extremely useful in understanding how best to deliver relationship-centred palliative dementia care.

An understanding of the care-giving/care-receiving relationship can inform ‘caring about’ and ‘taking care of’ at a political or societal level. All the levels of care must be considered together to approach a more complete understanding of relationship-centred palliative dementia care. Tronto (1993) suggests that the four levels can serve as ‘an ideal to describe an integrated, well accomplished act of care’ (Tronto 1993 p.109). Disruptions at any of these levels can impact on the integrity of the caring process. Analysing disruptions in the caring process and their potential impact on the caring relationship can reveal aspects of care which need to be addressed.

Tronto (1993) also identified four intertwined ethical principles of care which I draw on to interpret the care-giving/care-receiving relationship:

- **Attentiveness** – to recognise and be attentive to others, rather than simply focussing on ourselves. To be able to attend to others, our own needs must be adequately met. This highlights the importance of considering care-givers’ needs as well as care-receivers. Attentiveness can be considered at a political level but also on the face to face level.
- **Responsibility** – to take, or accept responsibility for action. Again this can be considered at a political level but also at a face to face level.
- **Competence** – caring work should be competently performed. At an individual level and a political level, attending to care needs and taking responsibility for them but failing to address the need to deliver it

competently, leads to the need for care not being met. If the competencies required in care-giving are not adequately understood or resourced at the political level of caring about and taking care of, then training of care-givers will be inadequate and the care process will be disrupted.

- Responsiveness – the position of care receivers and their responsiveness to the care given should be considered from their perspective. (Tronto 1993, Barnes & Brannelly 2008).

The following sections relate these ethical principles to the four levels of care as a way of interpreting the findings of this study. Considering the first two levels of care, ‘caring about’ and ‘taking care of’ addresses my first research question: How does the practice context of a care home shape relationship-centred care and the way selfhood is supported or undermined.

8.3 ‘Caring About’ and ‘Taking Care Of’

The policy context in Scotland aims to shift the balance of care for older people from institutions such as hospitals and care homes, to people being cared for in their own homes for as long as possible (Scottish Government 2011-2021). This means that the residential care sector will increasingly be focused on delivering 24-hour care to people with substantial care needs and that palliative care, with specialist clinical input, will be the core work of care homes (Scottish Government 2014, Scottish Care Home Census 2013). This change was reflected in Primrose Hill. In response to demographic changes, where the number of people in the general population with dementia is rising exponentially as the population ages (Alzheimer’s Disease International 2013), Primrose Hill had specialised in the care of people with dementia in 2009, having previously been a residential care home for older people. As a result, Primrose Hill was caring for an increasingly frail group of the oldest old people i.e. people over 85 years old. With an average age of 89.7 years, the residents in this study not only had dementia, but a range of co-morbidities such as cancer, heart failure, and arthritis. During the time of the study 15 people died.

However, the changes being experienced at the front-line due to policy and demographic changes had not been adequately matched with changes in staffing levels or skill mix which reflected the increasing complexity of the needs of the residents. For example, in Chapter Six, Betty reacts angrily to being moved from the room she chose to sit in to another room so that a member of staff could be freed up to help other residents to bed. Betty was understood by the staff to be at risk of falling if left in a room without staff supervision. The high level of dependency of residents in relation to the number of staff meant that, at certain times of the day, there was a malignant social environment (Kitwood 1997). This resulted in Betty becoming positioned as an object of care rather than an active agent who could choose where she wanted to sit. This undermining of her agency contributes to her social death. Inadequacies at the political level of ‘caring about’, where resident/staff ratios are determined, creates a situation at the level of ‘care-giving’ and ‘care-receiving’ where people with dementia become objectified. The care staff were acting with volition but their actions were conditioned by a series of system relations (Smyth & Holmes 2005). The caring process is disrupted by factors outwith their control.

As in Ahsberg & Carlsson’s (2013) study of the experiences of nursing assistants delivering palliative care, the care staff in Primrose Hill often felt compromised in how they wanted to care for the residents and how they actually cared, with one carer saying it made him feel ‘horrible’. In this thesis some care staff talked about the pressure to work faster in order to complete tasks (such as washing) knowing that other residents were waiting for their help and other staff might think them too slow. This not only undermines the dignity of residents but also undermines the dignity of those giving care. Stacey (2005) suggests that care workers:

“Draw meaning from their willingness and ability to perform dirty and mundane tasks that others avoid, knowing that their efforts improve the lives of clients. Taking on dirty work, therefore, is an important source of dignity for workers

whose labour is invisible and undervalued by the general public” (Stacey 2005 p845)³².

Care-givers understand the value of their work (Tronto 1993). Not being able to give the level of care they would like, due to inadequate staffing levels or training insufficient to meet the needs of the residents and their families (such as relieving agitation at the end of life), undermines the dignity of care staff who not only want to maintain the dignity of the residents, but also draw dignity and a sense of their own value from doing their job well (Tronto 1993). Care staff become the ‘residual casualties unable to compensate for the structural problems’ (Cohen 2015) endemic in care homes, in a society which does not take seriously the central place of care in human life.

Many care homes take part in the Customer Service Excellence Awards (<http://www.customerserviceexcellence.uk.com/aboutTheStandardCSE.html> 2015) which is a way of demonstrating a high quality of service to paying customers. Primrose Hill was part of this scheme which seeks to put the ‘customer’ at the centre of the service, and focuses on aspects of the service deemed to be important to the customer: delivery, timeliness, information, professionalism, staff attitude, user experience and measurement of customer satisfaction. Positioning residents as ‘customers’, seeks to empower them but it profoundly affects the nature of the caring relationship (Diamond 1992). Ungerson (2005) suggests that when care becomes a commodity to be purchased, rather than a process in which needs are identified through relational dialogue, and given and received through relationships (Barnes 2012), the basis of the care relationship becomes contractual as opposed to affective. Arguing the ‘pros and cons’ of a market-based approach to care is beyond the scope of this thesis and, as Tronto (2010) suggests, bringing money into the equation does not in itself erode care. However, the implications of positioning residents primarily

³² Stacey (2005) defines the work as dirty because it is emotionally and physically demanding, stigmatised, and offers few material rewards.

as customers (even though many are indeed paying for their care), requires important consideration in the context of caring for people living and dying with dementia.

The commodification of care and the replacement of the word 'care' by words such as 'support', 'assistance' and 'help' has developed as a challenge to paternalistic and oppressive 'care' practices which disempowered care-receivers (Barnes 2012). This shift has empowered certain groups of people, such as those who are young and disabled (Watson et al 2004). Language such as 'support' and 'assistance' was used in Primrose Hill and these words are useful descriptors of what happens in the process of meeting need. However, while challenging paternalistic and oppressive care practices is wholly appropriate, this language obscures the notion of 'care'. Within nursing and medicine too, increasingly technologically driven and outcome orientated, there is a concern that 'care' is being eroded (Nolan et al 2006). Watson (1999 cited in Koloroutis 2004 p.141) suggests that:

Within the dominant, modern, Western mindset, the caring-healing practices of nursing have been on the margins – have been repressed and silenced...it is time for the paradigm to change and for nursing to claim its caring-healing practice...caring calls for a moral commitment towards preserving human dignity rather than reducing a person to the status of an object' (Watson 1999 cited in Koloroutis 2004 p.141)

Obscuring 'care' in the context of palliative dementia care has potentially negative consequences for both care-receivers and care-givers. Barnes (2012), drawing on an Ethic of Care, suggests that writing 'care' out of social care in situations of vulnerability and dependency is problematic if it fails to recognise the ethical, emotional and relational nature of human interdependence and the necessity to respect not only the recipients of care, but the care-givers, and the relationship between them. It can lead to a situation where care workers are not trained or supported to care.

'Care' must be reclaimed within health and social care. The centrality of relationships and the body as a constituent of self are key factors to consider if high

quality palliative dementia care, which promotes quality of life until the end of life, is to be given and received.

The European Association for Palliative Care has conducted a Delphi study and made recommendations on optimal palliative care in older people with dementia (van der Steen et al 2013). There was full consensus on the need for person-centred care. However, the lowest priority for research identified was for ‘societal and ethical issues’ and ‘psychosocial and spiritual support’. Possible explanations given for this were an ‘underrepresentation of panellists with expertise (in these areas); a general focus on medical aspects of palliative care or a perception of research being less efficient in its ability to address these aspects specifically’ (van der Steen et al 2013 p.207). This points to an inadvertent misunderstanding of what person-centred care actually entails at the level of care-giving and care-receiving in a social care context where much palliative dementia care takes place. As this thesis identifies, palliative dementia care is riven with societal, ethical, psychosocial and spiritual complexities within complex care-giving/care-receiving relationships.

If there is a belief among the more powerful in our society, at the level of ‘caring about’ and ‘taking care of’, that action cannot be taken on these aspects of care for people with dementia, or a lack of appreciation of what care entails, then we fail to take *responsibility* for their care. This causes a disruption in the care process which is felt among the less powerful at the level of care-giving and care-receiving. This therapeutic paralysis, rooted in a narrow medicalised view of dementia as a disease with no cure, may be challenged by considering how we understand personhood at every level of the caring process.

Currently, as a society we have not paid enough *attention*, as an ethical principle of care, to ‘care-giving’ and ‘care-receiving’ in the context of advanced dementia in care homes. The notion of people with dementia as experiencing body-subjects is not taken seriously. Nor, have we grappled adequately with the tensions in reconciling two basic principles of ethics:

- The universal duty of good clinical care – the use of expertise to protect the life and health of people to an acceptable standard

- The universal duty to respect the autonomy of people (Clarke et al 2011)

Failure to grapple with this tension is apparent in care standards which are difficult to meet and a workforce, through no fault of its own, ill prepared in its *competency* to meet the increasing challenges it faces in caring for people with advanced dementia.

The National Care Standards for Care Homes for Older People (Scottish Government 2007) do not sufficiently account for dementia. For example, meeting the general principle to ‘enjoy safety but not be over-protected’ (Scottish Government 2007 p.8) is very difficult for a care assistant who is watching over 15 people with dementia in a lounge area and one of those people who is unsteady on their feet insists on getting up and leaving the room. Communal living is also not accounted for; the challenge of meeting the standard ‘You have no restrictions placed on the time you get up or go to bed’ (Scottish Government 2007 Standard 17 p. 45) takes no account of the complexity of negotiating the needs of 40 people with dementia at one time with 8 staff in the day time and 4 staff at night. This sets care homes up to fail.

Policy, care standards and regulatory approaches which overlook the relational and phenomenological aspects of care giving and care receiving treat care as straight forward and ignore the autonomy of people with advanced dementia. Thinking of ‘body work’ as unskilled and straightforward de-values care staff and inadvertently positions people with dementia as passive ‘body objects’, failing to acknowledge the ways they continue to express their subjectivity and autonomy in embodied ways. The tensions this creates for care-givers, between the duty to provide good clinical care and the duty to respect autonomy, are enormous. Ultimately, such tension leads to the mortification of the self (Clarke et al 2011), or social death, because residents are no longer active agents in their relationships with those who help them.

Five years on, the Standards of Care for Dementia in Scotland (Scottish Government 2011) address some of the deficiencies in the National Care Standards for Care Homes for Older People in relation to people with dementia. However, they still do not engage fully with the notion of personhood at a conceptual level. The definition of person-centred used is:

Putting the person who uses services at the centre of their support, care and treatment. Ensuring everything that is done is based on what is important to the person from their own perspective. (Scottish Government Standards of Care for Dementia in Scotland 2011 p. 51).

Such a definition obscures the relational dynamics of care and inherently assumes the person is rational, autonomous and capable of making a verbal choice, an assumption which excludes people with severe cognitive impairment. Barnes (2012) questions the orthodoxy of 'choice', central in current social policy centred on personalisation and self-directed support, suggesting that it reinforces marginalisation of the most vulnerable people, which includes people with advanced dementia. The definition of person-centred care above does not incorporate the embodied ways that people with advanced dementia continue to communicate and how this can support them to remain active agents in their relationships. Consequently embodied selfhood and intercorporeal personhood go unrecognised, contributing to social death. A full understanding of personhood and the implications of this in caring for people with advanced dementia and co-morbidities is missing. Nor does the above definition acknowledge the interdependency between people with dementia, their families and those who care for them.

The 'voice' of the person with dementia must be included; this study, echoing the findings of Kontos (2004) and Zeiler (2013), shows that people with advanced dementia continue to be fully present experiencing people who respond to the care they receive in embodied ways. In Scotland from April 2015 the regulatory body, the Care Inspectorate, are beginning to use a Short Observational Framework for Inspection (SOFI) during inspections of adult care homes (<http://carenews.careinspectorate.com/sofi-for-care-home-inspections/>). This is a welcome development and it will be interesting to see how this work evolves.

The following section addresses research questions two, three and four: the way that selfhood was enacted in day to day life in Primrose Hill; how this can be used to ensure people with advanced dementia remain active agents until the end of life; and how these concepts contribute to the development of relationship-centred palliative dementia care.

8.4 Care-Giving and Care-Receiving

The frailty of residents alongside the presence of dementia had significant implications for the way that care staff interacted with residents in Primrose Hill. The demands of living with and caring for 40 people with high levels of dependency presented many challenges to both care staff and residents. The residents' high levels of functional needs and dependency on care staff to meet those needs meant that the caring relationship revolved around body work such as washing, dressing, taking to the toilet, and feeding.

Hands-on care such as washing and feeding has since the 1990s in the UK become part of 'social care', as opposed to 'health care', and is generally considered to be 'unskilled' or less important work. Nurses or those wishing to advance their career in social care have become increasingly distanced from this type of work (Twigg 2000). Care-giving in the context of dementia is therefore significantly influenced by 'unskilled' care staff which underlines the importance of examining their work and its implications for people living and dying with dementia (Kontos et al 2010).

Cohen (2011, 2015) highlights that most of the recent scandals about poor care given to older people in care homes and hospitals have related to body work, for example, people not being given food or drink, not taken to the bathroom or not turned over in bed (British Broadcasting Corporation 2012, Francis 2013). Lawrence et al (2011) highlight that failing to attend to basic care needs can be distressing for dying people. They suggest that while focussing on pain and symptom control is central to a palliative care approach, it must not overshadow the imperative of basic care needs. This study has found that body work is a key tenet of palliative dementia care over a prolonged period of time.

This study was underpinned by an appreciative approach. Thus it was important to move beyond first impressions, which may have indicated a routinized task orientated approach dominated everyday life in Primrose Hill, in order to understand what was happening in the process of body work. Putting an analytical focus on body work revealed that 'care' is not a simple thing but is complex, often raising ethical issues around so called simple tasks such as washing and dressing or feeding. It also

included more complex ethical decision-making around recognising dying and how best to care for people who are on the cusp between living and dying, or indeed actively dying.

In my own participation in body work, such as feeding people or helping to get people up in the morning, I sensed the pressure to ensure people eat well, do not lie in bed or do not walk around if they are unsteady on their feet and are at risk of falling. This is considered to be quality care, protecting people who it is assumed have forgotten how to protect themselves. I had a sense of what it would feel like if someone fell and broke their leg while I was responsible for keeping them safe, and the prospect of contacting a family to tell them their relative had been injured. However, I also came to see how overlooking, or overriding, embodied expressions of autonomy, such as spitting food out, refusing to stand, or trying to get up and walk contributed to social death because it did not recognise that people with advanced cognitive impairment continue to have embodied autonomy.

Lloyd (2004) (citing Baldock and Ely 1996) uses the term ‘complex mundaneity’ to describe activities like bathing, or feeding or ensuring people do not fall; although they are mundane and seemingly straightforward they are actually highly complex and experienced as such by the person receiving care and those giving care. The presence of dementia adds to this complexity.

Tronto (1993) draws attention to the difference between protection and care:

‘...protection involves assuming a burden of care for others in the same way that caring does (but)..... involves a very different conception of the relationship between an individual or group, and others, than does care. Caring seems to involve taking the concerns and needs of the other as the basis of action. Protection assumes the bad intentions and harm the other is likely to bring to bear against the self or group, and to require a response to that potential harm’ (Tronto 1993 p. 104/105).

When a person lacks capacity due to dementia, the circumstances are created in care homes whereby protection becomes the priority, thus jeopardising any autonomy a

person with dementia retains. Adopting an Ethic of Care framework prompts consideration of the *response* of the care receiver to the care given. In the context of advanced dementia, considering the response to care and the autonomy of the person with dementia within negotiations about care must recognise the place of embodied autonomy, if care is to have integrity. In this study, the complex negotiations which took place daily between care staff and residents around issues such as getting up in the morning, having a shower or eating were evident, with family expectations being mentioned by care staff as part of this negotiation. Care staff tried to be proactive with families, explaining to them, for example, that their relative's finger nails were not cut because they refused to let the care staff do it and they couldn't force them. Robinson et al (2010) found that families questioned the appropriateness of respecting autonomy when their relative had advanced dementia, preferring that their relative be up and dressed and having three meals a day; the families view was that they knew best what was good for their relative. Taking this view to its logical conclusion means that people with advanced dementia will always be passive objects of care and their response to care will not be considered valid.

Families play an important advocacy role when their relative is in a care home. However, often families are in unfamiliar territory and are unaware of where their relative is on the disease trajectory (Forbes et al 2000, Caron et al 2005). Families require good communication and consistent partnership with care staff who know their relative well, are knowledgeable about advancing dementia and other co-morbidities, dying, ethical practice, palliative care, personhood, interdependency and relationship-centred care. This would enable appropriate goals to be explored, and confusion, burden and guilt to be reduced. This is not 'unskilled' work but requires a highly skilled workforce. Current approaches to training the care home workforce do not appear to reflect this level of competencies.

However, despite the many challenges in Primrose Hill the care staff who work there and the people with dementia who live there have important things to teach families, those working in dementia care, and the rest of society. Their experience of the

human encounter, when articulated and shared, challenges the stereotypes of people with advanced dementia as being ‘already dead’.

8.4.1 The Body and Selfhood

Lyman (1993) suggests that the actual delivery of care is inextricably linked to assumptions about the nature of selfhood and the body and that an important condition for the quality of care is recognising people with dementia as fully present. In this study, I was particularly interested in how residents were being positioned within body work interactions such as washing and dressing, mealtimes, and when someone was dying; were they recognised as experiencing body-subjects or were they treated as passive recipients of care?

There were times when I saw hands-on bodily care delivered in a perfunctory way, such as when someone’s reclining chair was dragged backwards without telling them what was happening, and when someone who was slowly dying was described as a shell, indicating an understanding of the self as being ‘gone’, and overlooking the body as a constituent of the self. Predominant cultural stereotypes of people with advanced dementia as ‘already dead’ legitimate such an approach. There is no doubt, as Bailey et al (2015) have found, that the severity of impairments of people with advanced dementia provide a constant challenge to care staff in recognising the persistence of selfhood. This makes the caring relationship in care homes complicated.

However, critical social research does not just identify the nature of oppressive forces but points to ways that they can be combated (Harvey 1990). As I observed daily life in the care home I often saw authentic human encounters or ‘moments that matter’ (McGilton et al 2012) between care staff and residents which were visibly enriching for both. There were many examples where care staff did not experience themselves as caring for a mere body, or an object, but ‘experienced’ people with dementia as experiencing body-subjects. In this study, even those who were classified as ‘palliative’, which was a euphemism for ‘dying’, were still seen as an experiencing body-subject by the majority of the staff; even in the last few days of

life. This was because people with dementia retained a basic openness to others which enabled them to engage in a way that carers ‘felt’ with their own bodies.

Theory on selfhood must square with practice and the phenomenology of care alongside the experience of the human encounter (Hughes 2011). The care staff’s continuing recognition of the person is not based on a philosophical argument about what a person is but instead comes from direct experience: *just by talking to the person, you do get a reaction (Anne)*. Anne is embodying three ethical elements of care identified by Tronto (1993); *attentiveness* to the person being cared for, taking *responsibility* for talking to her, and recognition of the *responsiveness* of the person receiving care. The majority of care staff recognised the responsiveness of the residents; that they inhabit the world, and experience it emotionally, rather than being ‘objects’ in the world (Matthews 2002). Merleau-Ponty argued that it is “through my body that I understand other people, just as it is through my body that I perceive things” (1962, p.186). These insights from the care staff and the way that through ethnographic approaches the visible experiences of people with dementia can be articulated are very important because so often people with dementia are assumed to be unaware of their surroundings or what is happening.

Recognising and supporting the continuity of the ‘selfhood’ of residents played an important part in body work in that the past life of the resident was important to their present situation. ‘Knowing about’ the residents helped the care staff to ‘know how’ to care for them. This happened in two main ways. Firstly, knowing the resident’s life story helped to make connections and gave a shared sense of identity; for example, as someone who was a mother or who went to church. This helped to break down distance between the carer and the cared for and the sense of ‘otherness’. It helped to shift body-work from being a task to an opportunity to relate to a person and to support the selfhood of the person.

Secondly, knowledge of the embodied story of the person in terms of how they liked to dress, whether they wore lipstick or jewellery or details such as wearing bedsocks were also important. Attending to these details could make the difference between a body work situation which went smoothly and one which did not. Knowing the

embodied story and recognising its importance can contribute to emotional care as it helps residents to remain calm and avoid agitation. As Kelly (2010) suggests, these embodied aspects of selfhood are underplayed in social interactionist constructions of identity as described by Sabat's (2001) three types of 'self' (See Section 2.6.1). Empirically in this study these embodied aspects of selfhood were found to be important, confirming Whitaker's (2010 p.96) description of the body as the 'existential nucleus' of ageing and dying nursing home residents.

Other aspects of embodied selfhood which were 'sedimented' as embodied memories (Kontos 2003) were also drawn on during body work. Examples are given in Chapter Six where Hilda is supported in the 'hold' of the Scottish dance, the Gay Gordon, to encourage her to walk forward, and when Quintin is reminded to march as he did in the army so he could move forward with his zimmer.

However, there also seemed to be limits to these embodied memories in that they could be compromised by agnosia (the loss of the ability to recognise objects). This was most obvious in the dining room where often residents appeared to not recognise a knife and fork or a bowl of food. However, often once the person was shown or prompted with what to do, they could then feed themselves. Weakness caused by frailty or restricted movements due to arthritic joints also compromised a person's ability to draw on their embodied memories to know what to do. Often, therefore, there were times when people did need assistance with their meals. As residents became weaker and immobile and eventually confined to bed, the expressions on their faces and movement of their eyes continued to be an important way that they expressed their subjectivity and embodied selfhood. This persisted until the end of life and recognition of this was of paramount importance in relieving suffering. It is essential for attending to the need for care and also assessing the response to receiving care.

In situations where the care staff were not aware of the life story of a resident, a shared sense of humanity and what they could learn by 'experiencing' the residents were important (Kelly 2013). However, in the absence of known life story, the staff tended to 'care for' the residents in a more detached or task orientated way than if

they knew their story, in which case they ‘cared about’ the person with more feeling (Ungerson 2005). It was more difficult for them to support selfhood in the absence of a meaningful life story. The visible and embodied knowing is important, but so too is the biographical. With people coming into care homes much later in their dementia, care staff depend on families and friends to provide them with this biographical detail. Some families took more responsibility for this than others, so care homes need to provide guidance and leadership on this for families. However, there were other ways that care staff were able to create a sense of being together in relationship between themselves and the residents and Zeiler’s (2013) work on intercorporeality helps to make sense of what was happening.

8.4.2 Intercorporeal Personhood in Day to Day Care Practice

In this study I was interested in how the notion of intercorporeal personhood ‘springing forth in joint activity’ (Zeiler 2013), was evident in the care-giving/care-receiving relationship as a way of seeing the person with dementia’s remaining capabilities and supporting selfhood. There were indeed examples of this happening. When a resident who rarely speaks is spoken to, has their hand held and is included and as a result they reciprocate with a word of thanks or a smile, something of that person’s remaining embodied selfhood and their agency ‘springs forth in joint activity’. They are being treated as an experiencing body-subject rather than a body object.

When a carer assists someone to get washed by enabling them to do the things they can still do, such as washing their face or combing their hair, something of that person, their remaining embodied abilities, ‘springs forth in joint activity’ in a way that it would not if the carer did everything for them. It was important for some residents, rather than remaining independent, to have their dependency acknowledged while having their remaining abilities recognised and supported where needed; abilities sedimented within their body at a pre reflective level through repeated motor activity over years as described by Merleau-Ponty (cited in Zeiler

2013). This helped avoid confrontations during hands on body work (as was the case with Betty) and may also, through supporting selfhood, bolster self-esteem.

The emergence of intercorporeal personhood is dependent on the care-giver and the care-receiver being open to each other, perceiving each other's bodily expressions and responding, creating a shared space of dynamic intercorporeal engagement (Zeiler 2013). This shared space can be anywhere, including during hands-on body work. The important thing is that it is recognised as such a space and opportunity and that care staff are open to seeing the person with dementia's openness.

On a very practical level, as I observed interactions in the care home and interacted with residents myself, I came to see how important it was for the care staff to be self-aware of what they were doing with their own bodies in creating these shared spaces; for example, the importance of approaching and entering the residents' personal space gently and not abruptly to avoid frightening them and leading to an angry outburst; the importance of making eye contact, getting the person's attention, and smiling.

When carers have the right mind set they can attend to the subtle signs indicating the person they are caring for is present. This then leads them to be open to connecting with them and attending to their response to receiving care. The relationship is asymmetrical in that it depends on the care staff intentionally taking the initiative. Sometimes the care staff lacked confidence in this phenomenological experience of care. Care staff in care homes need encouragement to be more confident that they are connecting with the real person whose selfhood, in their experience, is persisting, despite cultural norms which would suggest otherwise for those with advanced cognitive impairment. Crucially this would mean that people with dementia are given an 'agential role (in) the care assemblage' (Jenkins 2013 p9) which helps challenge social death.

The ability to recognise others is seen as the most important determinant of whether or not social death occurs (Sweeting and Gilhooly 1997). A two way relationship is one of the keys to not becoming an object of care. Taylor (2008) suggests that a consequence of the failure to recognise others is that the person with dementia may

then cease to be recognised, either as themselves or as a person. The findings presented in this thesis demonstrate the remaining capabilities of people with dementia for bodily expression, attunement and response to the other together with the other when there is a shared space of interaction; the shared space results in intercorporeal or inter-embodied capabilities (Zeiler 2013). This indicates that the person with dementia *perceives* the carer as well as *being perceived* by the carer, showing that people with dementia continue to ‘recognise’ another ‘person’ in a reciprocal way. Care staff often referred to residents remembering their faces even though they didn’t remember their names. The basis of this is intercorporeality.

At the crux of this is the importance of enabling people to come together to create the conditions in which intercorporeal personhood can ‘spring forth in joint activity’. While this can occur during body-work, it does not occur when residents in care homes are left sitting for long periods in front of a television. As explained in the literature review, Namaste Care involves up to eight residents with advanced dementia spending two hours in the morning and two hours in the afternoon, seven days a week in a dedicated Namaste space with an assigned Namaste worker. A calm ambience is created with music, scents and greenery. Elements of the programme include the presence of others, pain management, sensory stimulation, food treats/hydration, meaningful activity, life story, care staff education, family meetings and care of the dying. The afternoon session follows a similar pattern with varied activities. (Stacpoole et al 2014, Thompsell et al 2014).

Namaste Care creates the conditions in which intercorporeal personhood can ‘spring forth in joint activity’ outwith body work such as washing and dressing. Central to Namaste Care is supporting families in their loss and through the realities of disease progression, while also providing opportunities for them to recognise aspects of their relative which persist and are so often overlooked. This can help challenge the social death that people with advanced dementia often experience among their own family and friends who find visiting them in a care home difficult (Henning et al 2013). A roll-out of this low cost intervention across all care homes would benefit people with advanced dementia and their families.

Many aspects of body work cannot wait, for example if someone needs the toilet, or is feeling ill and needs help (Cohen 2011). The care staff in Primrose Hill had no choice but to prioritise body work. While care of the body is care of the self and can bring comfort both physically and emotionally, the busyness of a care home with 40 dependent residents with dementia and other co-morbidities means that care staff have little time with residents outwith hands-on body work. A consequence of this is that emotional or spiritual care, or simply keeping someone company, becomes sidelined. Chapter Seven of this study has demonstrated the emotional impact of giving and receiving care in the context of advanced dementia and dying in a busy care home.

8.4.3 Intercorporeality and Emotional Care

The findings presented in this thesis highlight the interdependency of the care-givers' and the care-receivers' emotions. If a resident was happy and showed this by smiling, the care staff felt rewarded. Often however the residents displayed emotions such as sadness or agitation which upset the care staff. Residents often expressed their feelings in an embodied way, rather than with words. The staff then embodied the residents feelings, whether contentment or agitation. This is the basis of bodily empathy; our understanding of bodies, and bodily expressions, is rooted in the bodily understanding of ourselves. It is more than emotional knowing, it is felt, embodied intersubjective experience (Finlay 2005, 2008).

When a smile is reciprocated with a smile it shows that people with dementia, even with severe cognitive impairment, continue to be able to interpret the smile, or indeed the indifference, on the face of another and respond to it. The staff's feelings in response to the residents are publicly available to the residents and can be 'read' by them in an embodied way because we live in shared world where the meaning of a smile or a grimace is shared. One staff member described how the residents can 'feel your feelings'. This mutual exchange of feelings between bodies, or intercorporeally, has an effect on both the residents and on the staff. There is an 'interplay of intersubjectivities (Twigg et al 2011 p.174); care staff simultaneously affect a resident's experience and are affected by it (Farber & Farber 2006).

Bailey et al (2015) found that, in order to empathise with people with dementia with very severe impairments, health care assistants first required ‘to ‘detach’ to accept the medical positioning of their patients as passive victims of an uncontrollable illness’ (Bailey et al 2015 p.253). This detachment was seen as an active emotional choice necessary to avoid becoming irritated or burning out; not engaging fully was seen as better than engaging negatively. However, Bailey et al (2015) acknowledge the potentially damaging effects of detachment which may prevent staff from noticing problems or engaging with solutions.

Tresolini et al (1994 p.22), in the context of relationship-centred care refute the view that the physician can be a detached observer of the patient but rather ‘the healer and sufferer... form an inseparable unit of interdependent subjects’. This thesis supports the view that there is interdependency, or intertwining, between the feelings of the residents and the feelings of the staff. If carers are not aware of their own emotions, or not supported to cope with them, it can lead to distancing between them and those they care for. People with dementia can ‘feel the feelings’ of those caring for them therefore emotional distancing can lead to an exacerbation of agitation and prolongation of suffering. This would suggest that some degree of emotional connection is necessary for good dementia care. Merleau-Ponty’s (1962, 1968) view of perception provides insight into why this happens. Human beings are part of the world they experience and experience it in the course of active involvement in it pre-reflectively, before beginning to theorize about it; feeling another’s feelings is not dependent on cognition but is embodied.

How care staff respond in the face of suffering is critical to the caring relationship and the position of people with dementia within it. Twigg (2000) suggests that carework is intrinsically about emotions so that a cold carer, even if they are super-efficient, can never be a really good carer. Lyman suggests that:

“one of the paradoxical tasks of dementia care then is to enable caregivers to cope with the stress of their work without contributing to the distress of their clients” (Lyman 1993 p.85)

Emotional labour is defined as the effort workers must make to bring their feelings or visible emotional displays into line with organisational or managerial requirements, the so-called 'feeling rules' (Hochschild 1983 cited in Lopez 2006). The 'feeling rules' in Primrose Hill were shaped by the notion of the residents as 'customers' and viewed emotional attachment to residents as unprofessional. While there was some level of support given to staff, especially after a death, the predominant view was that emotions needed to be contained to get the job done.

Benner and Wrubel (1989) suggest that a detached view of emotions, which sees them as needing to be controlled, cuts the carer off from being involved in the situation in a complete way, precluding higher levels of expertise in the care process. While they do not advocate a 'let it all hang out' (Benner and Wrubel 1989 p.96) view of emotion, recognising that emotions need to be coped with so that a situation can be attended to, they suggest a respect for emotions for the knowledge and wisdom they can bring in guiding thoughts and actions. Indeed, while the intensity of the caring relationship places emotional demands on care workers, Ryan et al (2008) suggest these relationships are central to the care workers' own feelings of purpose, achievement and significance.

A strong emotional connection may enable good care and give care staff a sense of purpose, achievement and significance, but it can also have negative implications for the care staff. Twigg et al (2011) suggest that the emotions generated through body work are not easily shed or cast off when the worker leaves the workplace. Rather care work has an unbounded quality and can move into the family-like sphere (Twigg 2000). Lawrence et al (2011) in an interview study with staff caring for people with dementia found that forming close relationships with people with dementia in the final stages of their lives could be deeply distressing and that overlooking the needs of care staff working with people with dementia is unacceptable and counterproductive (Lawrence et al 2011). Weiner (2006) suggests that while it is understandable for inadequately trained carers to adopt avoidance behaviour, what is unacceptable is a lack of training, and I would suggest a lack of support, to manage these emotions. Bailey et al (2015) highlight the importance of organisations taking responsibility for the emotional lives of staff.

Lopez (2006) distinguishes ‘organised emotional care’ from emotional labour. Organised emotional care involves organisational support for ongoing human relationships and *emotional authenticity*, and negotiation of the rules by the participants rather than ‘feeling rules’ imposed by the organisation. He argues that ‘organised emotional care’, rather than emotional labour, is more appropriate in care work, (as opposed to the work of flight attendants where the concept of emotional labour was first mooted). A lack of commitment to ‘organised emotional care’ not only undermines the humanity of residents but dehumanises care staff (Lopez 2006). Care staff are not machines devoid of emotion; they too are experiencing body-subjects.

The importance of attending to the emotions of staff and providing support is well established within specialist palliative care (Vachon & Mueller 2009, Katz & Johnson 2006). However, it appears to be less well established within palliative dementia care in care homes. The findings presented in this study point to a heightened need for ‘organised emotional care’ in the context of palliative dementia care because of the heightened interdependency between the feelings of the care staff and the feelings of people with dementia. Failing to pay *attention* to the needs of care-givers means their needs go unmet and their capacity to care is compromised (Barnes & Brannelly 2008). If care staff are not supported to face the ‘dark cloud’ they associate with palliative care, then high quality palliative care which relieves suffering by being with the person with dementia in caring ways that draw upon their remaining emotional, relational and creative capacities (Post 2000), reviewing the goals of care, timely symptom management and comfort care, and guiding families through unknown terrain, will continue to be postponed until the last few days of life.

There is a complex power dynamic at work in the care-giving/care-receiving relationship which can tip either way; care staff can be seen as demeaned body servants or as exercising paternalistic power over vulnerable people with dementia who become infantilized (Twiggy et al 2011, Tronto 1993). Either of these extremes is dehumanising for care staff. Hughes et al (2006) suggest that care staff retain their humanity by being supported to remain engaged with and respecting those who rely on them for their care. Hughes et al (2010) suggest that emotional and spiritual needs

are nurtured when people feel loved, safe and cherished. There needs to be a context created where this can happen. The Senses Framework (Nolan et al 2006 See Section 2.7) provides a basis from which to consider the conditions in which relationship-centred care for people living and dying with dementia in care homes can flourish. In the context of advanced dementia, the Senses Framework needs to expand its notion of personhood to include embodied selfhood, the phenomenology of caring and intercorporeality and recommendations for how this might be achieved are outlined below in Section 8.5.3.

An expanded understanding of personhood which incorporates embodied selfhood and intercorporeal personhood must become core to relationship-centred palliative dementia care throughout the whole care process at the levels of ‘caring about’, ‘taking care of’, care-giving and care-receiving. This understanding, alongside the relational emphasis of an Ethic of Care, reclaims ‘care’ within health and social care. It provides new therapeutic direction for creating the conditions within care homes which enable care workers to give care, and residents to receive care, in a way which supports the sense of self of all parties. The recommendations arising from this study are now considered.

8.5 Recommendations from the Research for Relationship-Centred Palliative Dementia Care

8.5.1 Caring About

Personhood must be redefined in dementia care and palliative care policy and in care standards to include embodiment and intercorporeal personhood as vital aspects of personhood that persist despite advanced dementia. This draws attention to responses to care which can be easily overlooked, recognising the ways that people with dementia continue to express autonomy in embodied ways and taking seriously their contribution in everyday ethical decision making. This is necessary so that people with dementia do not inadvertently become passive recipients or objects of care, thus undermining their human dignity and contributing to their social death.

Regulators such as the Care Inspectorate must recognise people with advanced dementia as experiencing body-subjects who continue to express their views in embodied ways. This would involve moving beyond simple outcome measures to incorporating an understanding of the relational process of care and the complex day to day ethical decision making which lead to outcomes being achieved or not.

The effects of policy and demographic changes which have resulted in the care home population changing requires a re-evaluation of staffing levels and skills. This in turn has implications for how care is commissioned and investment in service provision.

8.5.2 Taking Care Of

Organisations responsible for training the health and social care workforce in care homes, for example NHS Education Scotland and the Scottish Social Service Council, must review the competencies required in care homes which are becoming increasingly focused on palliative care of frail older people with dementia. The increasing clinical needs of the care home population would suggest that all care homes should have a nurse on every shift, rather than community nurses popping in and out. This would recognise the centrality of establishing relationships and that care cannot be separated from the person performing it.

The nursing care required may not be highly technical, although it involves an increasing need for timely symptom assessment and management, but care homes do need a highly skilled workforce. The long trajectory and prolonged period of dependency experienced by people with dementia mean that hands-on body work, recognising and supporting selfhood and witnessing and responding to suffering are key tenets of a palliative care approach for people with dementia. The complexities of these key tenets must be recognised within educational approaches. Competencies as mentioned above must include; knowledge about advancing dementia and other co-morbidities, dying, ethical practice, a palliative care approach, personhood including embodied selfhood and intercorporeal personhood, interdependency, relationship-centred care and excellent communication skills.

In addition to the above competencies, the following skills need to be included: role modelling, challenging sociocultural values which tolerate inadequate resources to

care for older people, entering into a dialogue and advocating in the policy arena and in organisations, and understanding regulations and where barriers can be challenged (Siegel et al 2012). This would mean a shift in the numbers of care home staff at the 'Informed' and 'Skilled' levels of the Promoting Excellence Framework (Box 2 Chapter 4) which currently predominates in care homes to an emphasis on those at the 'Enhanced' and 'Expertise' levels. More administrative support is also required to cope with the volume of paperwork which more deaths and more admissions produces, and other aspects of managing a care home such as maintaining the building and fire regulations.

Organisations which are influential in the development of palliative care policy and practice for people with dementia, such as the European Association of Palliative Care and Marie Curie Cancer Care must recognise the different theoretical approaches to understanding dementia. Within this a conceptual understanding of personhood, including embodied selfhood and intercorporeal personhood will open the way to considering new therapeutic possibilities for people with advanced dementia in the area of psychosocial and spiritual care and ethical practice.

Service providers must be aware of the emotive nature of palliative dementia care and take responsibility for the emotional lives of the care staff they employ through 'organised emotional care', recognising the interdependency, or intertwining, of staff emotions with quality of care. This would mean providing regular times for critical reflection on situations which are emotionally or ethically challenging in day to day care-giving and care-receiving and providing the conditions within which relationship-centred care can flourish. This is explored further below in the development of the Senses Framework.

8.5.3 Care-Giving and Care-Receiving

This empirical work shows the importance of building the care-giving/care-receiving relationship as an overarching goal of care and a means to delivering care with positive outcomes. Within this, the study has identified three key facets of palliative dementia care:

- Body work, which includes care in the dying phase but also during the prolonged period of care before this phase is reached
- Recognising and supporting selfhood
- Witnessing and responding to suffering.

These areas need to be recognised as core aspects of care which shape the face to face relationship between care-givers and care-receivers. These three facets of care along with a broad view of personhood which incorporates the body are now used to develop the Senses Framework as shown in Table 5 below. This is a way of expanding understanding of the conditions required for relationship-centred palliative dementia care to occur in care homes.

Table 5 The Senses Framework (Adapted from Nolan et al 2006 p. 35 & 36. Recommendations from the current study are in shaded areas)

<p>A Sense of Security</p> <p>For older people: Attention to essential physiological and psychological needs, to feel safe and free from threat, harm, pain and discomfort. To receive competent and sensitive care.</p> <p>For staff: To feel free from physical threat, rebuke, or censure. To have secure conditions of employment. To have the emotional demands of work recognised and to work in a supportive but challenging culture.</p> <p>For family carers: To feel confident in knowledge and ability to provide good care without detriment to personal well-being. To have adequate support networks and timely help when required. To be able to relinquish care when appropriate.</p>
<p>Factors this study adds to achieving a Sense of Security</p> <ul style="list-style-type: none"> • For staff to attend to the embodied ways that people with dementia respond to their environment and their care. Recognition that people with dementia perceive their environment in an embodied way and that excess noise or busyness may cause them to feel insecure or frightened.

- Recognition that the feelings of people with dementia and those who care for them are intertwined and so both need to be supported.
- Organised emotional care which supports staff and provides space and opportunities to talk as a team and critically reflect on emotionally or ethically challenging situations including end of life care and ‘after death’ discussions.
- For families to feel secure that staff are competent in guiding them through unknown territory for them in the dementia journey of their relative.

A Sense of Continuity

For older people: Recognition and value of personal biography; skilful use of knowledge of the past to help contextualise present and future.

Seamless, consistent care delivered within an established relationship with known people.

For staff: Positive experience of work with older people from an early stage of career, exposure to good role models and environments of care. Expectations and standards of care communicated clearly and consistently.

For family carers: To maintain shared pleasures/pursuits with the care recipient. To be able to provide competent standards of care, whether delivered by self or others, to maintain involvement in care across care environments as desired/appropriate.

Factors this study adds to achieving a Sense of Continuity

- Gathering a detailed biography of the person with dementia to include their usual routines and embodied identities such as wearing lipstick, a shower cap, or bedsocks.
- Recognising the importance of knowing ‘the face’ of another person, even if names are forgotten and considering this in daily work allocation.
- Helping staff find a shared sense of identity with residents which helps them to connect person to person, for example, if they grew up in the same

place or both have children. Supporting staff from other countries who may have a different cultural background in this.

- Understanding the intention of family members to preserve the sacred self of their loved one and that this might be driven by fear, grief and desperation. With this understanding, supporting families in their grief when their loved one seems to lose interest in things which were once important to them, acting as a guide to them as they travel along the dying trajectory.
- Role modelling authentic human encounters with families, using this as a way to show them their relative is still fully present, helping them to tune into the way they are still themselves, while supporting them with the grief they are experiencing due to changes in their relative.

A Sense of Belonging

For older people: Opportunities to maintain and/or form meaningful and reciprocal relationships, to feel part of a community or group as desired.

For staff: To feel part of a team with a recognised and valued contribution, to belong to a peer group, a community of gerontological practitioners.

For family carers: To be able to maintain/improve valued relationships, to be able to confide in trusted individuals to feel that you are not alone.

Factors this study adds to achieving a Sense of Belonging

- Taking responsibility for creating a space for an authentic human encounter, a space for the person to emerge, both the person with dementia and the care giver.
- Recognising that the 'space' can be during hands-on body work or in more social situations such as in a Namaste Room.
- Entering that space gently by explaining, making eye contact and getting the attention of the person with dementia.

- Being open to connecting and recognising the person with dementia is open to connecting
- Recognising the person with dementia as fully present and continuing to be able to take part in relationships in a meaningful way.
- Recognising that families will need support and guidance to continue in their role as a daughter/son/husband etc. if they so wish, showing them ways of making their visits to the care home good and giving them a sense of belonging there
- Recognising how people with dementia continue to show agency and building on this to challenge social death

A Sense of Purpose

For older people: Opportunities to engage in purposeful activity facilitating the constructive passage of time, to be able to identify and pursue goals and challenges, to exercise discretionary choice.

For staff: To have a sense of therapeutic direction, a clear set of goals to which to aspire.

For family carers: To maintain the dignity and integrity, well-being and personhood of the care recipient, to pursue (re)constructive/reciprocal care.

Factors this study adds to achieving a Sense of Purpose

- To recognise body work, supporting selfhood and witnessing and responding to suffering as key facets of an overall therapeutic goal of relationship centred palliative dementia care.
- Affirming that authentic human encounters in all aspects of care, including ‘activities’ and body work, matter.

- Reframing from focussing on independence (and seeing dependence as a failure) to focussing on interdependence between residents, staff and families
- Recognising and supporting embodied autonomy of the person with dementia and drawing on this in decision making day to day and at the end of life.

A Sense of Achievement

For older people: Opportunities to meet meaningful and valued goals, to feel satisfied with ones efforts, to make a recognised and valued contribution, to make progress towards therapeutic goals as appropriate.

For staff: To be able to provide good care, to feel satisfied with ones efforts, to contribute towards therapeutic goals as appropriate, to use skills and abilities to the full.

For family carers: To feel that you have provided the best possible care, to know you've 'done your best', to meet challenges successfully, to develop new skills and abilities.

Factors this study adds to achieving a Sense of Achievement

- Recognising that hands on body work is not a task to be achieved for the benefit of the organisation but is a key aspect of supporting selfhood and caring for the whole person.
- Attending to the subtle signs which can easily go unrecognised, indicating that the person with dementia is present, even in the last days of life.
- Affirming that this is an authentic human encounter that matters and that in itself is an achievement for the care giver and care receiver.
- Talking about and documenting authentic human encounters to enhance their legitimacy. In this way the embodied selfhood of people with dementia could be recognised by all those involved in the process of care: families, service

managers, commissioners, regulators and policy makers, as well as care staff and managers at the front line.

A Sense of Significance

For older people: To feel recognised and valued as a person of worth, that one's actions and existence are of importance, that 'you matter'.

For staff: To feel that gerontological practice is valued and important, that your work and efforts 'matter'.

For family carers: To feel that one's caring efforts are valued and appreciated, to experience an enhanced sense of self.

Factors this study adds in achieving a Sense of Significance

- Attending to the person with dementia's response and taking this seriously, recognising them as fully present.
- Recognising the significance of the body and using embodiment as a resource
- Recognising the intertwining of the residents and the carers and that both matter in the caring relationship.
- Emphasising the role of the family in supporting the selfhood of the resident and balancing this with attending to their losses.
- Recognising that caring is a partnership between all parties.

8.6 Reflections on Methodology

My final research question asked how the theory of embodied selfhood and intercorporeal personhood can inform a methodology to understand relationship-centred care from the perspective of people with advanced dementia towards the end of life and their carers in a care home. This section responds to that question.

It was important to be able to include people with advanced dementia and care staff in this study so that the care-giving and care-receiving relationship could be explored. The methodology adopted and the theoretical underpinning gave an opportunity to access embodied experience and embodied presence, through bodily empathy (Finlay 2006). For example, in Chapter Five when I described Annie's transition from living to 'dying' and her weariness as the staff brought her to the dining room and she sat slumped, too weary to lift a spoon, or her head, bodily empathy helped me to understand something of her lived experience of receiving care. Or in Chapter Six where I described Betty's anger at being moved out of the room she wanted to sit in; her anger at not being allowed to walk around when she wanted, and her pleasant smiles when she was given the option to do things for herself, bodily empathy helped me to understand something of her lived experience of receiving care.

I was not simply a spectator looking through the window of Primrose Hill; I was actively involved in it in a two way interaction between myself and the residents in care-giving and care-receiving. Reflecting on these real life interactions has enabled a nuanced account of the life worlds of people living and dying with dementia in a care home (Hughes 2013b). Sitting holding Lillian's hand and getting a smile or a thank you helped me to experience her as fully present. Dancing with Katie helped to see more of her as a person spring forth in our dancing together. So too, I gained insights through bodily empathy into the care staff's lived experience as a care-giver as I tried to feed a resident who was spitting food out on the table or getting someone up in the morning who wanted to stay in bed. Or the sense of going home with unpleasant smells on my skin and clothes after cleaning up an incontinent resident or the sweat worked up when manoeuvring residents in heavy hoists in the limited space of a bedroom on a hot July day. Or the way that time moved very slowly when

watching over 15 snoozing residents in the sitting room with the TV on as the care staff bustled in and out taking people to the toilet, and the relief of having a chat when the kitchen assistant arrived with the tea trolley.

These experiences gave me a basis from which to explore the care staff's experiences further in interviews. It also helped me to empathise with the care staff's predicament and the challenges of relationship-centred palliative dementia care. I ask myself if this, combined with my appreciative stance, caused me to over-empathise with the care staff, and overstate the responsibility at the level of 'caring about' and 'taking care of' when things were not perfect. I hope I have given a balanced account of what I saw and that my participation rather has pushed the analysis further, giving new insights and underlining the importance of identifying disruptions at all levels of the caring process if care is to have integrity.

8.7 Study Limitations

All studies have limitations and the findings of this study should be considered in the context of its limitations, which are listed below:

- I had a pre understanding of embodied selfhood and intercorporeality which could increase the risk of over interpretation. However it also facilitates noticing and identification of important information that might otherwise be missed.
- I began this study with an assumption that selfhood persists even in late stage dementia and that subjectivity can be accessed through observation, both of which may have led me to see aspects of selfhood and/or overstate my understanding of the subjective experience of people with dementia. It is important to remember that people do not always wear their hearts, or their minds, on their sleeves but manipulate their corporeal expressivity to create certain impressions of the self and subjectivity (Crossley 1995). However, this may occur less in people with dementia who are recognised as being more expressive on an emotional level (Hellstrom et al 2007). I acknowledge, as stated previously, that we can only ever contribute to understanding in a

partial, provisional and perspectival way, even if our research participants are able to talk about their experiences. I have used a continuous process of reflexivity and rigorous analysis in an attempt to produce responsible knowledge.

- While, from the outset, I recognised the importance of ‘myself’ as the research tool in my methodological approach and sought to be reflexive, I recognise that there are limits to reflexivity in terms of the degree to which we can really as researchers know our own subjectivity, and what influences our research. Doucet (2008) suggests that we should be cautious about how much we claim to know about what influences our research, and also I would suggest the effects of our presence in the field as this may only become apparent over time.
- This research was carried out in one care home and cannot, therefore, claim to be generalizable. It does, however, provide a contextualised understanding of the caring relationship between carers and people living and dying with dementia and has been used as a base through which to compare other studies and provide a framework for thinking about how to develop relationship-centred palliative care for people with dementia in care homes.
- The focus of this study was on the relationship between care staff and residents and inclusion of families and examination of relationships between staff was beyond its scope. However it is acknowledged that all three types of relationships are critical in relationship-centred care and in practice require balanced attention (Tresolini et al 1994, Koloroutis 2004).

8.8 Suggestions for Future Research

- Research is required on how ‘organised emotional care’ can be put into practice, not just after a death but throughout the long process of caring for people living and dying with dementia in care homes.
- Research is required into how a fuller understanding of personhood can help families stay in relationship with their relative with advancing dementia while

at the same time be supported in their losses, and how care staff can facilitate this.

- Research is required into how to support ethical decision making, including end of life decision making, in care homes in a way which supports the autonomy of people with advanced dementia and families and avoids the prolongation of suffering. This would include consideration of how embodied autonomy is recognised and agency supported and how acceptable levels of risk are negotiated when people have advanced dementia and yet are physically mobile and living in a care home.
- Research is required on care homes' experiences of interpreting and trying to meet current National Care Standards for Older People in Care Homes.
- Research is required to consider further the question of 'What is harm?' in a care home, particularly in relation to the notion of selfhood in advancing dementia towards the end of life.
- Research is required on producing care standards which, when met, would support quality of life and a high quality of care until the end of life and how this differs from quality of service for people with advanced dementia in care homes.

8.9 Conclusion

This thesis makes an original contribution to knowledge by combining theory with empirical work to develop the conceptual underpinning of relationship-centred palliative dementia care in care homes. It makes visible the ways people with dementia continue to be present and contributing meaningfully within their relationships until the end of life and the importance of creating a space for their personhood to emerge. It is vital to draw on the phenomenology of care-giving and care-receiving and the persistence of this two way interaction if people with dementia are to avoid becoming objects of care or seen as socially dead. This gives an opportunity to build competence and integrity in caring relationships.

This is not to overlook the severe losses that advanced dementia brings. However, as a society, we must find ways of shifting the narrative³³ from one of despair to an achievable and realistic narrative of hope by paying attention to what remains of the person and reconstructing the final phase of life with dementia. The theory of embodied selfhood and intercorporeal personhood is helpful in developing our understanding of how people with dementia can be supported to continue to be active agents in their relationships with those who help them. The theory also illuminates how conflict can arise in care-giving/care-receiving relationships when selfhood is undermined, and ways that this might be alleviated. This thesis sheds new light on the care-giving and care-receiving relationship which can inform practice as well as policy and the planning of health and social care delivery for people living and dying with dementia in care homes.

As a society, if we expect care homes to care with integrity and deliver high quality relationship-centred palliative dementia care which relieves suffering, then the complexity of care-giving and care-receiving must inform how we as a society ‘care about’ and ‘take care of’ older people with dementia living and dying in care homes. It demands our attention because it is the responsibility of us all and affects us all. Our lives are intertwined.

³³ Bury (1982) describes biographical disruption and narrative reconstruction in the context of illness.

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Zwakhalen, S.M.G. (2006) Pain in elderly people with severe dementia: A systematic review of behavioural pain assessment tools *BMC Geriatrics* 6(3)

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Appendix 1: Protocol for Researchers Encountering Bad Practice in Care Homes

1. Take a detailed factual record of the incident which took place.
2. Discuss this as soon as possible with my academic supervisors (Dr Heather Wilkinson and Dr Marilyn Kendall and my clinical supervisor (Dr Sarah Rhynas) to determine if what has been witnessed constitutes bad practice.
3. If it is established that bad practice has taken place, an informal complaint would be made to the care home manager, verbally and in writing with a copy retained. It would be requested that the care home manager provides feedback on how the issue is being resolved.
4. If, along with my supervisors we are dissatisfied with the way the concerns have been dealt with, the Care Inspectorate would be informed.

Enabling Research in Care Homes www.dendron.org.uk/enrich

Appendix 2: Ethics Approval Letter

**Scotland A Research Ethics
Committee**

Secretariat
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
Fax: 0131 465 5789
www.nres.nhs.uk



Mrs Julie E Watson
PhD Student
Centre for Research on Families and
Relationships
University of Edinburgh
23 Buccleuch Place
Edinburgh
EH8 9LN

Date: 12 September 2012
Your Ref.:
Our Ref.: 12/SS/0116
Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Mrs Watson

Study title: Understanding the caring relationship between people with advanced dementia and care staff in a care home in the last months, weeks and days of life

REC reference: 12/SS/0116

Thank you for your letter of 06 September 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the Scotland A REC. A list of the Sub-Committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Adults with Incapacity (Scotland) Act 2000

I confirm that the Committee has approved this research project for the purposes of the Adults with Incapacity (Scotland) Act 2000. The Committee is satisfied that the requirements of section 51 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

Appendix 3: Relative Invitation Letter

CARE HOME headed paper

PhD Research Study: Understanding the caring relationship between people with dementia and care home staff in [Name of Care Home]

Dear

[Name of Home] is taking part in a PhD research project with an experienced researcher, Julie Watson, from the University of Edinburgh. Julie has worked as a nurse for 19 years and more recently as a researcher with a special interest in the care of people with dementia in care homes. The research study is about understanding the caring relationship between people with dementia and care home staff. Your relative [] is eligible to take part in the study.

If you would like to find out more information about the study then please return the reply slip enclosed, in the stamped addressed envelope. Your response is not a decision to take part but only to find out more information. Julie will then post out two information sheets and, with your permission, follow this up with a phonecall to explain things further and allow you to ask questions. If you prefer, you can meet with Julie in the care home. After this, when you are ready, you can consider if you would like [] to take part in the study. It is entirely your decision.

If you have any questions then please feel free to get in touch.

Yours sincerely

Care Home Manager

Appendix 4: Relative Information Sheet General Observation



Understanding the caring relationship between people with dementia and care home staff in



A research project by

Julie Watson



**Centre for Research on Families and Relationships
University of Edinburgh**

**Information Sheet for Relatives
General Observation**

(Or Welfare Attorney or Guardian)

Julie Watson would like to ask your permission to invite your relative to take part in a research project which will begin in October 2012 and finish in September 2013. Before you decide, you need to understand why the research is being done and what it would involve for your relative. This sheet tells you the purpose of the study and how your relative would be involved. Please take time to read it carefully and talk to others about it if you wish. Please ask if there is anything that is not clear or if you would like more information.

What is this study about?

People with dementia and care staff in a care home are in a relationship where care is given and received – the caring relationship. Good quality caring relationships are known to be important for good quality care. The purpose of this research is to understand more about what good quality caring relationships are like and the ways in which the organisation of everyday life in the care home enables good caring relationships to occur.

Why is this research being done?

Care staff often find it difficult to form and maintain caring relationships with people with dementia who have memory problems and language loss. This can contribute to isolation, poor quality of life and poor quality of care for people with dementia. However people with dementia continue to communicate their needs and relate to others in different ways and it is possible for care staff to have good quality caring relationships with people with dementia. The normal organisational routines and the way that things are done within the care home have an impact on the quality of caring relationships and understanding more about this is an important focus of this study. Often normal routines become taken for granted or unnoticed by those who experience them every day. Observation by the researcher is therefore an important way of putting the organisational routines and interactions which contribute to good quality caring relationships into words so they can be discussed and shared.

Why is this care home being invited to take part?

This care home has been invited to take part because it has been identified as having a good standard of care by the Care Inspectorate and expertise in caring for people with dementia. The care staff have experience of interacting and forming good quality caring relationships with people with advanced dementia and it is important that we learn from them by observing what they do, how they interact with the residents and what works well in the organisation of everyday life in the care home.

Why is your relative being invited to take part?

During this study the researcher will spend time in communal areas of the care home, such as the sitting room and dining room, observing the normal everyday routines and interactions. All the residents of the care home are being invited to take part as they usually spend time in these areas at some point in the day and therefore may be included in observation and informal conversation with the researcher. It is important that the experience of people with dementia is included in research and this can be done by observing behaviour and non-verbal communication during everyday life in

the care home. This can help us learn more about caring relationships from the perspective of people with dementia.

Why am I being asked to give permission?

Your relative would have difficulty giving informed consent and under the Adults with Incapacity Act, Scotland (2000) it is a legal requirement that a guardian, Welfare Attorney or nearest relative grants consent for them to take part in research.

What will happen if I agree to my relative taking part?

The researcher will contact you in 2 days to check that you have read this and so you can ask any questions you have. If you agree to your relative taking part, the researcher will ask you to sign the consent form included in this pack and return it to her in the stamped addressed envelope.

The researcher, who is also a trained nurse, will spend time getting to know your relative initially, with guidance from the staff. The researcher will station herself in communal areas of the care home such as the sitting room or dining room and observe the normal everyday routines and interactions between the care staff and the residents. She may also at times engage in informal conversations with residents and staff about what she is observing. Observations would happen for a maximum of five hours per week at different times of the day, over 10 months. The researcher will write some notes in a small notebook at the time and more detailed notes once the observation period is finished. The level of observation will be equivalent to what a visitor or volunteer would observe if they were visiting the care home and no personal or intimate care will be observed.

Does my relative have to take part?

It is up to you to decide whether your relative takes part, based on your knowledge of your relative and what you believe they themselves would want. You can also change your mind and withdraw your relative from the research at any time without giving a reason. Your relative's willingness to take part in the research will be assessed at every stage and if there was any indication that they are unhappy to take part they would not be included. This would not affect any of the services you or your relative receives.

What could be the benefits of taking part?

In other research studies care staff have reported that they have learnt from taking part so this could potentially directly benefit your relative. It is hoped that the research will add to our understanding of caring relationships between people with dementia and care staff in care homes and this understanding may help improve care in the future more widely.

What could be the risks or disadvantages of my relative taking part?

The risks or disadvantages of your relative taking part are negligible. The usual care your relative receives will not be disrupted by the research and their right to dignity and privacy will be protected at all times.

What will happen to the results of the study?

The results will be used to help improve the care of people with dementia in care homes. The results of the study will be published as a PhD thesis and in academic and practitioner journals and shared with other individuals and organisations who are interested in the care of people with dementia in care homes, in order to be as useful to as many people as possible. Findings included in the publications will be completely anonymous (no names will be used). If you would like to receive a copy of the study findings, this will be arranged for you.

Will the fact that my relative is taking part in the research be kept confidential?

Staff in the home will know that your relative is taking part but all information gathered will be treated in confidence and all names or other identifying information will be removed. If a quote from your relative or a description of their non-verbal behaviour is used, the word 'resident' would be put beside it. All information will be stored on password protected computers or in locked drawers at the University of Edinburgh. No personal information would be shared with any other organisations except in the exceptional circumstance that during the course of the research serious problems with care standards comes to light. A protocol is in place should this occur and you would be kept informed.

Procedures for the handling, processing, storage and destruction of data comply with the Data Protection Act 1998.

Who is organising, funding and reviewing this study?

This is a PhD study led by Julie Watson with the support of Dr Heather Wilkinson and Dr Marilyn Kendall at the University of Edinburgh. It is funded by the Economic and Social Research Council (ESRC). It has been reviewed by the ESRC, the University of Edinburgh and the NHS Scotland A Research Ethics Committee.

Who should I contact for further information about the study?

If you would like more information or would like to discuss any aspect of the research further then please contact Julie Watson Tel. 07812026321

What if there is a problem?

If you have a concern about any aspect of this study, please contact Julie Watson Tel 07812026321 Centre for Research on Families and Relationship, 23 Buccleuch Place, Edinburgh, EH8 9LN. She will do her best to answer your questions. Any complaint about the way you have been dealt with in the study will be addressed. If you wish to speak to someone else about this, you can contact Dr Heather Wilkinson, Centre for Research on Families and Relationships, University of Edinburgh, 23 Buccleuch Place, Edinburgh, EH8 9LN Tel. 01316511832

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team 2nd Floor Waverley Gate 2-4 Waterloo Place
Edinburgh EH1 3EG Tel: 0131 465 5708

Thank you very much for reading this information sheet

Appendix 5: Relative Information Sheet Focussed Observation



Understanding the caring relationship between people with dementia and care home staff in



A research project by

Julie Watson



**Centre for Research on Families and Relationships
University of Edinburgh**

Information Sheet (1) for Relatives

(Or welfare attorney or guardian)

Julie Watson would like to ask your permission to invite your relative to take part in a research project which will begin in October 2012 and finish in September 2013. Before you decide, you need to understand why the research is being done and what it would involve for your relative. This sheet tells you the purpose of the study and how your relative would be involved. Please take time to read it carefully and talk to others about it if you wish. Please ask if there is anything that is not clear or if you would like more information.

What is this study about?

People with dementia and care staff in a care home are in a relationship where care is given and received – the caring relationship. Good quality caring relationships are known to be important for good quality care. The purpose of this research is to understand more about what good quality caring relationships are like and what helps them to develop. Because people with dementia often require help with everyday activities such as washing and dressing or at mealtimes, these are important times for care staff and people with dementia to get to know each other and form relationships. It is on these everyday caring activities that the research will particularly focus.

Why is this research being done?

Care staff often find it difficult to form and maintain caring relationships with people with dementia who have memory problems and language loss. This can contribute to isolation, poor quality of life and poor quality of care for people with dementia. However people with dementia continue to communicate their needs and relate to others in different ways and it is possible for care staff to have good quality caring relationships with people with dementia. This study is needed to understand more about when and how this can happen in daily life in a care home.

Why is this care home being invited to take part?

This care home has been invited to take part because it has been identified as having a good standard of care by the Care Inspectorate and expertise in caring for people with dementia. The care staff have experience of interacting and forming good quality caring relationships with people with advanced dementia and it is important that we learn from them by observing what they do, how they interact with the residents and what works well in the organisation of everyday life in the care home.

Why is your relative being invited to take part?

Your relative is being asked to take part in this research because they have dementia which has caused them to have difficulties with memory and using language, and because they have experience of receiving help with everyday caring activities. It is important that the experience of people with dementia is included in research and this can be done by observing behaviour and non-verbal communication during everyday caring activities. This can help us learn more about caring relationships from the perspective of people with dementia. The care home manager thinks your relative may be able to help with this study.

Why am I being asked to give permission?

Your relative would have difficulty giving informed consent and under the Adults with Incapacity Act, Scotland (2000) it is a legal requirement that a guardian, Welfare Attorney or nearest relative grants consent for them to take part in research

What will happen if I agree to my relative taking part?

The researcher will contact you in 2 days to check that you have read this and so you can ask any questions you have. If you agree to your relative taking part, the researcher will ask you to sign the consent form included in this pack and return it to her in the stamped addressed envelope.

The researcher, who is also a trained nurse, will spend time getting to know your relative initially, with guidance from the staff. The researcher will then observe the normal everyday care your relative receives by working alongside staff in delivering everyday care such as washing and at mealtimes. This would happen for a maximum of one hour per day, one or two days per week, over 6 months. The researcher will record detailed notes of the interaction, once the observation period is finished. The researcher will also look at records kept by the care home about the care of your relative.

Does my relative have to take part?

It is up to you to decide whether your relative takes part, based on your knowledge of your relative and what you believe they themselves would want. You can also change your mind and withdraw your relative from the research at any time without giving a reason. Your relative's willingness to take part in the research will be assessed at every stage and if there was any indication that they are unhappy to take part they would not be included. This would not affect any of the services you or your relative receives.

Would I also have the opportunity to take part?

At times when you might be visiting your relative you can also be involved while your relative is being observed, and in conversation with the researcher. The same safeguards and conditions as outlined for your relative would also apply to you (please see the Information Sheet for Relatives enclosed). (Not included but if you would like this just let me know)

What could be the benefits of taking part?

In other research studies care staff have reported that they have learnt from taking part so this could potentially directly benefit your relative. It is hoped that the research will add to our understanding of caring relationships between people with dementia and care staff in care homes and this understanding may help improve care in the future more widely.

What could be the risks or disadvantages of my relative taking part?

The risks or disadvantages of your relative taking part are negligible. The usual care your relative receives will not be disrupted by the research and their right to dignity and privacy will be protected at all times.

What will happen to the results of the study?

The results will be used to help improve the care of people with dementia in care homes. The results of the study will be published as a PhD thesis and in academic and practitioner journals and shared with other individuals and organisations who are interested in the care of people with dementia in care homes, in order to be as useful to as many people as possible. Findings included in the publications will be completely anonymous (no names will be used). If you would like to receive a copy of the study findings, this will be arranged for you.

Will the fact that my relative is taking part in the research be kept confidential?

Staff in the home will know that your relative is taking part but all information gathered will be treated in confidence and all names or other identifying information will be removed. If a description of your relative's non-verbal behaviour is used, the word 'resident' would be put beside it. All information will be stored on password protected computers or in locked drawers at the University of Edinburgh. No personal information would be shared with any other organisations except in the exceptional circumstance that during the course of the research serious problems with care standards comes to light. A protocol is in place should this occur and you would be kept informed.

Procedures for the handling, processing, storage and destruction of data comply with the Data Protection Act 1998.

Who is organising, funding and reviewing this study?

This is a PhD study led by Julie Watson with the support of Dr Heather Wilkinson and Dr Marilyn Kendall at the University of Edinburgh. It is funded by the Economic and Social Research Council (ESRC). It has been reviewed by the ESRC, the University of Edinburgh and the NHS Scotland A Research Ethics Committee.

Who should I contact for further information about the study?

If you would like more information or would like to discuss any aspect of the research further then please contact Julie Watson Tel.07812026321

What if there is a problem?

If you have a concern about any aspect of this study, please contact Julie Watson Tel 07812026321 Centre for Research on Families and Relationship, 23 Buccleuch Place, Edinburgh, EH8 9LN. She will do her best to answer your questions. Any complaint about the way you have been dealt with in the study will be addressed. If you wish to speak to someone else about this, you can contact Dr Heather Wilkinson, Centre for Research on Families and Relationships, University of Edinburgh, 23 Buccleuch Place, Edinburgh, EH8 9LN Tel. 01316511832

If you wish to make a complaint about the study please contact NHS Lothian: NHS Lothian Complaints Team, 2nd Floor, Waverley Gate, 2-4 Waterloo Place Edinburgh, EH1 3EG, Tel: 0131 465 5708

Thank you very much for reading this information sheet

Appendix 8: Basis for Ongoing Consent Form



PhD Research Project: Understanding the caring relationship between people with dementia and care home staff in [REDACTED]

Record of communication of consent for residents

(To be filed in the resident's notes during the study)

Name of Resident -----

Detail the way in which the resident usually gives consent to everyday activities

Detail the way in which the resident usually communicates that they do not want to do something

Detail the way in which the resident usually communicates they are unhappy or distressed

Signature of Researcher----- Date -----

Signature of Member of Staff ----- Date -----

Appendix 9: Resident Information Sheet

Understanding good caring relationships between residents and care home staff in [REDACTED]

A research project by

Julie Watson



**Logos Here
University of Edinburgh**

(Black font 16 on yellow laminate)

I am interested in understanding what happens in your care home day to day

I am particularly interested in understanding how residents and care staff can have good relationships with each other

I would like to ask if you would mind if I spent time in the sitting room and dining room watching what is happening and occasionally chatting with you about what life is like in the care home

If you do not want me to include you, then its fine for you to just say so – tell me or a member of staff

If you are happy for me to spend time with you in the sitting room and dining room I will take notes about what I see and hear

I would like to ask you if I could use these notes when I write up the results of the study. I am happy to show you these notes if you would like to see them

I will not use your name so other people will not be able to identify you

I will also ask yourto make sure he/she is happy for you to take part in my study

I will come back tomorrow and talk with you again in case you have any questions

Thank you for reading this information sheet

Julie Watson

Appendix 10: Information Poster

Understanding good caring relationships between residents and care home staff in [REDACTED] [REDACTED]

A research project by

**Julie Watson
University of Edinburgh**



If you would like to talk about this research or have more information, please feel free to speak to Julie when she is here or contact her by telephone or email:

Telephone: 07812026321

Email J.E.Watson-1@sms.ed.ac.uk

Logos Here

Appendix 11: Staff Invitation Letter



Research Study: Understanding the caring relationship between people with dementia and care home staff in [REDACTED]

Dear Member of Staff

[REDACTED] is taking part in a research project with me, Julie Watson, a PhD researcher from the University of Edinburgh. I have worked as a nurse for 19 years and more recently as a researcher with a special interest in the care of people with dementia in care homes. The research study is about understanding the caring relationship between people with dementia and care home staff. You have experience of interacting and forming good quality caring relationships with people with advanced dementia and it is important that we learn from what you do and hear your views about what it is like and what you find works well in everyday life in the care home.

An information booklet is enclosed with the details. Please read the information booklet and then please complete the enclosed slip and either give it to me or put it in the pink folder marked 'research project consent' in the office. I will be in the home at various times over the next few weeks so please feel free to ask me questions if things are not clear or phone me on Tel. 07812026321

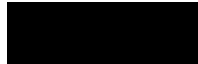
Yours sincerely

Julie Watson RGN, BSc(Hons), MSC, MRes
PhD Researcher

Appendix 12: Staff Information Sheet



Understanding the caring relationship between people with dementia and care home staff in



A research project by

Julie Watson



**Centre for Research on Families and Relationships
University of Edinburgh**

Information Sheet for Care Home Staff

Julie Watson would like to invite you to take part in a research project in [REDACTED] which will begin in October 2012 and finish in September 2013. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about it if you wish.

What is this research about?

People with dementia and care staff in a care home are in a relationship where care is given and received – the caring relationship. Good quality caring relationships are known to be important for good quality care. The purpose of this research is to understand more about what good quality caring relationships are like and what helps them to develop. The study focuses on what works well for you and the people with dementia living here. Because people with advancing dementia often require help with everyday activities such as washing and dressing or at mealtimes, these are important times for care staff and people with dementia to get to know each other and form relationships. It is on these everyday caring activities that the research will particularly focus.

Why is this research being done?

Care staff often find it difficult to form and maintain caring relationships with people with dementia who have memory problems and language loss. This can contribute to isolation, poor quality of life and poor quality of care for people with dementia. However people with dementia continue to communicate their needs and relate to others in different ways and it is possible for care staff to have good quality caring relationships with people with dementia. This study is needed to understand more about when and how this can happen in daily life in a care home.

Why is this care home being invited to take part?

You are being invited to take part because this care home has been identified as having a good standard of care by the Care Inspectorate and expertise in caring for people with dementia. The staff have experience of interacting and forming good quality caring relationships with people with advanced dementia and it is important that we learn from what they do and hear their views about what it is like and what works well in everyday life in the care home.

Why am I being invited to take part?

You are being invited to take part because you work in this care home. You have experience of interacting and forming good quality caring relationships with people with advanced dementia and it is important that we learn from what you do and hear your views about what it is like and what you find works well in everyday life in the care home.

Do I have to take part?

It is up to you to decide whether or not you take part in any part of this research and you are also free to withdraw at any time without giving a reason. This will not affect your working practice in any way.

What will happen if I agree to take part?

Julie will be back in the care home tomorrow and over the coming week. She will ask if you have read this information and if you have any questions. If you would like to participate she will ask you to sign the consent form included with this pack.

The research involves several steps:

General observation

Julie will spent time in communal areas such as the sitting room generally observing the life of the care home and interactions between the residents, families and care staff.

Focussed Observation of Care

Julie (a trained nurse) will work alongside you for periods of up to one hour, one or two times per week, as you give care to the residents, such as washing and dressing and during mealtimes. This will happen with 4 to 6 selected residents over 6 months. The purpose is to get a fuller picture of caring relationships and what works well in practice, including the opportunity to observe the behaviour of people with dementia during these times. Julie will also chat with you informally during or after these times about the relationships you have with the residents and how you find caring for them. Julie will record detailed notes of observations, once the observation period is finished. She will also look at records kept by the care home about the residents.

Group Discussion

You would be invited to attend 3 group discussions, each lasting 1 hour. These would be informal and run in a café style. More information about these will be given out nearer the time.

Group Discussion 1

At this we would discuss the following questions together in twos and then as a group:

- Tell each other about a time when you had a really positive connection with a person with advanced dementia in the care home
- Tell each other about a relationship you have with a person with dementia in the home which you think is good quality?
- What makes it good quality for you?
- What do you think it might mean to the person with dementia?
- What do you think helps it go well?
- What do you do?
- What does the person with dementia do?
- How does it feel?

Group Discussion 2

At this we would discuss together what we think is important in good quality caring relationship with people with advanced dementia – our values and beliefs.

Group Discussion 3

At this session we would review the good practice that has been identified in the research and decide how this can happen more often in the future, learning from each other.

All of these group sessions will be audiorecorded.

What could be the benefits of taking part?

It is hoped that the research will draw on your practical knowledge of what works in practice and will add to our understanding of caring relationships between people with dementia and care staff in care homes. This understanding may help improve care in the future more widely.

In other research studies care staff have reported that they have learnt from taking part and from each other.

What could be the risks or disadvantages of taking part?

The research will involve discussing your experiences of caring for people with advanced dementia. For some people this may feel upsetting. The research will be conducted sensitively and the researcher will ensure that you will receive support during sessions and afterwards should you require talking things through privately or linking with the appropriate support mechanisms within the care home.

The work of caring for the residents is your top priority and every attempt will be made to ensure the study minimises unnecessary disruption. Julie is flexible and will work around what is best for you and the residents.

What will happen to the results of the study?

The results will be used to help improve the care of people with dementia in care homes. The results of the study will be published as a PhD thesis and in academic and practitioner journals and shared with other individuals and organisations who are interested in the care of people with dementia in care homes, in order to be as useful to as many people as possible. Findings included in the publications will be completely anonymous (no names will be used). If you would like to receive a copy of the study findings, this will be arranged for you.

Will my taking part be kept confidential?

All information gathered will be treated in confidence and all names or other identifying information will be removed. If a quote from you is used the words ‘staff member’ would be put beside this. All information will be stored on password protected computers or in locked drawers at the University of Edinburgh. You can view any information collected from you at any time on request.

No personal information would be shared with any other organisations except in the exceptional circumstance that during the course of the research serious problems with care standards comes to light. A protocol is in place should this occur and you would be kept informed.

Procedures for the handling, processing, storage and destruction of data comply with the Data Protection Act 1998.

Who is organising, funding and reviewing this study?

This is a PhD study led by Julie Watson with the support of Dr Heather Wilkinson and Dr Marilyn Kendall at the University of Edinburgh. It is funded by the Economic and Social Research Council (ESRC). It has been reviewed by the ESRC, the University of Edinburgh and the NHS Scotland A Research Ethics Committee.

Further Information

If you would like more information or would like to discuss any aspect of the research further then please contact Julie Watson Tel.07812026321

What if there is a problem?

If you have a concern about any aspect of this study, please contact Julie Watson Tel 07812026321 Centre for Research on Families and Relationship, 23 Buccleuch Place, Edinburgh, EH8 9LN. She will do her best to answer your questions. Any complaint about the way you have been dealt with in the study will be addressed. If you wish to speak to someone else about this, you can contact Dr Heather Wilkinson, Centre for Research on Families and Relationships, University of Edinburgh, 23 Buccleuch Place, Edinburgh, EH8 9LN Tel. 01316511832

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team
2nd Floor
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5708

Thank you very much for reading this information sheet

Appendix 14: Feedback on Whiteboard

14/11/2012

Quotes Presented in speech bubbles. Fieldnotes presented in boxes. Font size 20

‘Some examples of the positive ways staff relate to residents at the Primrose Hill’.
Any Comments?

I think it is a privilege to look after people when they are dying

A resident was crying in the sitting room – the carer stayed with her and wrapped her arms around her to comfort her

At the handover she said that she sat with the lady who was ‘palliative’ for a while

Some people think you can’t connect with people with dementia but you can if you take the time and you think you can

The resident was sitting in the hallway getting organized to go out with her friend. The carer came out and sat down with them and chatted to them both, talking about what kind of morning the resident had had. They had a nice warm rapport - the resident really seemed to know and like the carer and there was a lot of laughing

I love talking to the residents because some of them talk about their lives and they are so interesting

Knowing that my wee family down there are depending on me gets me up in the morning

20th Dec

Cicely Saunders Quote: *You matter because you are you, and you matter until the last moment of your life.*

‘Just wanted to share this quote with you, I find it really helpful when thinking about caring relationships’.

Also put date I’ll be back after Christmas.

17/1/2013

Dates of group discussions and also reflective cycle

Observe – reflect- discuss – plan – act - observe

24/1/2013

Cicely Saunders Quote: *How people die remains in the memory of those who live on*

‘This is one reason why good end of life care is important. The good end of life care you have all given to the residents who have died here over the last few weeks will be helping their friends and relatives now as they live on with their memories.’

14/2/2013

Seeing the person behind the dementia:

Maybe two minutes later they will forget about everything you did, but I know that moment we enjoyed together and we were doing things... it is so important for them... so if I can give one minute of a smile or laughter, whatever happens, for me that's what matters

...we talk about the things they used to do, maybe sing the songs they used to sing... maybe that helps

I enjoy discovering the person behind the dementia

... she likes to be in company and you acknowledge her and speak to her and give her hand a wee rub ...and she's happy ...and I think that's what's important about getting to know people and getting to know what they like and dislike

I Poem

I love you,

I love your face

My friend.

Still alive,

Feeding the baby.

I like it here,

I love you.

Still alive,

I'll be quite happy when it's all over.

I'll stay with you if you stay with me,

My friend,

I love you.

(Do you recognise the person behind this I Poem? What do you think it tells about the person?)

...in his room there was the Bible and there was just suggested wee readings and I went in and read one to him and he actually moved his head, he didn't smile as a proper smile but you could see there was a recognition ... that's what he wanted so I think that's important too to see each individual as a person and what they like, and respect them until the end

You can't do it if you don't have a relationship, if you don't spend time to get to know them and see how they express themselves and trying to understand what they are thinking about, what they are doing, what they really are trying to say to you

... sitting down with someone and holding their hand, if they don't want to talk, you just give them a cuddle and sit there for five minutes...and people walk in and think you are doing nothing, but we are you know

4/4/2013

'Research Study – Starting 7th March interviews with Julie about your relationships with the residents – everyone invited'.

24/4/2013

Displayed the poster that I presented about the study at Scottish Dementia Congress

26/6/2013

8 care giving pointers when people with dementia behave in ways which are challenging

- People with dementia understand far more than they are ever given credit for. Take care what is said in their presence and don't exclude them from conversations or decisions
- Don't try and stop people with dementia from doing something just because it isn't being done properly - give them time to do things in their own way and at their own pace

- Bossiness is just not on – it is very easy to confuse ‘caring’ with ‘controlling’ and nothing winds any of us up more than the sense that someone else is controlling our lives
- Ask the question – ‘Who is it a problem for, us or them?’ – Does it really matter that he wants to go to bed with his trousers on, doesn’t want a wash right now, eats mashed potatoes with his hands or says there are little green men in the garden? Don’t scold, argue or contradict – go with the flow, however bizarre it seems
- Preserve their autonomy for as long as possible by giving them choice e.g. what to wear, and celebrate what they can still do rather than bemoan what they can’t
- There is always a reason for agitation – often something or somebody in the environment. Try to spot the cause and change it if possible.
- If they can’t enter our world, we must enter theirs and affirm it. Forget reality orientation – what day is it? where are you? who is the Prime Minister – who cares? Enjoy fantastic adventures with them instead in their ‘real’ world. Be prepared to time travel backwards with them in their personal history
- Look behind the illness and reach out to the frightened person still in there who needs to feel secure, respected and cherished

‘Written by a carer who looked after her husband who had dementia at home until he died. Some good points. Can these still work when there are 40 people to look after? From the Dementia UK website’

26/8/2013

‘Goodbye for now. I’ll be back in October to give you some feedback and talk with you more.’

Appendix 15: Research Update Newsletters



Understanding the caring relationship between people with dementia and care home staff in [REDACTED]

Research Update Number 1, January 2013, from Julie Watson

The research project is now well under way. I have spent time over the last few months getting to know the staff and residents involved in the project and observing what life is like in [REDACTED] for both residents and staff. Many aspects of the organisation of [REDACTED] provide a foundation for caring relationships to be nurtured between the residents and the staff. One example is the key working system which helps in building caring relationships. There is also a shared sense of purpose among the staff who strive to ensure that the quality of life of each resident is as good as it can be for them. Each resident is recognised as being unique and valued as a person. Values such as these are foundational to building caring relationships. This reminds me of a quote from Dame Cicely Saunders, who founded the modern hospice movement:

“You matter because you are you, and you matter until the last moment of your life.”

I will continue with my observations of daily life in [REDACTED] and also spend time over the next few months discussing with the staff, both one to one and in groups, views, challenges and ideas about good practice in caring relationships.

Many thanks for your on-going support

Julie Watson (Researcher)

Research Project Update June 2013

Logos Here

Understanding the caring relationship between people with dementia and care home staff in the [REDACTED]

Hello there - just wanted to give you all an update on the research project. I have now been in the [REDACTED] since November and I have conducted around 140 hours of observation, 3 staff group discussions and 17 staff interviews. I am beginning to build up a picture of the way that carers and residents relate to each other and what helps good relationships to develop and be maintained as residents become frailer. I am particularly interested in how the carers talk about 'learning the language of residents', who have perhaps lost verbal language skills due to dementia, and how 'feeling the feelings' of each other can help in mutually rewarding interactions and in assisting with care. I plan to continue the work over the summer.

I displayed a poster about the research at the Scottish Caring and Dementia Congress in Edinburgh in April. This was a way of exchanging knowledge about the project with a wide audience of practitioners, policy makers and educationalists in dementia care.

If anyone has any questions or would like further information about the project then please don't hesitate to contact me by email J.E.Watson-1@sms.ed.ac.uk or telephone 07812026321

With many thanks Julie Watson

Research Project Update September 2013

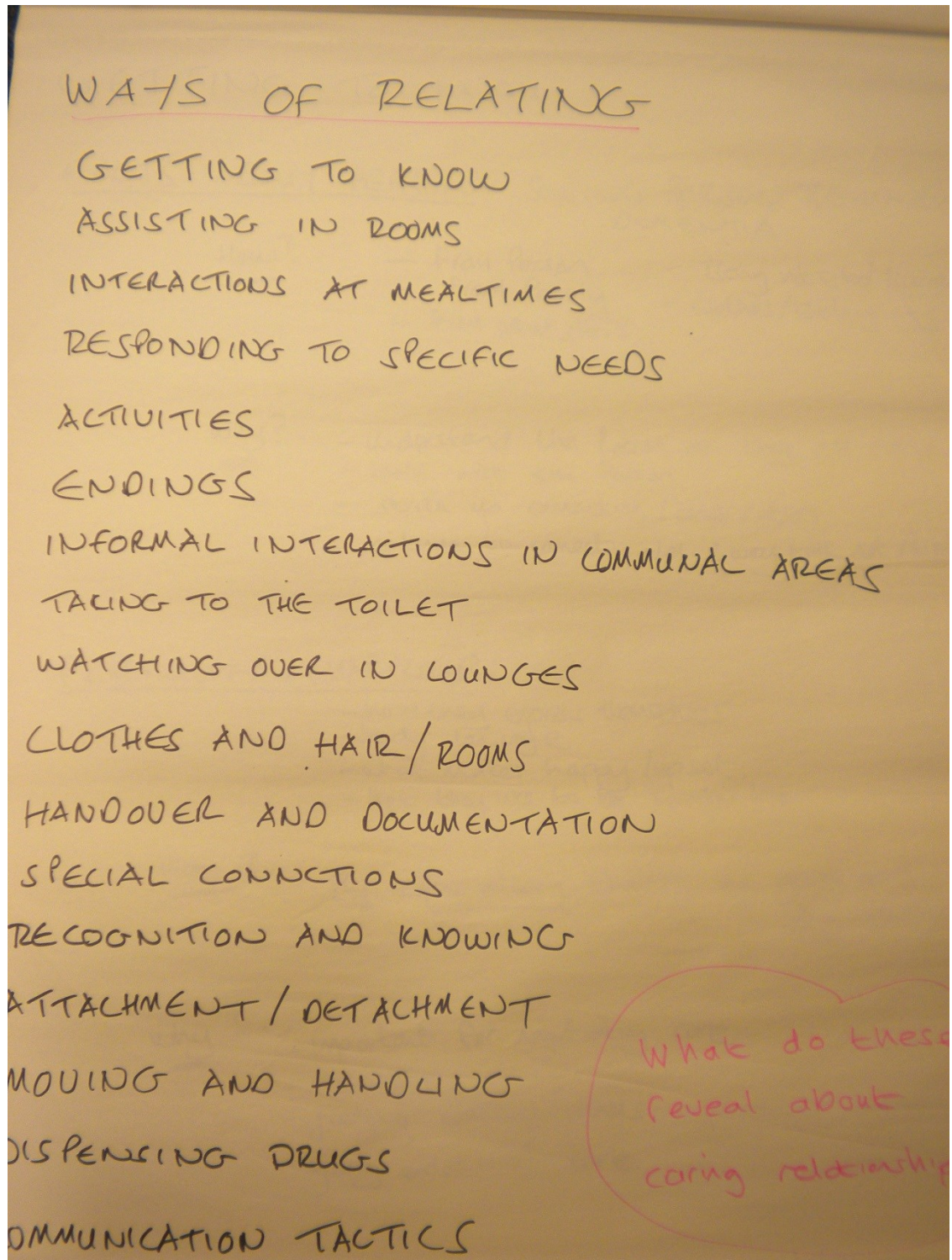
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Understanding the caring relationship between people with dementia and care home staff in [REDACTED]

Dear all – I have now completed the data collection phase of my research project and begun the analysis and writing phase which will last for the next year. This phase involves a period of sorting and sifting the data, all the time looking for patterns and themes which can help add to an understanding of what makes a good caring relationship between staff and residents with dementia in a care home. At the moment I am mapping the different types of interactions which occur in relation to the various and changing needs of the residents, physical, emotional and spiritual. I am exploring how the staff build up a picture of the person behind the dementia, both as an important end in itself in supporting their personhood but also to enable them to care well for the person, helping the staff to connect with the residents and to value and take pride in their work in the home. I will keep you all informed of my progress over the next year. As always, please get in touch with me if you have any questions at J.E.Watson-1@sms.ed.ac.uk. I'd just like to take this opportunity to thank you all for the support you have given me in this project and for allowing me access to [REDACTED]

[REDACTED] Many thanks Julie Watson

Appendix 16: Emerging Findings Charts



GETTING TO KNOW

• FACTS ABOUT PERSON - SEEING PERSON BEHIND DEMENTIA

How?

- From person
- From family
- From other staff
- Being interested / curious
- Clothes / belongings

Why?

- understand the person as they are now
- hold onto the person
- strike up connection / conversation
- continue to connect when 2 way talk not possible

• PERSONALITY + CHARACTER

- how they express themselves
- body language
- what makes happy / upset
- how they like to be spoken to.

How?

- By experiencing them eg. giving care, doing activities

Why?

- important for negotiating care
- motivating
- judging wellness / illness
- giving emotional care.

CHALLENGE - people coming to care homes later.

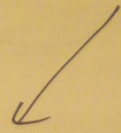
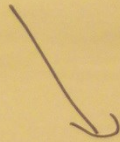
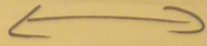
GETTING TO ROOM

ASSISTING IN ROOMS

Staff

GIVING INSTRUCTIONS

ENGAGING MORE DEEPLY ONE TO ONE WITH THE PERSON IN THEIR SPACE



END POINT

PROCESS

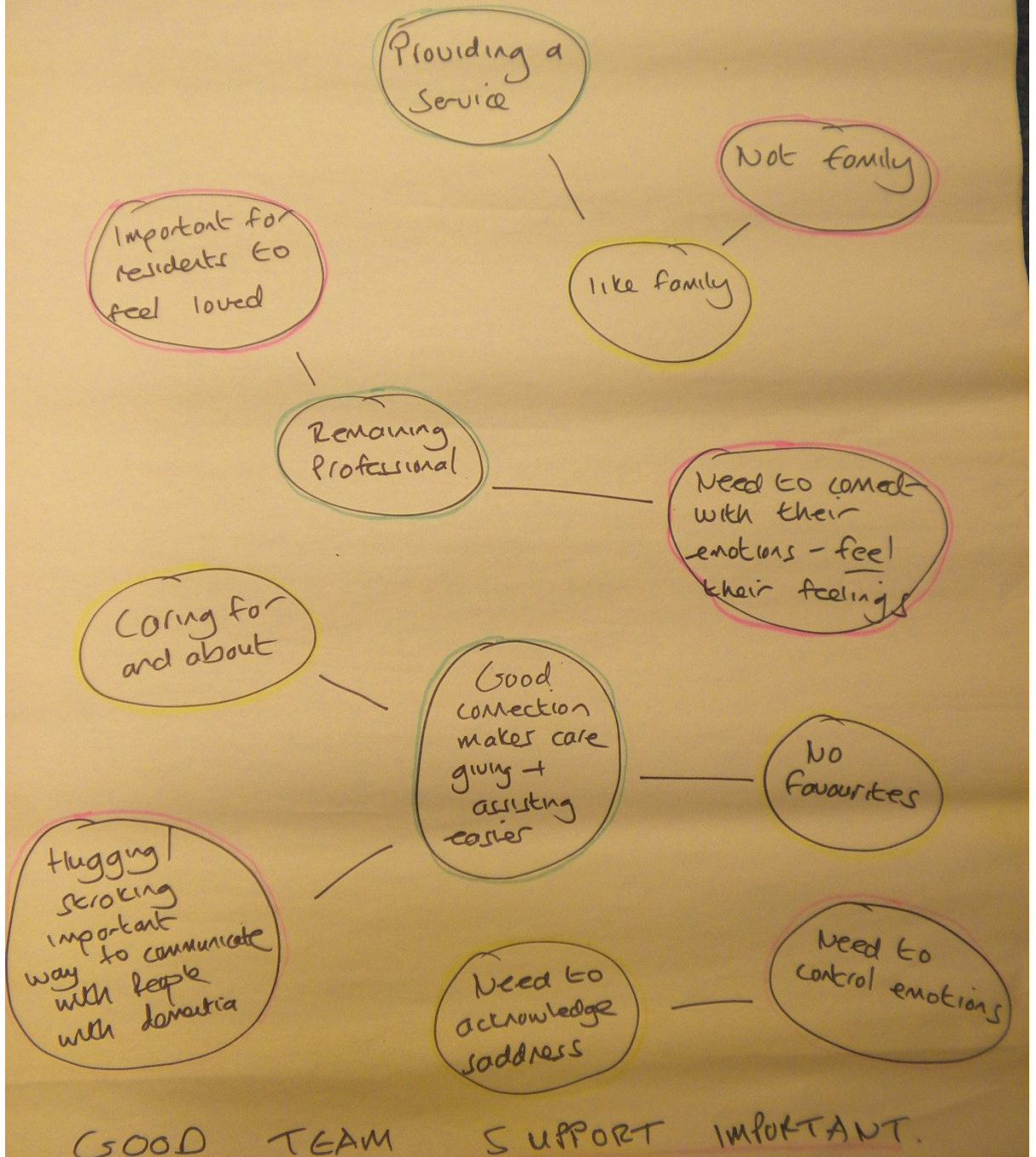
up and dressed.
+ clean.

- affirming personhood
- clothes/jewellery/hair
- Assessing

Residents

- Passive
- Co-operative
- Participative - v. important for some
- Resistant - care is a negotiation

Attachment to residents - TENSIONS



Appendix 17: Timeline of Data Generation Methods

Method	2012				2013							
	SEPT	OCT	NOV	DEC	JAN	FEB	MARCH	APRIL	MAY	JUNE	JULY	AUG
Recruitment												
Descriptive observation												
Focussed Observation												
Selective Observation												
Group Discussion												
Interviews												
Documentary Analysis												
Manager Meetings												

Appendix 18: Group Discussion Guide

First explain purpose

- An opportunity to reflect on what happened, what went well and anything you think could have happened differently

EACH PERSON

Tell me what happened –

- Did they go downhill suddenly or what point did you realise they were dying. Who realised? What was the decision making process – how did you decide what the plan of care would be?
- What time did they die – at night?
- What were they like when they were dying? Settled? Any medication needed?
- What involvement if any was there from the GP/DN?
- How were the family supported?
- What about other residents – do they get told?
- What about after the death – how do you deal with the body, undertakers etc.?
- Funeral? Memorial?

What do you think you did well?

Anything you would like to have done differently?

What was challenging?

Appendix 19: Interview Outline

- Could you tell me about a relationship you have with a resident in the home which you think is good?
- What makes it good?
- What do you think it might mean to the resident?
- What does it mean to you?
- What do you think helps it go well?
- What do you do, or what is your role in making a good relationship with residents?
- What do residents do that contributes to good relationships?
- What role do families play in helping you form relationships with residents?
- Is connecting with residents while you are assisting them different from connecting with them at other times? In what way?
- How do you continue to relate well to residents as they become less well?
- How do you continue to relate well to residents as they are dying?
- What difference does it make to you as a care worker to relate well or have a good connection to residents?

Appendix 20: Sample of Fieldnotes

12/11/2012 11am to 14.20 (anonymised)

Met with Wendy, Elsie not there as she was at a funeral – gave her a list of all the residents for whom I have consent for inclusion, for her records. Asked if there are a core of relatives who are quite involved – there are some who are in a lot and some who are quite vocal (do they complain?). Also there are some who are not there very much. Wendy commented on one relative, who did give consent for her father, who doesn't visit very much but who lately has been becoming more involved in the life of the home e.g. if they have a jumble sale. **What makes relatives not visit when they live close by?** Also gave her the dates I will be in over November and December. Showed her the basis for consent forms and that I planned to spend today getting to know the residents and trying to complete the basis for consent form with any staff with time to help me. To store these in Wendy's office - this is locked. Also explained to her how I would like to try to find ways to feed back to the staff the things I am observing and to open up a conversation. She arranged for me to get a pin board from the store room but actually I think I will just get a white board because it means I can write things on it such as questions about the comments I print out. This means that I didn't get the comments up today but I will get them up on Thursday. Wendy has been there 4 years. She seems easy going and genuine. She doesn't seem to get flustered by anything although I think she was a bit nervous at the relatives meeting. Met the administrator – she was sorting out the bill for the newspapers.

Wendy then showed me around the building. There seemed to be two long corridors with bedrooms off either side. Each door had a picture of the person whose room it is and their name. There were also some bathrooms with hoisting bath seats for getting people in and out. It all looked very functional and the corridors were quite featureless. I did feel like I couldn't immediately have found my way around and I will need to wander around a bit more to get my bearings. I felt reluctant to do this today and I didn't want to look like I was snooping although Wendy did say to just wander wherever I want. The bedroom part is quite plain compared to the communal areas at the front in the old part of the house. There is a small meeting room and quite a large staff room. The handyman was painting a bathroom a nice blue colour. All the rooms I see from the care inspectorate reports have ensembles. There is a library area they are planning to do up although it really is very small – a small hallway going off with a window at the end. Might be a nice place to sit but quite far away from everything else. There is an area called 'the beach' – need to go and look at it again. Also there are nice little garden spaces outside. Need to look more closely at these too and the activity room. My initial impression is that it did not seem to be particularly dementia friendly – I was confused as to the layout. I could see a

summer house in the garden but the garden is on a downwards slope with steps so not particularly accessible for people who are wobbly on their feet.

Went downstairs to the sitting room where there was a carer (Gemma) sitting with a resident looking at a picture book. I think she was doing 'personalised time' as she is this lady's key worker. I went over to speak to them and to explain to the carer that I was trying to work out who was who and also fill out the basis for consent forms. It is difficult to speak to the carers without feeling like I am taking them away from residents (which I am but I hope this will become less so as I get to know who is who and feel more comfortable being there and hopefully they will notice me less as time goes on.) She was happy to help me as she said there always has to be somebody in the room anyway to keep an eye on people as they are so unsteady on their feet. I had my folder with me with the names of people I have consent for (although I realised that this maybe looks like I'm going about with a clipboard which I want to avoid). She went through these with me and filled out the ones who were there – for most of them she said they would give consent by saying 'yes' or 'no' although for some people whose speech was not good they would communicate 'no' or unhappiness by facial expression. Now that I'm using the basis for consent form I'm not sure about the questions – they seem a bit repetitive. Of the residents that we spoke about, the carer said that most would be able to give consent by saying yes or no. This doesn't seem to match up well with their experience of doing resident questionnaires where 66% of residents had difficulty doing it (this seems to be a requirement of the care inspectorate and this statistic is on their website – double check this). I do find it difficult getting information about residents because they are inevitably in the room at the time and I feel that I am ignoring them while I am talking about them with the staff although I always try to acknowledge them by introducing myself. This carer, probably in her thirties, seemed to know what to do to care for the residents, or to give the care that is expected e.g. I asked about getting up out of bed in the morning and how people give consent to that – she said that although when asked if they want to get up the resident will often say 'no', they get them up with gentle persuasion by saying 'do you want to come and get a cup of tea?' and then people happily do get up – so although she was telling me that people can say 'yes' or 'no' I'm not sure these responses are taken seriously in the everyday life of the home because there is an expectation that people will get up and not lie in bed all day and an expectation that it is right to persuade people to eat their lunch even if they are communicating either verbally or by shutting their mouth or turning away that they don't want it (or perhaps don't like it.) **Although I'm sure it is good care to get people up and dressed and not have everybody lying in bed because they say no to getting up, how do they decide when 'no' really is 'no' and the person needs a lie in or is not well?** I think people do have lie-ins because there was some discussion in the dining room at lunchtime about somebody who hadn't got up yet.

At lunchtime in the dining room I asked if I could help to feed someone who required help. I sat at a table of four and fed one lady (who I have consent for).

All the cross conversations between staff, between me and the staff, and between me and the residents are difficult. I do find myself checking with the staff if for example someone can eat a particular thing as I don't want to make somebody choke (the lady I was feeding was on a soft diet) but I don't think if I'd asked her what she could or couldn't eat she would have been able to tell me – is this my own assumption or am I labelling her? Is this is what Kitwood would see as a sign of malignant social psychology? Am I treating the residents as 'objects' and the task is to feed them – get the job done? **How do the staff continue to see the residents as people with agency when there is an expectation to 'get the job done' – or 'get people to do things'** - I felt it myself when I was feeding the lady I was with.

Was this spitting out the tablet and refusing food the wisdom of the body that Dekker's describes? – How do you know when to take this seriously or when is it neglectful to not try to get someone to eat- this lady looked totally fed up –

Dekkers (2010) suggests that bodily autonomy, or the wisdom of the body, may be used as a guide when difficult moral and ethical end of life decisions are to be made. For example he suggests that bodily actions such as pushing away a spoon, spitting out medication or pulling out a feeding tube, alongside facial expressions or bodily defensive movements should be taken seriously when treatment decisions are to be made, such as whether to transfer a person with dementia from a care home to hospital for aggressive medical intervention. (The next day and the next week this lady seemed to be eating fine – assessments need to be longer term and not one off)

The lady I was feeding (Maureen) kept called me 'my friend' – she was very pleasant in that she smiled a lot which felt like positive feedback for me – the carer earlier in the sitting room told me that this lady was lovely and when she first came to the home and she was more able she would always welcome new people and was a warm friendly person. You could still see that in her. As the carer was completing another basis for consent form, when it came to the bit about communicating unhappiness, the carer said about one resident that she is never happy, nothing pleases her, there is always something wrong with whatever they do – tea needs more milk, now it is too milky – her daughter says she has always been like this – **how do they relate to people who do not necessarily have nice personalities because that is the way they have always been?** Just because you've got dementia doesn't mean that you are going to become a person who people will like, if you've always been a person who didn't particularly get on with people – how does this work in community living. How does it work with 'unconditional positive regard'? Also during lunch another lady had fed herself independently but had struggled to cut up her food and in the end it seemed that she gave up trying. I held back from offering help as none of the carers came over to help. Then when her pudding came I thought

that she hadn't seen it and I said to her that her pudding was there and could she manage – she snapped back quite angrily 'of course I can'. **There does seem to be an undercurrent of anger with a number of the residents - I'm not sure where this comes from – is it the environment, do they feel undermined, or does dementia do this to them?**

*I think I have been used in the hospice to people who are very weak and therefore need help because they have no energy. I find it difficult to sit back and see someone struggling but the staff very much are of the mindset that they want people to feed themselves and not to lose this skill – this is seen as empowering I think and to do otherwise is to disempower. Empowerment is not a word heard much in palliative care although choice is talked about more often. **Empowerment is an element of good dementia care, which is much more influenced by a human rights framework, but not if it is negated by other factors such as infantilization, labelling as 'a feeder', invalidation (if they really don't want to eat but this is not taken seriously and they are persuaded and maybe go along with it) – Kitwood signs of a malignant social psychology? Is empowerment given more emphasis in dementia care training than other things?** The roots and underlying philosophy of palliative care and dementia care are very different historically.*

From board paper - In a study which identified a positive association between care provider's positive relational behaviours and the positive mood and affect of residents with dementia, it was found that the most effective relational behaviours were most often observed during interpersonal interactions where direct care was not being provided and that positive relational behaviours were much more challenging for care providers during direct care activities such as mealtimes (McGilton et al 2011). McGilton et al (2011) suggest that conceptually this is important as it indicates which situations present challenges to care providers' ability to relate well.

Dignity is thought to thrive in the context of equal power relationships (Levinson 2007) – where does the power lie at mealtimes – with the staff or with the residents – are residents treated with dignity at mealtimes?

I personally did find it very challenging to relate in a person-centred way during the mealtime as I had a sense of needing to get the job done and good care being ensuring residents eat properly. I need to unpack this more with the staff – need to try to put this into a question or a set of questions. Does 'positioning' people with dementia as having something to communicate go out of the window at mealtimes?

The lady I was feeding does require help and has a soft diet and build up added to her soup. There was no salt or pepper on the table and I thought the build up would probably make it a bit tasteless. When I asked her how the soup was she said 'it's not great' which seemed like an appropriate answer to the question I was asking. A few times she turned her head away and didn't open her mouth but then when I tried

again she did take it. She ate most of the soup but by the time we finished it would have been cold I think – I would hate to be fed cold soup but at that moment I did not feel in a position to do anything about it – I think this is a daily occurrence as they all eat so slowly – but not everyone hates cold food. No one was rushed and everyone was left to eat at their own pace. **The lady I was feeding did say to me at one point ‘helping the baby’ – do they feel like they are treated like babies?** By the time the lady I was feeding got her chopped up ravioli, I had moved to the other side of the table to help another lady (for whom I do not have consent) and she actually fed herself – PWD are very variable in their abilities.

Staff start moving people into the dining room for lunch about 11.50 – there are 24 table and 40 residents so more people are brought in as people finish. It was soup, ravioli on toast or fish cakes and chips and then fruit salad or yoghurt. It seemed that people who could feed themselves were in first and then the people who needed more help were brought in slightly later – there were at least 3 in wheelchairs – people who looked very thin and quite contorted (is this contortion part of advanced dementia?). One lady (Ursula – no consent) who had been up and about walking independently a few weeks ago was in a large recliner chair – I wondered if she had had a stroke but it turns out she has a virus – she was being fed – they made the effort to bring her to the dining room – keeping her part of the rhythm of the home. (They spoke about a lady at the handover who had spent four days in hospital – they wanted to keep her in the home and give her fluids and antibiotics but because she wasn't on the system (NHS 24 electronic record) as having DNACPR, NHS 24 did not listen to this request and sent an ambulance – at the time she was clammy, her breathing was noisy and they thought she might be dying because of her breathing, but because her pulse was rapid this made them not sure – is this the same lady?). I asked if they are able to give fluids in the home and they said yes using the syringe - I realised afterwards that when they say ‘give fluids’ they mean orally with the syringe whereas I was thinking they meant IV fluids – I'm making assumptions. I feel like I never quite finish conversations and feel a bit worried about this but I need to remember to follow things up – I will be there for a year so it just takes time and there is time – I can't do it all at once – today I stayed 3 hours and 20 minutes and really felt I needed to go if I'm going to be able to write it all up asap before I forget everything. Took some scratch notes while I ate my sandwich in Wendy's office after she had gone.

Wendy left her door of her office open for me to use and had locked the outer door into the section where the offices all are. However, during this time the outer door and been left unlocked by one of the staff and a resident had come in and taken the doorstep and now had it in her pocket as she continued touring the home looking for things to do. This lady had on a previous occasion got into Wendy's office and had ‘organised’ the papers on her desk and had then gone into the duty room and taken

the budgie out of the cage before she was discovered. This lady had previously been a QC and so 'organising' was perhaps her being herself and made sense to her – I wonder if they give her things to do which would allow her to continue doing this but in a less destructive way? (Later found out she sometimes does come into Wendy's office and chat or sort things). She has lots of energy. I am becoming aware of a lot going on below the surface. I noticed the lack of conversation in the dining room at lunchtime – a carer put on music and it felt like it was to break the silence. **However there is a lot going on below the surface – emotions are there but they are expressed in different ways – do the staff try to contain these emotions or do they allow them to be expressed?** At report they talked about a resident who was very weepy all morning. Her daughter had been visiting from Australia for three weeks and had just gone back. They were going to get her to watch the film they were showing that afternoon - 'Sister Act' a comedy - which she enjoys. Earlier in the sitting room the carer told me about another lady who communicates her distress by shouting or throwing herself on the ground. She also calls out her sister's name continually at times, even when her sister is there with her. They don't know what this is about. They have told me before about how they find this lady's distress distressing. The raging emotions remind me of the book 'The Keeper'.

After lunch the late shift were arriving - I asked John if he would be able to help me do some of the basis for consent forms. We were sitting under the stairs on the settees. A lady (Betty) came over distressed because she couldn't find her handbag and thought she had left it there. John went to look for it and found it in the sitting room. She was delighted to have it back and was full of smiles. She stood for a while with us – I introduced myself and she was then able to tell me her name – she kept standing and smiling and seemed unsure what to do. I asked if she wanted to sit with us but she just kept standing and smiling. Eventually John asked if she wanted to go and watch a film they were setting up in the sitting room and she went off. **He seems to speak to residents in a respectful way – what do I mean by this?** I think he listens, takes what they are saying seriously, gives them time, doesn't talk over them or down to them, looks at them, acts on what they saying. The residents warm to him and show this by smiling, looking at him, looking relaxed and maybe affirmed? **I asked him how he finds mealtimes – he says they can be difficult but he likes to help people to stay independent and use their abilities to feed themselves – maybe a tread I need to pull on is this idea of empowering people as part of good caring relationships and what that looks like as people become less well and perhaps don't want to eat – what does empowering look like as dementia progresses? How does it fit with agency for example.**

Again John was saying for most residents they would give consent for everyday activities by saying yes or no but he did talk about how for some people you know by their face that they don't want to do something – and mentioned 'going

red' a few times. I think it is hard to put these things into words sometimes as a lot of what they do or the way they 'read' residents is intuitive – there are things that go without saying so they are difficult to say – but how do they learn these things or do they come naturally to some more than others? Do they just know these things because they spend time with the residents caring for them so they learn how to get the job done but it is never really shared – they each work out ways of getting the job done? I feel a bit silly doing these forms although I think it is a way for me to get to know the residents. John got up to help one of the female carers who was dragging a big recliner chair with a resident in it across the hallway which is carpeted. He then went to look for another resident who someone was trying to find – I realised that I had nabbed him at quite a busy time and said to him I'd catch up with him another time. He is very friendly and nice and I must watch I do not put too much pressure on him because he is quite open. I need to get used to being around without having to talk to someone – just observing – at the moment it feels uncomfortable – maybe I even feel guilty as they are all so busy and I should be helping instead of sitting on the settee looking like I'm doing nothing – this is me being a nurse instead of a researcher. Need to learn to feel comfortable with the uncomfortable.

Went up to the office where two team leaders were sitting – one from the morning shift was having her lunch and one who was coming on seemed to be writing notes. I showed them the basis for consent forms and explained what I was doing. One of them then started giving me passport sized photos of all the residents to put in my folder – they use these on drug cardexs so they don't make drug errors by giving them to the wrong person – in the hospice they introduced name bands for this very reason - here it is less institutionalised but the safe practice still has to be thought about. I explained to them again why I had needed to wait until after the relatives' meeting in order to get started and that I would be in again on Thursday – realised that I needed to bring in a copy of the times I would be in for them too. Also explained that it would probably take me a bit of time to get to know the residents and for people to get used to me being around. I explained the notice board for feedback and the possibility of a newsletter. Seemed to think it was a good idea. Mentioned that they hadn't heard any feedback from the relatives' meeting. I told them about the changes the CPN had talked about and also that Wendy had given out the end of life care policy. Muriel reflected that this is quite a sensitive area. At this point they then talked about the lady mentioned earlier who did not have a DNACPR record and who ended up in hospital but is now back. I asked the other carer Hilary about her interest in palliative care as one of the young carers told me that Hilary had given her good information when one of the residents was dying. She said she is interested in a palliative care and she helped write the end of life care policy. She felt this was something they needed to do as it was a gap in their care and also that it is

something that young carers especially need support with – **I think I need to interview Hilary –how did she get interested in palliative care? What does she think the gap was? What does she think they do well? What does she hope the policy will achieve? What sort of things does she talk to the young carers about?**

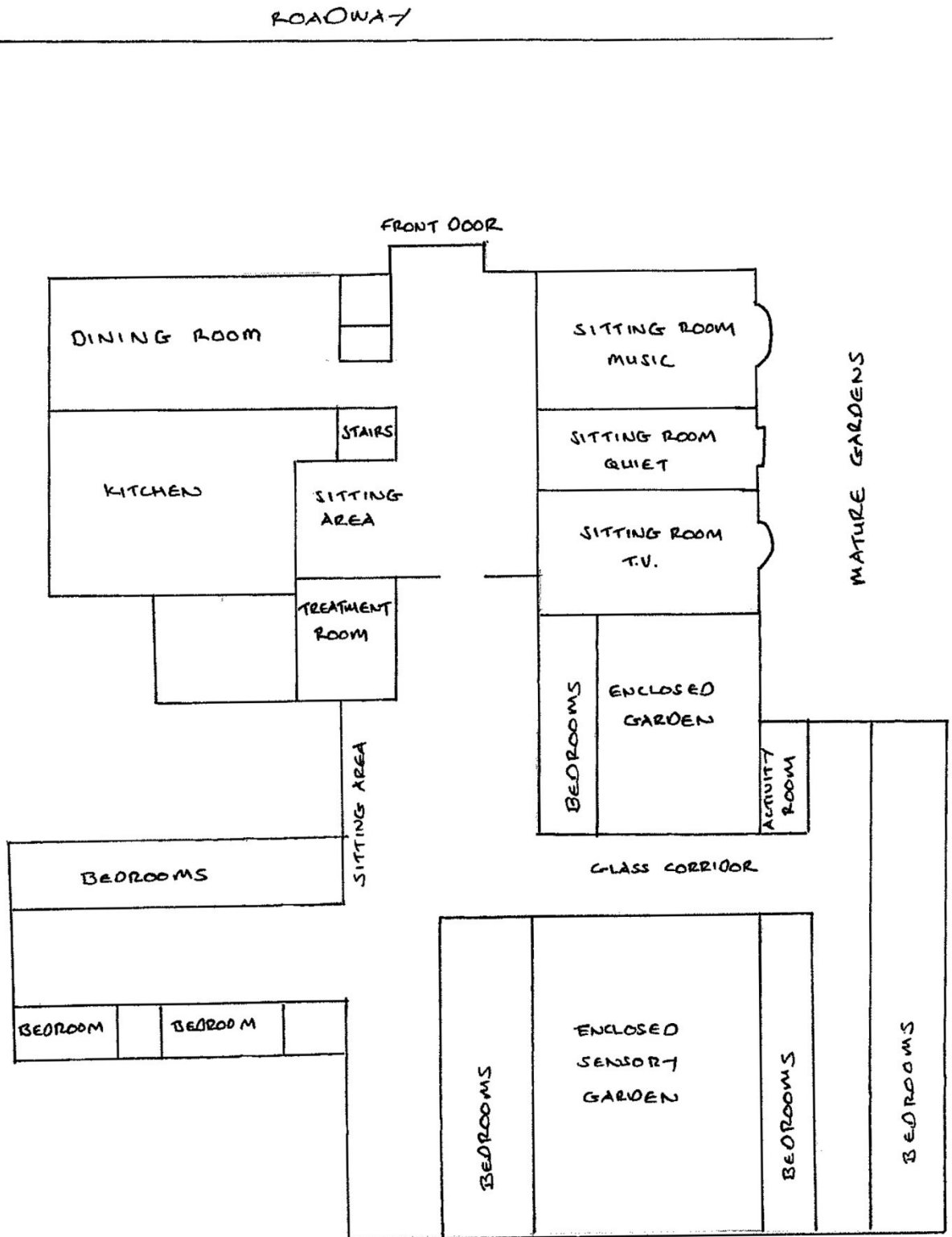
I think the online course and some of the tools at St Christopher's would be of interest to her. During report she records in detail in a big book how every body is and is able to look back and say that something is a change or that for a few days in a row someone hasn't wanted to get up – it's really good that she does this but I don't know if this is just her book or if others look at it – the prospective prognostic planning tool might make this more of a team thing. She has worked at the Primrose Hill a while – she worked there for a few years when she left school then went and worked with people with leaning difficulties for 3 years then came back as a senior (for how long?) – she worked her way up through the organisation's development programme – she is very knowledgeable and I think keen to learn and progress.

Sat in on report. Started with a prayer - asked for patience and wisdom (and something else I've forgotten) **what do their prayers tell me about what is required for the job?** Updates on who still needed a shower.

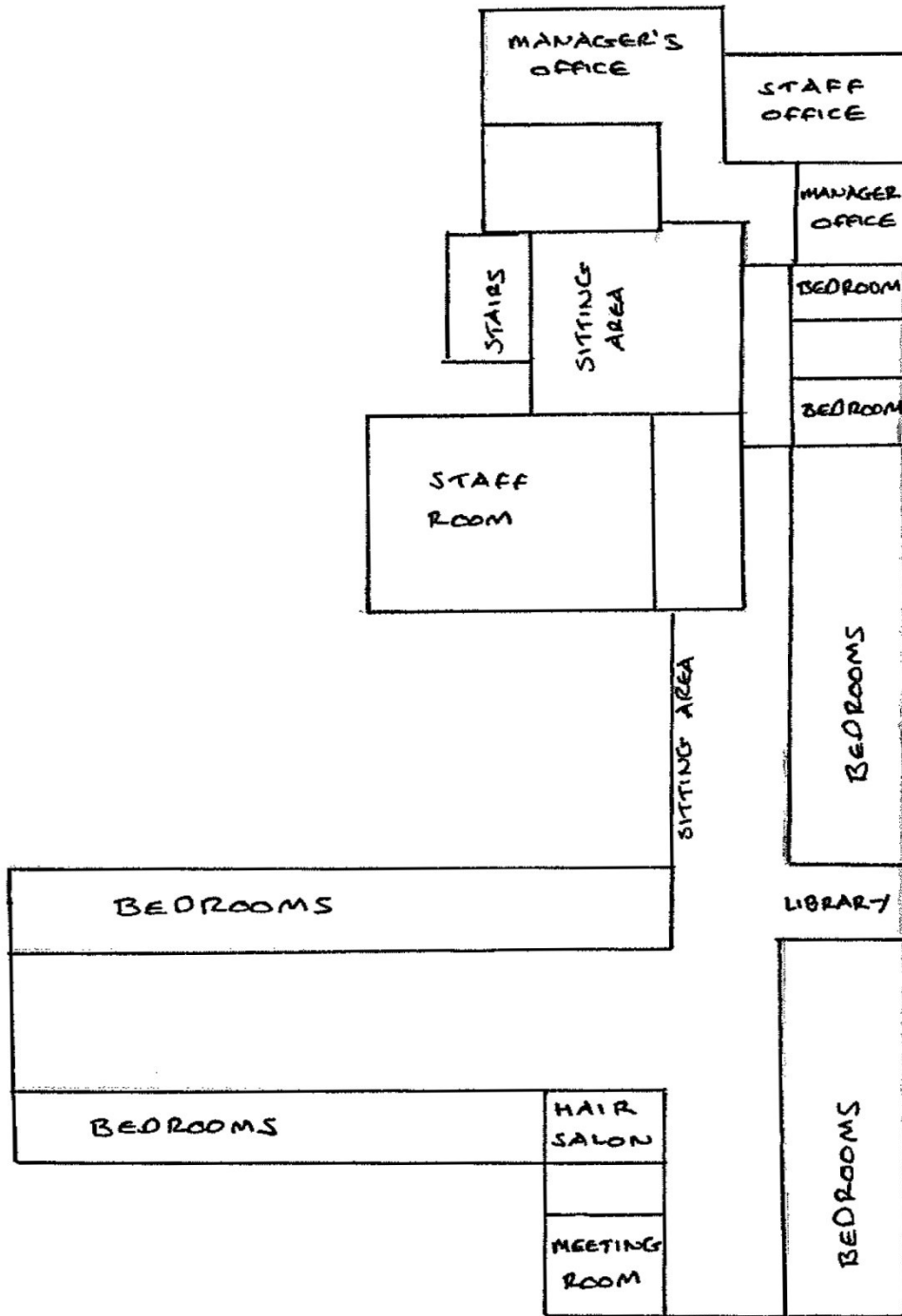
Found out that the lady they thought was dying a few weeks ago was at the table with me in the dining room today (no consent) – she is up and about again – she was in a wheelchair and was very thin with no speech but she was eating. An agency carer was helping her for a bit but then she was asked to go and bring someone else into the dining room. I then helped her – she kept trying to pick the ravioli in tomato sauce up with her hands and feed herself. Although she had a 'bib' on she was getting in quite a mess. When I said her name a few times she eventually would turn around and look at me - this seemed like Sabat's self 1 in that she still knew herself. She was keen to eat and didn't refuse any food. I can see why they focus on food so much – I'm focussing on it myself as it not only takes up a lot of time, and being fed is seen as part of good care and not neglect but it also a barometer of how close someone is to death.

I am not remembering things verbatim, at least not confidently so but rather I am paraphrasing or writing what I hope is reasonable recall – things come back slowly over a number of hours and into the next day and I write up as I remember – I'm worried about the accuracy of it and how I can be sure of that – is there a better way to do this? I can't notice everything but what am I not noticing?

Appendix 21: Map of Care Home Layout – lower floor



Appendix 22: Map of Care Home Layout – upper floor



Appendix 23: Characteristics of Residents

July 2013 (Not static) – Mean age 89.7, median age 91 years, 3 men, 17 women

Name	Age	Receptive Communication	Expressive Communication Verbal	Expressive Communication Non verbal	Functional Level	Palliative Care Plan Status	Time in care home (July 2013)
Maureen	89	Appears to understand speech as indicated by occasional verbal responses and responsive action. Responds well to, and interacts with, company. Able to read and respond to body language of others.	Yes and no responses. Conversation very limited but uses short sentences which convey contentment and praise or unhappiness with the current activity. Sings. Occasionally initiates social contact with eye contact and smiles.	Clear facial expressions of positive or negative emotion and uses her body in intentional ways – e.g. closing her mouth or turning her face away if she has had enough to eat.	Walks with the assistance of one or two. Needs full assistance with washing and dressing and at mealtimes. Normally up and dressed in sitting room everyday.	Anticipatory Care Plan Palliative Care Plan Preferred place of care is the care home. DNACPR in place	9 yrs
Penny	90	Occasionally gives surprising verbal responses indicating comprehension. Sometimes responds actively.	Very limited and rare verbal communication except occasional 'yes'. Does not initiate contact.	Uses facial expression particularly smiling, laughing and eye contact to communicate happiness or willingness to	Requires wheelchair to move around but can stand with the help of two carers. Requires full assistance with washing and	Anticipatory Care Plan Palliative Care Plan Preferred place of care	4 years

				cooperate. Avoids eye contact if unhappy or to convey unwillingness to do something.	dressing and at mealtimes. Normally up and dressed in sitting room everyday.	is the care home. DNACPR in place Died Spring 2014	
Sandra	95	Appears to understand as indicated by verbal responses and responsive action and responds positively to company. Able to read and respond to body language of others.	Very poor short term memory. Very limited verbal communication but can respond with yes or no and occasional short sentences. Initiates contact by shouting and wailing.	Uses facial expression and body posture to communicate positive or negative emotion and also uses wailing although it is not always clear what she is communicating by this (pain regularly assessed).	Requires wheelchair to move around. Can stand with the help of two carers. Can feed self independently. Requires full assistance with washing and dressing although is able to participate a little e.g. can dry her hands on a cloth. Up and dressed in sitting room most days although has occasional days in bed.	Anticipatory Care Plan Palliative Care Plan Preferred place of care is the care home. DNACPR in place	7 years
Quintin	92	Appears to understand as indicated by verbal	Can have short conversations about	Often communicates intentions or needs	Mobility variable either with a	Anticipatory Care Plan	3 years

		responses and at times by responsive action. Able to read and respond to body language of others.	younger life when prompted.	by intentional movements.	zimmer and supervision or sometimes requires wheelchair and a hoist. Full assistance required with washing and dressing. Can feed self independently with repeated prompting. Normally up and dressed in sitting room every day.	Palliative Care Plan Preferred place of care is the care home. DNACPR in place	
Lillian	91	Very able to read facial expressions and responded well to company and kindness.	Speech limited to 'yes' and 'no' but sometimes says yes and means no and vice versa.	Facial expression was always clear – pleasure or displeasure at the thought of what is offered. Smiled a lot when happy and also sometimes cried and difficult to ascertain the reason. If unhappy about doing something makes no	Required wheelchair for moving and hoist for transferring. Required full assistance with washing and dressing. Occasionally managed to feed self but usually required help. Normally up and	Died March 2013 in care home. Expected death.	7 years

				eye contact and purses lips.	dressed daily in sitting room until last two weeks of life.		
Catriona	93	Good comprehension of speech and responds verbally and with actions. Able to read and respond to body language of others.	Conversation very limited by memory loss but words clear and able to engage in two way conversation in the present moment on social niceties. Often initiates social contact.	Communicates happiness or unhappiness with clear facial expressions and, when able to walk, by intentionally walking away or joining company.	Varied over course of year. Initially fully mobile but has had fracture and now confined to wheelchair. Requires full assistance with washing and dressing. Able to feed self with prompting and reminders. Spends time dressed in sitting room and activity room.	Anticipatory Care Plan Palliative Care Plan Preferred place of care is the care home. DNACPR in place Died October 2013	5 years
Betty	81	Very good comprehension of speech clearly illustrated by actions. Able to read and respond to body language of others and responds well to company.	Appears to have very good understanding but words she responds with do not make sense. Initiates social interaction with eye contact, smiling and waving.	Clear facial expression of positive or negative emotion and also body posture communicates happiness or	Variable mobility – sometimes can walk with zimmer but requires wheelchair for distance. Finds this very frustrating and	Anticipatory Care Plan Palliative Care Plan Wishes for place of	1 year

				displeasure and frustration.	very much wants to be independent. Able to feed self. Able to do some washing and dressing with constant help. Sits in sitting room daily.	death not yet discussed No adults with incapacity in place as still able to make own decisions.	
Oswald	93	Some comprehension of speech as indicated by verbal responses and at times by responsive action. Able to read and respond to body language of others.	Conversation limited and words jumbled but often had very lucid moments. Did not initiate social contact but responded positively to contact.	Communicated with facial expression and also by bodily actions such as pushing food away if not wanted.	Over course of study had been mobile with assistance, requiring full assistance with washing and dressing, but able to feed self. Usually in sitting room but last week of life was in bed.	Died in December 2012 in care home. Expected death.	2 years
Rose	88	Some understanding of speech as indicated by verbal responses and at times by responsive action.	No short term memory. Able to engage in conversation focussed on social niceties in the moment. Does not tend to initiate interaction	Communicates emotion with facial expression, particularly smiles. Often looks contented.	Requires to be pushed in a wheelchair but can stand to transfer. Full assistance required with	Anticipatory Care Plan Palliative Care Plan	1.5 years

			although occasionally does with eye contact.		washing and dressing but able to feed herself independently with prompting. Up and dressed in sitting room everyday.	No DNACPR or preferred place of care Died Spring 2014	
Abi	93	Appears to have limited understanding of speech but at times shows some comprehension by responsive action.	Verbal communication limited to yes and no. No short term memory. No initiation of social contact	Face often quite expressionless and difficult to read emotion but communicates with body whether has understood or wants to cooperate or not e.g. nodding.	Mobile with company but requires a wheelchair for distance. Requires full assistance with washing and dressing. Able to feed self with prompting. Up and dressed in sitting room everyday.	Anticipatory Care Plan Palliative Care Plan No DNACPR or preferred place of care	1 year
Hilda	88	Very good understanding of speech indicated by responsive speech and action. Able to read and respond to body language of others.	Appears to have good understanding and engages in conversation when initiated by others but words very jumbled and very difficult for listener to make sense of conversation.	Very expressive with her face and body language – using dramatic effect to communicate emotion and intention.	Can walk with assistance of one or two people. Full assistance required with washing and dressing. Can feed self with repeated	Anticipatory Care Plan Palliative Care Plan Preferred place of care	5 years

					prompting and reminding. Up and dressed in sitting room everyday.	is the care home. DNACPR	
Floss	87	Very good comprehension indicated by responsive speech and action.	Poor short term memory but can engage in conversation in the present. Does at times initiate contact but usually only if needs something.	Depends largely on verbal communication but facial expression of positive or negative emotion also clear.	Fully mobile. Can wash and dress herself but needs constant reminding and prompting. Independent with food. Spends most of time in sitting room but also own room and activity room.	Anticipatory Care Plan Palliative Care Plan Preferred place of care is the care home. DNACPR in place	1.5 years
Gail	67	Very good comprehension indicated by responsive speech and action. Able to read and respond to body language of others.	Appears to understand and engages in conversation when initiated by others but words very jumbled and difficult for listener to make sense of the order of the words. Quite private but occasionally initiates social interaction with eye contact.	Communicates emotion and mood with clear facial expression of happiness or annoyance, for example smiling or pursed lips and going red and shaking head.	Fully mobile. Washing and dressing is challenging for carers and a lot of persuasion and supervision is required. Able to eat independently. Spends most of time in sitting room or walking	Anticipatory Care Plan Palliative Care Plan Preferred place of care is the care home DNACPR	1.5 years

					around, sometimes in own room.		
Dot	94	Good comprehension indicated at times by responsive speech and action.	Poor short term memory. Very verbal but conversation often appears confused.	Depends a lot on verbal communication but also communicates intention by getting up and walking away. Facial expression difficult to read for emotion.	Full mobile with walking trolley. Requires prompting with washing and dressing. Able to feed self independently with reminding. Spends most of time in sitting room or walking around.	None in place	1 year
Ingrid	93	Good comprehension indicated at times by responsive speech and action although sometimes this is very compromised by confusion and paranoia.	Able to engage in conversation in the moment but quite disorientated to time and place and prone to suspicion. Sometimes initiates social interaction or asks for help.	Largely depends on verbal communication but also communicates emotion clearly with facial expression and bodily posture and actions.	Fully mobile with stick. Walks around a lot. Requires guidance with washing and dressing. Independent with meals. Spends most of time in sitting room or walking around, sometimes in own	Anticipatory Care Plan Palliative Care Plan Preferred place of care is the care home. DNACPR in place	1 year

					room or activity room.	Died October 2013	
Katie	93	Very good comprehension indicated by responsive speech and action. Able to read and respond to body language of others and responds well to company.	No short term memory although is able to have a conversation in the moment or about the past. Disorientated to time and place. Often initiates social interaction.	Clear facial expression of positive and negative emotion and enjoys non-verbal means of one to one contact such as dancing.	Fully mobile. Requires full assistance and persuasion to wash. Feeds self with prompting. Spends most of day walking around the whole care home and sometimes goes to activity room.	Anticipatory Care Plan Palliative Care Plan Preferred place of care is the care home. DNACPR in place	2.5 years
Annie	97	Very good comprehension indicated by responsive speech and action. Able to read and respond to body language of others and responded well to company.	Poor short term memory but sometimes surprisingly lucid moments. Could engage in conversation about the past. Sometimes disorientated about time and place. Initiated social contact at times with eye contact and smiling.	Very clear facial expression of positive or negative emotion. Also would get up and down from chair and seek out assistance if unhappy about something. If content tended to stay seated.	Fully mobile with company. Some guidance needed with washing and dressing. Able to feed self independently. Spent days in sitting room except in bed last two weeks of life.	Died May 2013 in care home. Expected death	1.5 years
Emma	88	Good comprehension indicated by responsive speech and action and	Words very difficult to understand. Mumbled a lot	Body posture often slumped and wailed conveying	Fully mobile and walked around a lot. Full	Died December 2012	4 years

		responded well to company at times. Able to read and respond to body language of others.	although some surprisingly lucid moments.	unhappiness. Did not initiate social contact but often smiled with close one to one contact.	assistance required with washing and dressing. Often able to feed self independently with prompting. Spent days in sitting room or walking around the ground floor.	Expected death	
Nigel	91	Unknown	Very quiet. Did not communicate verbally	Difficult to read body language. Appeared to be very private and self-contained.	Fully mobile. Spent days in sitting room until day before death when in bed.	Died December 2012 Expected death	1.5 years
Joanna	91	Some understanding of speech indicated by responsive speech and action.	No short term memory limited conversation in the moment. Can ask for assistance. Initiated contact if looking for help or guidance.	Clear facial expression of positive or negative emotion. If unsettled walked around a lot shouting for help.	Fully mobile with zimmer. A lot of guidance required with washing and dressing. Spent days in sitting room or walking around ground floor until day of death.	Died December 2012 Expected death	2.5 years

Appendix 24: Published Journal Article

Watson, J. (2013) What is Dementia? Implications for Caring at the End of Life End of Life Journal 3(1) 1-9

WHAT IS DEMENTIA? IMPLICATIONS FOR CARING AT THE END OF LIFE

Julie Watson

Dementia is understood in a number of different ways within different fields of practice, e.g. health and social care. In Western society, predominantly biomedical ideas of dementia influence the experiences of people who have dementia. Limitations of biomedical models of dementia have led to the development of other ways of understanding dementia. These include the social-psychology, critical gerontology and disability models. However, such models are also limited, particularly in the context of advanced dementia and dying. This article demonstrates that the way dementia is understood is important with regard to the care considered possible or appropriate at the end of life. A move away from polarised understandings of dementia is proposed in favour of a broader understanding that offers therapeutic potential to those with advanced dementia at the end of life. Ways in which such a broader understanding might influence end-of-life care are explored, including the importance of relationships in supporting the sense of self of a person with dementia and the role of physical care as a way of developing positive relationships. *Conflicts of interest: none*

KEY WORDS

Advanced dementia
End-of-life care
Models of dementia
Personhood
Selfhood

The number of people who have dementia is rising exponentially. It is estimated there will be over 1 million people with dementia in the UK by 2021 (Comas-Herrera et al, 2007; King's College London and London School of Economics, 2007; Department of Health (DH), 2009). The care of people with dementia is described as a national challenge and delivering improvements in dementia care and research is a government priority (Alzheimer's Society, 2012; DH, 2012). Dementia

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care has been identified as a national priority in England and Scotland with the publication of the *National Dementia Strategy* (DH, 2009) and Scotland's *Dementia Strategy* (Scottish Government, 2010). The occurrence of dementia has profound implications for the individual in terms of living and dying. It also affects the experience of family and professional carers (Small et al, 2007). Recent studies show that people with advanced dementia often experience poor care and suffering at the end of their lives (Brazil et al, 2004; Sachs et al, 2004; Audit Scotland, 2008; Hall et al, 2011). Many questions remain regarding how best to care for individuals/families affected by advanced dementia (Sachs et al, 2004; Birch and Draper, 2008).

The important question with regard to dementia is the way in which it is understood by practitioners, families and society. Such understanding has implications for people living and dying with dementia. Downs et al (2006) suggest the way in which dementia is understood, or how people with dementia are perceived, has consequences for the person with dementia in terms of:

- ▶▶ The experience of care
- ▶▶ Determining how care is delivered and how priorities are made
- ▶▶ The quality of relationships
- ▶▶ The options considered possible or appropriate in terms of caring for a person with dementia.

Drawing on current thinking regarding theoretical models used to understand dementia, this article explores consequences for practice and, in turn, the lives of people with end-stage dementia. It begins by considering dementia as a disease and goes on to explore how dementia came to be considered as a disability. This somewhat simplifies the different ways of thinking about dementia. Other theoretical models, which inform and influence practice and policy development, include social-psychological perspectives and critical social gerontology (Innes and Manthorpe, 2012). However, biomedical and disability models are more commonly adopted in care settings, e.g. hospitals or care homes, and are used in this article as a way of illustrating how different understandings of dementia influence care practices. The limitations of biomedical and

disability models, in the context of advanced dementia at the end of life, are explored before considering the possibilities for end-of-life care, taking a broader, less polarised view of dementia.

Dementia — a disease

Biomedical ideas about dementia predominate in Western society and heavily influence the experience of people with dementia. Innes and Manthorpe (2012) note that within the disease model, dementia may be considered in a number of ways:

- ▶▶ As a mental illness
- ▶▶ As a disease of later life
- ▶▶ As a long-term condition
- ▶▶ As an element of frailty.

In Western clinical practice, dementia is used as an umbrella term for a number of different disease classifications, including Alzheimer's disease, vascular dementia, dementia with Lewy bodies, fronto-temporal dementia, mixed dementias, Korsakoff's syndrome and Creutzfeldt-Jakob disease (DH, 2009). The most common type of dementia is Alzheimer's disease (DH, 2009) and is the dementia most often referred to within this work. Symptoms, as defined by the Scottish Intercollegiate Guidelines Network (SIGN, 2006), include memory and language problems, a progressive deterioration in the ability to perform basic activities of living, and behaviour changes, mainly apathy, social withdrawal and behavioural disturbances. Alzheimer's disease causes abnormal function and eventual death of selected nerve cells in the brain. It is a terminal illness and the average survival period following diagnosis is 8–10 years, although people often die from other causes before their dementia reaches the end-stage (Jolley, 2010). Advanced dementia is poorly defined and it is difficult to prognosticate accurately. However, there are common indicators of the last 6 months of life (Table 1). Although much remains unknown and confusing about the aetiology of Alzheimer's disease, Hughes (2011) describes how it conforms to the five characteristics of disease classification (Table 2).

A diagnosis of probable Alzheimer's disease is made from a combination of brain imaging, screening for co-morbid conditions and cognitive testing, with the Mini-Mental State Examination (MMSE) (Folstein et al, 1975) being most commonly used (SIGN, 2006). As Hughes et al (2006) point out, the individual components of dementia

occur, to some degree, in normal ageing and so a degree of evaluative judgement is required in making a diagnosis. However, diagnoses are made with some degree of certainty and can be used to predict certain types of deterioration and forms of treatment or resources, which may help. A differential diagnosis of dementia is seen to be important for a number of reasons:

- ▶▶ Availability of licensed treatment for the symptoms of Alzheimer's disease
- ▶▶ Dementias caused by some hormonal imbalances or vitamin deficiencies are reversible
- ▶▶ The potentially serious side-effects of the use of anti-psychotic medication in people with dementia with Lewy bodies (SIGN, 2006).

A key target of UK dementia strategies is for more people to receive early diagnosis, so that they gain access to information and support, when it is likely to be of most benefit (DH, 2009, 2012; Scottish Government, 2010). Support may come from a variety of professionals, including geriatricians, psychiatrists, neurologists, psychologists,

Table 1

Common prognostic indicators of the last 6 months of life in dementia

- Language/speech loss
- Inability to walk without assistance
- The need for help with all activities of living
- Incontinence
- Poor food intake
- Recent weight loss

Source: Gold Standards Framework and Royal College of General Practitioners (2011)

Table 2

The five characteristics of disease classification in relation to dementia

1. It has clearly recognisable symptoms and signs. That means there is some certainty in diagnosis, although diagnosis remains only probable until post-mortem
2. A postulated aetiology, e.g. a possible genetic contribution and the 'amyloid cascade hypothesis', leading to senile plaques
3. There is an established disease course and prognosis, in that steady deterioration in cognitive ability may be predicted, while recognising that changes in behaviour show great individual variation
4. It satisfies the need for a pathological lesion, in that characteristic features include numerous senile plaques in the cerebral cortex, hippocampus and subcortical structures, neurofibrillary tangles, amyloid deposits in blood vessels, granulovacuolar degeneration and Hirano bodies in the hippocampus, and loss of nerve cells (myelin)
5. A possibility of treatment exists. Anticholinesterase drugs can, potentially, modify symptoms and enhance activity in some people and there is also evidence for the efficacy of non-pharmacological interventions, e.g. education and support for caregivers, cognitive training, cognitive stimulation and activities of living training

Sources: Tyrer and Steinberg (1993), SIGN (2006), Olazaran et al (2010), Hughes (2011)

GPs, social workers, community nurses, specialist nurses and the voluntary sector; indicating the complexity of dementia care.

Considering dementia to be a disease means that specific services can be developed to support people with dementia and their families. It also means scientific and clinical research is conducted, which may eventually lead to better dementia treatments. However, while it may be clinically and scientifically useful to think of dementia as a disease, such thinking is not without consequences.

Limitations of the disease model in advanced dementia

The MMSE is a cognitive test, commonly used as part of a battery of tests to make a diagnosis of dementia. Looking at the impact of this test on people with dementia usefully highlights the limitations of thinking about dementia as a disease. The MMSE breaks cognitive function down into discrete elements, such as attention, memory, perception and learning, which can be measured objectively, uncontaminated by situational factors or social cues. However, Sabat (2001) points out that people with dementia depend heavily on social context for information that helps them to behave in a coherent way. The clinical context in which the MMSE test is taken may exaggerate weaknesses and overlook strengths — in everyday life the cognitive functions measured by the MMSE are not isolated from their specific social context. In clinical practice, while it is recognised that people may function better in their own environments than their test scores may indicate, the danger is that people with dementia become defined by deficits and are seen then in terms of what they cannot do. This may weaken their sense of self-worth and self-esteem, increasing their sense of being burdensome (Sabat, 2001). Even statistical data predicting rising numbers of people with dementia, often frames the issue in terms of a 'demographic time-bomb' and therefore a burden that has to be managed (Gott and Ingleton, 2011).

Post (2000) coined the term 'hypercognitive culture' to describe our contemporary culture which holds rationality and consciousness as core values, ignoring other aspects of being human, such as emotional, spiritual, relational and aesthetic aspects. Fontana and Smith (1989) associate the progression of dementia with the 'unbecoming' of self and Davis (2004) suggests that the progressive nature of dementia is the 'very splintering of the sedimented layers of being, until, ultimately, there is nothing left'. These views equate the loss of cognition and memory with the loss of self. Those without cognition are seen as non-persons and this contributes to the marginalisation of people with dementia. An example of this might be the situation in which a person with dementia is spoken about in their presence, as if they were not there, such that their subjective feelings are denied or overlooked. This eventually leads to 'social death' or 'death that leaves the body behind' (Kitwood and Bredin, 1992).

The ability to recognise others is seen as the most important determinant of whether or not social death occurs (Sweeting and Gilhooly, 1997). Taylor (2008) suggests that a consequence of the failure to recognise others, is that the person with dementia may then cease to be recognised as an individual or a person. A survey exploring public attitudes and knowledge of dementia showed that 46% of those surveyed thought that, 'as soon as someone is diagnosed with dementia, they are not treated as a human being any more', 75% thought that, 'once they have dementia the person you knew eventually disappears', 73% thought that 'people with dementia are like children and need to be cared for as you would a child', and 83% thought that 'there comes a time when all you can do for someone with dementia is keep them clean, healthy and safe' (Economic and Social Research Council and Northern Ireland Access Research Knowledge, 2011).

The focus on cognitive deficits as dementia progresses, may lead to

diagnostic overshadowing, in which all behaviours, e.g. anxiety or distress, are attributed to dementia, leading to the misuse of psychotropic medication (Banerjee, 2009). Banerjee (2009) found that anti-psychotic medication is often used as a first-line response to behavioural difficulty, rather than a considered, second-line response to the failure of other non-pharmacological approaches. If dementia is seen as being bounded in the individual brain and a matter of neural processes (Moser, 2011), a 'filter' is created, through which all behaviour is interpreted (Sabat, 2010) and attention is diverted away from other explanations of behaviour such as the reasonable distress of a person with dementia attempting to make sense of their world or communicate their needs, such as thirst or the need for pain relief.

Thinking about dementia as a disease is part of the picture, but it is not the whole picture. Hughes (2011) suggests that, 'If carers, clinicians or neuroscientists were to mistake the disease model for the whole picture, the effect would be clinically, socially and ethically disastrous'. Limitations in the biomedical model have led to the development of the disability model of dementia, which is now examined.

Dementia — a disability

Sabat (2001) shows how the effects of dementia derive from more than neuropathological changes, but from the way the person with dementia is positioned in relation to others in the social world. 'Excess disability' exists when the functional incapacity of a person with dementia is greater than that warranted by their neuropathological impairment, but is rooted in the social world they inhabit. Sabat suggests the possibilities for minimising those limitations are greatest in the social domain. Sabat (2001) collected systematic case studies of people with severe dementia and identified capacities/abilities that remain, despite the dementia (Table 3).

Sabat (2001) recommends an 'intentional stance', whereby the person with dementia is positioned

as having something to communicate and supported to express their wishes. While not denying the real losses that dementia brings, actively noticing capacities that remain, rather than focusing on incapacity, can transform the care of people with dementia.

The concept of dementia as a disability has emerged in order to correct the limitations of the biomedical/disease model, which focuses on cognitive deficits (Innes and Manthorpe, 2012). Kitwood (1997), while not denying the role of neuropathology, was one of the first people to draw attention to the interpersonal and social-psychological factors that affect people with dementia, for good or ill. Drawing on social-psychological and gerontological perspectives and the Social Model of Disability (Oliver, 1996), Kitwood (1997) proposed an alternative to the biomedical model, which has been highly influential in the field of dementia-care policy and practice. The Social Model of Disability claims that society disables people with impairments, by creating a physically and socially hostile environment (Gwilliam and Gilliard, 1996). In this model, the person with dementia would be defined as a 'disabled person', in that they have impaired functioning, but it is the

reaction of other people and society as a whole which is disabling. Applying the Social Model of Disability to dementia means that the focus moves from 'the dementia' towards 'the person' and their needs, wants and rights (Gwilliam and Gilliard, 1996).

Thomas (2004) describes two domains for thinking about disabilities that differ in emphasis and aim. The first domain, which exists within the discipline of disability studies, has emancipatory goals. It is committed to assist people with disability to fight for full equality and social inclusion. It considers disability as a form of oppression from wider society and focuses on wider social, political, cultural and economic factors shaping the experiences of people with disability, within a human-rights framework. It tends to underplay the role of the 'body' as a cause of disability. The second domain, which exists within the discipline of medical sociology, differs in that, while it recognises the restrictions caused by environmental, social and cultural contexts, it does not sever the causal connection between bodily impairment and disability. Severing said connection would be to deny the daily realities of people with impairment and those who care for them. There is no doubt that thinking about dementia as

a disability in both these domains has brought many improvements to the lives of people with dementia through influencing practice and policy, enabling people with dementia to live well, often for many years. This is encapsulated in the Prime Minister's Challenge on Dementia (DH, 2012) which states that: 'As a society, we must make sure that people with dementia, their carers and families can be active citizens with the potential to live well with dementia at every stage of the condition.' Another example is the advances that have been made in designing dementia-friendly environments, which draw on understandings of the cognitive effects of dementia and seek to enable rather than disable the person (Davis et al 2009). However, as with the disease model, it is not the whole picture.

Limitations of the disability model in advanced dementia

The emphasis on 'living' with disability, while crucial, may mean the disability model of dementia inadvertently overlooks the progressive and ultimately terminal nature of dementia and the issues people face when they are dying with or from dementia. This leads to an artificial divide occurring between dementia and dying within health and social-care systems and public policy. The result is a lack of discussion about what it means to die well with dementia. This negatively affects the end-of-life experiences of people with dementia and raises clinical, ethical and social uncertainties. A similar artificial divide has occurred between ageing and death as a result of the 'successful ageing' movement (Gott and Ingelton, 2011). Dementia-care policies, until recently, rarely mention death, dying or palliative care (Kellehear, 2009), diverting attention away from the multiple and complex losses experienced by people with dementia and their families (Holman et al, 2004). Complex end-of-life care decisions are, therefore, postponed and become reactive. It may be that so much effort has been required to bring about developments that enable people with dementia to live better lives that the concept of palliative care, and its historical associations with cancer and

Table 3

Capacities and abilities that remain in dementia

- The capacity to experience shame and embarrassment
- The capacity to experience pride and maintain dignity
- The capacity to feel concern for the wellbeing of others
- The capacity to formulate personal and group goals
- The ability to use extralinguistic forms of communication to compensate for linguistic impairment
- The ability to communicate effectively when others help
- The capacity to manifest and experience selfhood in a variety of ways
- The capacity to manifest indicators of wellbeing
- The capacity to experience and the ability to work effectively at maintaining feelings of self-esteem
- The capacity for spiritual awareness and expression

Source: Sabat (2001)

dying, goes against the grain. However, one of the principles espoused by the World Health Organization (2004) is that palliative care intends neither to hasten nor postpone death, but promote quality of life until death. Current UK dementia strategies are beginning to address this aspect of dementia care (DH, 2009; Scottish Government, 2010).

It is possible that different professional groups working in health care, social care or policy development have different understandings of dementia. Such lack of consensus causes problems for people with dementia as they navigate the differing professional care systems. Many questions remain about how to best care for people with advanced dementia and their families (Sampson et al, 2005; Birch and Draper, 2008). People with advanced dementia are in the paradoxical position of having their needs in relation to dying neglected, either because they are seen as 'already dead', or because they are not seen as having a terminal illness, leading to overzealous treatment and lack of opportunity for them and their family to prepare for dying (Small et al, 2007).

A better way of living and dying with dementia

Hughes (2011) concludes that models of dementia, including the disease model or the disability model, should be left behind, because they limit therapeutic possibilities for people with dementia, suggesting a broad view should be embraced. Innes and Manthorpe (2012) also propose a move from polarised views of dementia to an integrated approach drawing on different ways of understanding. In practice, different ways of understanding dementia often blur and interact with each other. Moser (2011) suggests that, in the best of worlds, they make the best of each other. Accepting the complexity of dementia may help practitioners to rise to the moral challenge of dementia as proposed by Post (2000):

- ▶▶ First, the challenge is to think ethically about how to avoid burdening people who have dementia with invasive medical treatments that prolong suffering.

- ▶▶ Second, the challenge is to reduce the stigma associated with dementia, by being with those who have dementia and caring in ways that draw upon their remaining emotional, relational, spiritual and aesthetic capacities.

Establishing realistic care goals to relieve suffering

A first step towards establishing realistic goals is recognising the progressive and terminal nature of dementia in order that systems, such as the Gold Standards Framework (GSF), can be put in place. The GSF is a systematic, evidence-based approach that optimises the care of people nearing the end of life, whether their prognosis is months, weeks or days (GSF, 2012). As mentioned above, advanced dementia is poorly defined and difficult to prognosticate accurately. However, common physical and cognitive indicators exist that suggest those diagnosed with dementia are in the last 6 months of life (see *Table 1*).

In the UK, people with advanced dementia and their families are seldom informed of the terminal nature of their illness and so never have the opportunity to discuss their future goals (Thune-Boyle et al, 2010). The GSF, however, enables regular review of changes in health status and the setting of realistic goals of care. Such goals should be discussed by health and social care staff and families, taking into account previous wishes of the person with dementia about the many complex issues associated with end-stage dementia, including pneumonia, refusing food, weight loss and swallowing difficulties. This may help prevent the, often, aggressive treatment given to people with advanced dementia. Aggressive treatments include hospitalisation from care homes for pneumonia and tube feeding, which are of limited benefit in end-stage dementia (van der Steen et al, 2002; Pinderhughes and Morrison, 2003; Mitchell et al, 2004; Pasman et al, 2005; Helton et al, 2006; Hertogh, 2006), and can result in the person with dementia dying in unfamiliar surroundings, away from people they know (Hockley et

al, 2010). Mitchell et al (2009), in a study exploring the clinical course of advanced dementia, found physical suffering was common and an increase in distressing symptoms towards the end of life, the frequency and pattern of which are similar to those of terminal cancer. Again, recognition of the progressive and terminal nature of dementia, with its cognitive and physical effects, while adopting a palliative-care approach, means that attention will be paid to end-stage symptoms and diagnostic overshadowing will not occur (i.e. attributing all behaviour to the disease process).

Recognising the 'person' with advanced dementia

The potential for dementia to undermine personhood has led to a number of people working in the field of dementia care to address the question, 'What is a person?', and to challenge the underlying assumption of the loss of the person to dementia (Innes and Manthorpe, 2012). This offers therapeutic potential to people with dementia at the end of life.

Kitwood (1997) was one of the first to consider personhood in dementia, although he did not specifically apply it to end-of-life care. Kitwood suggests that personhood is, 'a standing or status bestowed on one human being by another; in the context of relationship' (Kitwood, 1997) and that person-centred care seeks to support and maintain personhood through relationships, recognising the need for attachment, comfort, identity, occupation and inclusion. One of the biggest challenges people with advanced dementia experience is that family and professionals view them as 'already gone' and, therefore, unable to connect in relationships.

In contrast, Sabat (2001, 2010) has identified three types of self and, through systematic collection of case studies, has considered their relevance to people with advanced dementia:

- ▶▶ The first self is one of personal identity, expressed in terms of first-person pronouns, such as 'I' and 'me'. Sabat found this self to be intact, even in advanced dementia.

- ▶▶ The second self relates to the attributes of a person, e.g. a good sense of humour; being a graduate, having a particular religious belief, and even the attribute of having dementia. Other people play a role in paying attention to the life story of the person who has dementia, the things they value and the positive attributes that remain intact, rather than allowing the diagnosis of dementia to be the predominant attribute. Understanding the person who has dementia, therefore, involves understanding their life story and using it as a means to comprehend behaviour while forming or maintaining connections. In the context of end-stage dementia, the act of acknowledging death as the end of the story is significant. Every life is bounded by birth, living, decline and death (Lesser, 2006), and to overlook dying is to diminish personhood.
- ▶▶ The third self is that which is constructed socially and requires community. It might include being a mother; a brother or a friend. This self is profoundly important for people with dementia, as it affects how others see them. The third self may be inhibited or facilitated by the behaviour and practices of others (Sabat 2001, 2010).

When the 'person' with dementia and their various 'selves' are recognised as whole, the therapeutic emphasis can shift towards building connections with the person, while creating opportunities for them to engage. Moser (2011) suggests that the suffering and isolation experienced by people with dementia can be diminished by holding the person with dementia in connection and making them part of the daily life of a hospital ward or care home. This may involve the use of alternative channels for communication, such as music, or using eating as an opportunity for contact and interaction, plus being involved with the rhythm of a collective life.

The role of the 'body' in advanced dementia

The previous section emphasised the importance of relationships for supporting personhood and selfhood.

Kontos (2004) drew attention to the importance of embodied selfhood, i.e. the way in which self is enacted in the movements of the body. She conducted an ethnographic qualitative study of 13 residents with moderate to severe Alzheimer's disease in a Canadian long-term care facility. She suggested that movements of the body, facial expressions (smiles and frowns), eye behaviour (blinking, winking, direction and length of gaze, pupil dilation) and posture, all carry meaning and play a role in inter-personal communication, often conveying praise, blame, thanks, support, affection, gratitude, disapproval, dislike, sympathy, greeting or farewell, and are intentional, communicative, informative and interactive (Kontos, 2004). Kontos presented examples from her research of continued ability to perform religious rituals practised over a lifetime, sociability and the demonstration of empathy between people with dementia, demonstrating their mutual recognition of one another as persons, indicating that memory is not confined to the brain but is embodied in the muscles, nerves and sinews of the body (Kontos 2006, 2011). Kontos aimed to draw attention to the importance of recognising and supporting these subtle and easily overlooked forms of self-expression, as a way of enhancing dementia care.

Over emphasis on physical care is often used as a criticism to draw attention to a lack of holistic care or poor psychosocial or spiritual care. There is no doubt that, if physical care is seen as a task to be completed and is conducted in a perfunctory manner; or to meet organisational needs, then the above is a valid criticism. However, in the context of end-of-life care in advanced dementia, bringing the body centre stage and seeing it as the site of holistic care, has the potential to transform the caring encounter. Thinking of bodily care as a space and time set aside for recognising and supporting the self-expression of the person with dementia has the potential to transform physical care into holistic care. In the context of advanced dementia, where physical frailty increases and the person may not be able to verbalise, close

attention to bodily cues and signs of wellbeing (or ill-being) is necessary. Bodily care can provide comfort, but particularly in the context of dementia, it is also a way of valuing and respecting the person, an opportunity to recognise and support their embodied selfhood and a means of forming or maintaining a relationship. In the context of caring relationships, Kontos and Naglie (2009) suggest that a common bond of embodied experience, e.g. knowing what it is to feel wet or cold, uncomfortable or embarrassed, can facilitate a connection between a nurse/carer and the person with dementia, helping to avoid the person with dementia becoming an object of care.

Everyday caring routines in a care home have been shown to be an important starting point for developing positive relationships. The nature of such interactions can greatly influence relationships in the care home (Brown-Wilson et al, 2009). As mentioned above, this requires taking an intentional stance, whereby the person with dementia is viewed as having something to communicate and being given support to express themselves (Sabat, 2001). Communication, relationship and connection with the human spirit can be enhanced through the body by stimulating the senses using music, light, perfumes, tastes and touch (Dekkers, 2010; Simard and Volicier, 2010).

'Being with' when facing death, a key principle of end-of-life care espoused by Dame Cicely Saunders, the founder of the modern hospice movement, involves deep involvement, while accompanying someone on their spiritual journey towards death (Saunders, 1965; Saunders and Baines, 1983). In practice, this may be different in the context of dementia than in the context of cancer. However, building on the idea of embodied selfhood and connecting with the spirit through the body may offer therapeutic potential and requires further exploration in practice. Dekkers (2010) suggests that bodily autonomy, or the wisdom of the body, may be used as a guide when difficult moral and ethical end-of-life decisions are to be made. For example,

he suggests that bodily actions such as pushing away a spoon, spitting out medication, or pulling out a feeding tube, and facial expressions or bodily defensive movements, should be taken seriously alongside other factors, such as discussions with the family, when treatment decisions are to be made.

The importance of the care context

Of the 700,000 people in the UK with dementia, 244,000, or one-third, live in care homes, and many of these residents have severe cognitive impairment (Alzheimer's Society, 2007). That means care homes play a key role in caring for people living and dying with dementia. In the UK, people with dementia over the age of 65 years occupy a quarter of hospital beds (Alzheimer's Society, 2009), although only a proportion of these people will be in the end stages. In the context of institutional care, Nolan et al (2006) suggest that interpersonal relationships, including caring relationships, particularly in the context of advanced dementia, can be demanding and can impact on the identity and sense of self of caregivers. They build on the idea of person-centred care, advocating relationship-centred care, which seeks to recognise the needs of those giving care, as well as those receiving care.

Emphasising relationship-centred care moves the focus from being solely on the person with dementia, creating an environment in which the support needs of the staff and the family are considered alongside those of the person with dementia. They have developed the Senses Framework (Nolan et al, 2006), which outlines the conditions required for relationship-centred care to occur. In the context of end-of-life care, Nolan and Ryan (2011) suggest that the conditions outlined in Table 4 are necessary.

Focusing on these points may help practitioners to understand how care work can be satisfying and rewarding and make it more possible for staff and family carers to support the selfhood of people with dementia without the feeling of being consumed or burned out in the process. It recognises that we are all interdependent and part of our sense of personhood comes through relationship. Upholding the personhood of someone with advanced dementia is undoubtedly demanding and the need for an enriched environment in dementia-care settings is particularly pertinent. Relationship-centred care is in keeping with the recommendations of the Nuffield Council on Bioethics (2009), which suggest that caring for

people with dementia includes caring for the carers and that more research is required on how health and social care can best be supported in providing care which genuinely respects the personhood of everyone with dementia.

Recommendations for practice

This article has drawn attention to the different ways of understanding dementia and how such understanding influences the care considered possible for people with dementia. Downs et al (2006) suggest that the implicit assumptions brought to the care of people with dementia can be powerful inhibitors to thinking that will allow improvements to end-of-life care. It may be helpful for practitioners to reflect on the assumptions that underpin their dementia-care practice and how they influence the type of care they think is possible. As the numbers of people with dementia rise in all care settings, it may be that as individual practitioners reflect on their own assumptions about dementia and perhaps think in new ways about the possibilities for good care, small steps will be taken towards creating enriched care environments for people with dementia and those caring for them.

Conclusion

Palliative care intends neither to hasten nor postpone death, but promote quality of life until death. Drawing on different understandings of dementia, practical knowledge and research from within the fields of dementia care and palliative care offers therapeutic possibilities for people with advanced dementia, right through to the end of life. This approach can bring quality of life back into the often slowly dwindling existence that so many people with dementia experience, until their death. [EOLJ](#)

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Table 4

Conditions required for relationship-centred care in the context of end-of-life care

- **Sense of security:** for family carers and staff to feel safe to raise difficulties and sensitive issues in a supportive and facilitative environment
- **Sense of belonging:** for both family carers and staff to feel part of a valued group who share similar values and beliefs
- **Sense of continuity:** to be able to establish relationships over time and to be able to relate the present situation to the past and the future
- **Sense of purpose:** to recognise the complexity of end-of-life care for family carers and to work actively with them to prepare them for their role and their loss, now and in the future, to enrich their remaining time with their loved one and to reduce the latter's suffering and to enhance the positive aspects of caring
- **Sense of achievement:** for the above to be seen as important and valued outcomes of care
- **Sense of significance:** for end-of-life care with family carers to be seen as valued and important, something that really matters

Source: Nolan and Ryan (2011)

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Key Points

- ▶ The way in which dementia is understood has implications for the care that people with dementia receive at the end of life.
- ▶ In care settings, dementia is commonly thought of as a disease or a disability.
- ▶ The disease model and the disability model are limited in advanced dementia.
- ▶ Taking a broad view of dementia, which draws on both the disease and disability models, offers therapeutic possibilities to people with dementia at the end of life.