‘The Time that Used to Go’: A Psychosocial Study of the Care Relationship in Residential Care Homes for People with Dementia

Thesis

How to cite:


For guidance on citations see FAQs.

© 2017 The Author

Version: Version of Record

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online’s data policy on reuse of materials please consult the policies page.
‘The Time that Used to Go’:
A Psychosocial Study of the Care Relationship in Residential Care Homes for People with Dementia

Esther Ramsay-Jones
Abstract

This thesis aims to explore the relational field in dementia care by focusing on the particularity of experiences between carers and residents in two dementia care homes, while also keeping in view the social context of such experiences. Drawing on psychoanalytical ideas, the study examines in detail the dynamic psychic processes which took place between the people who lived and worked in both care settings, as well as noting the ways in which they came to inform the organisational culture of each site which was simultaneously constitutive of the relational field and also constituted by it.

Using research methods influenced by psychosocial ideas, data was gathered through two psychoanalytically informed observations of the care settings, a series of loosely structured interviews with staff and residents and notes from a personal research diary. There is a discussion of Living Well: A National Dementia Strategy, which focuses on the appropriateness of the ‘living well’ discourse for people in advanced stages of dementia, in which the experience of decline, dependency and death is present.
Acknowledgements

Thank you to Dr Gail Lewis and Dr Peter Redman for all their encouragement and for sharing their ideas, thoughts, and approaches. And to my lovely family, who have supported this endeavour all along the way.
# Table of Contents

**List of participants** 1  

**Introduction**  
The Socio-Political Background 6  
This Project 10  
Research Question 11  
Outline of Chapters 12  

**Chapter 1: Literature Review**  
Introduction 15  
Relationality in Dementia Care 18  
Mother-infant Relationships 23  
Organisational Relatedness 35  

**Chapter 2: Methods and Methodology**  
Ethics and Reflexivity 44  
Infant Observation 46  
Psychoanalytic Observations in Dementia Care 47  
Interviews 59  
Data Analysis 63  

**Chapter 3a: Findings**  
Introduction 68  
Themes 73  
Time 76  
Concluding Time 114  

**Chapter 3b: Findings**  
Mother/s 115  
Death 136  
Conclusion 148  

**Chapter 4: Analysis**  
Time 153  
Mother/s 170  
Death 178  
Thinking about class and race 181  

**Chapter 5: Policy and Practice**  
Introduction 187  
The Strategy 189  
Living Well 193  
The Relational Field 205  
The Workforce 211  
Conclusion 216  

**Conclusion** 219  

References 223  
Appendix A 232  
Appendix B 233  
Appendix C 235
# List of Participants

**Winston Grove**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>Resident</td>
</tr>
<tr>
<td>April</td>
<td>Permanent Carer</td>
</tr>
<tr>
<td>Bridget</td>
<td>Housekeeper</td>
</tr>
<tr>
<td>Chaya</td>
<td>Permanent Carer</td>
</tr>
<tr>
<td>Daphne</td>
<td>Resident, subject of observation</td>
</tr>
<tr>
<td>Diane</td>
<td>Permanent Carer</td>
</tr>
<tr>
<td>Dirk</td>
<td>Resident</td>
</tr>
<tr>
<td>Elaine</td>
<td>Manager of the home</td>
</tr>
<tr>
<td>Erica</td>
<td>Original keyworker of Daphne</td>
</tr>
<tr>
<td>Gaynor</td>
<td>Resident</td>
</tr>
<tr>
<td>Gemma</td>
<td>Activities Co-ordinator</td>
</tr>
<tr>
<td>Lynn</td>
<td>Temporary Deputy Manager</td>
</tr>
<tr>
<td>Margot</td>
<td>Resident</td>
</tr>
<tr>
<td>Maude</td>
<td>Resident</td>
</tr>
<tr>
<td>Sue</td>
<td>Resident</td>
</tr>
<tr>
<td>Ursula</td>
<td>Part-time carer</td>
</tr>
<tr>
<td>Violet</td>
<td>Resident</td>
</tr>
<tr>
<td>Wend</td>
<td>Business Administrator</td>
</tr>
<tr>
<td>Zalee</td>
<td>Temporary Carer</td>
</tr>
</tbody>
</table>

**Whittinghall**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>Manager of the home</td>
</tr>
<tr>
<td>Dorothy</td>
<td>Resident, subject of observation</td>
</tr>
<tr>
<td>Dr Dhillon</td>
<td>Resident</td>
</tr>
<tr>
<td>Dr Jesmond</td>
<td>Resident</td>
</tr>
<tr>
<td>Ellen</td>
<td>Resident</td>
</tr>
<tr>
<td>Evie</td>
<td>Resident</td>
</tr>
<tr>
<td>Nancy</td>
<td>Senior Carer, subject of observation</td>
</tr>
<tr>
<td>Prashid</td>
<td>Permanent Carer</td>
</tr>
<tr>
<td>Sonia</td>
<td>Senior Nurse</td>
</tr>
</tbody>
</table>
I don’t know what to say
Yep
I’m making a statement.

The Things between Us, Living Words: Anthology 1.
Words of people experiencing dementia. (2014, p. 150)
Introduction

I go total blank... Trying to work out what it’s like without the... most of the pieces aren’t here so I can’t put names to them. And we’re dropping downhill slightly. I planted these up but I can’t remember now what we are really looking at... and some of them are growing very well... that’s lovely. Some are not so good because they are not in a good place. And I start asking where I live and where I am and so on and I can’t tell you now let alone then. I can’t... I’ve forgotten about it all and why... I don’t feel I was together at all and my hair’s all over my eyes which is driving me crackers.

Ellen, 18 August 2015, Whittinghall Care Home.

The seed of this thesis was sown over a decade ago when I started work as a carer in a residential care home for older people in London. People had warned me that it would be hard work, and that I was over-qualified. My husband feared the work would be demeaning, as if it were also a narcissistic blow to our combined sense of self, and our aspirations for the future. There was, and perhaps still is, a sense of shame that surrounds care work with older people with dementia (Clough, 2016). It is viewed as low-status and carers are heard to describe themselves and their colleagues as ‘arse-wipers’ (Jervis, 2001, p. 89). As Clough (2016, p.33) points out, ‘In a culture where money determines value, many care workers feel grossly undervalued’ and, she goes on to write, quoting Sander et al (2011),

As a society, we displace our discomfort with human frailty by removing it to hospitals and care homes, packaging it with targets that attempt to regulate and sanitise it and creating a culture of shame when these targets cannot be met. (Quoted in Clough, 2016, p. 33)

Back in 2003, I did not reflect long on issues of institutional shame. I was also unaware that people with dementia in care homes, and their carers, could be split off from the rest of the wage-earning community, ghettoised in groups of failing populations. Nonetheless, I must have been unconsciously drawn to this hidden old age and to death and to experiences which would often escape words, try as you might to fix them down.

Certain memories come to mind when I ask myself what drew me to care work for older people: me as a pre-pubescent child, noting my insignificance in relation to the full expanse of the planet and knowing that one day I would die; a neighbour in her seventies, who called me in from our street for lemon and honey tea, garishly dressed, recounting stories from her days as a fashion buyer; my grandmother, Faith1, who, with Alzheimer’s maintained a belief in both people and God, which seemed to help her to settle into a care home in Wales, easing her journey into death. Somehow, both these older women seemed to come to accept the expunging of breath and of existence – my

1 All names and identifying features have been anonymised in this thesis.
greatest fear. Perhaps for existential reasons I have needed to get closer to decline, dependency and death in order to know more about how any of us, as temporal beings, become reconciled with our own finitude.

Choosing to work with people with dementia, in particular, relates consciously to my grandmother’s experience, and to the experience of confused voices and voicelessness. In this study, one of my prime concerns has been to find ways to make known those voices that either struggle to articulate in language their own experience or those who – like professional carers – are left silenced because society undermines their contributions, which cannot often be monetised. The experience of newborns, for me, is a powerful evocation of the need to make feelings known: the baffling cries of my own babies; my newborn self even, outside the order of words, a new Mum, anaesthetised, tired and in pain, her baby behind an incubator without her; Dad anxious and alone. And there back home, the newborn screaming, legs up to chest contorted in colicky distress and parents rocking and rocking and rocking her. All of these unknowns and imaginings play out when I begin to think about my reasons for entering the field of dementia care, leading me to ask questions of self and other, and of what it is to care, how hard it can be to do so.

Yet questions about what constituted professional dementia care only really began to emerge when I met Melie, in London. Melie had thick white curled hair and it stayed on her head precariously like billowing candyfloss. She had her own teeth still but they were yellowing and cracked and uneven. She had small eyes that squinted, and which didn’t let much light in until, that is, we started to play and Melie burst into life with me. I was her keyworker, one of the first people I had ever keyworked. I felt unknowing and amateur, but with Melie I knew that we worked together. We would often walk around the home, making mischief. She would hide behind curtains and pop out, a glint of knowing in her eyes followed by lots of deep and meaningful laughter. For want of a better word, I thought that I loved Melie as a friend, as someone I cared for, as a surrogate grandmother, who knows? But I looked forward to work because I looked forward to seeing Melie.

Looking back on the work I did with Melie reminds me now of a scene in May Sarton’s (1973) As We Are Now, a beautifully nuanced account of being abandoned in a care home, narrated by Caro Spencer, a 76-year-old former teacher:

> Sometimes Anna can sit down for a minute after my breakfast ... She is not a talker. I feel perfectly at peace when she is there and we do not need words. She seems to understand me in a way I have needed for years... it is being cared for as though I were worthy of care. It is being not humiliated but treasured. (p. 92)
Melie and I were perhaps more playful than Caro and Anna, but we were open to one another, quite possibly we had to be because Melie had lost all capacity to speak. She articulated sounds, walked, ate, she could even dress the bottom half of her body. But speech had gone. So we created a new language that moved around between us through bodily mirroring, eye contact and plain noticing. We noticed the other, each other, and did a dance in which both selves could take turns.

Melie could never say she wanted to go to the toilet and so she rocked, her torso reaching out into the room and her bottom half rubbing up against the cushioned sofas. Over time, I knew what this meant, and others did too. She could see when I got tired and sometimes her hand would reach out to my cheek, as if she knew that I had had a busy day.

Of course, this kind of gentleness (sometimes seen as sentimentality) doesn’t always sit well in what can be a brutally task-driven institutional environment where jobs have to be done, and timetables have to be adhered to. In fact, not all interactions with Melie were gentle. This kind of relating changed into something altogether more confrontational when it came to cleaning Melie’s teeth. The intrusion of an object into her mouth – the mouth that could no longer speak – infuriated her. She would bite down on the toothbrush, shake her head, check her rage out in the bedroom mirror, and sometimes scream ‘No’, the only word she had kept hold of. You learned to go slower at tooth-cleaning time. You learned to offer Melie the brush, letting her assess it. Sometimes you would take the brush yourself and play at brushing your own teeth. Sometimes this worked; sometimes it didn’t. And what you began to ask was, given Melie was in her late eighties, what shame was there in her failing to brush her teeth? There was more shame in her going to sleep unsettled with clean teeth whose shininess had been forced upon her.

This time with Melie taught me about relating outside the order and structure of language, and it conveyed something profoundly human. You could see her desire for continued connection, for play, for struggle, for agency, for dependency, interdependency and independence. When I became a mother, the spectre of Melie was around. This is not to say that she was a pre-verbal newborn baby, a toddler or a child, but it is to say that these very human needs, so visible in babyhood, manage to last with us, I think, to our dying days.

This thesis is an investigation into the experiences of seemingly voiceless people, who can be spoken for and about without reference to the complexity of their experience. My job here is of course about research, meaningful and robust methodology, finding some semblance of an answer to the questions that I started out with. But it is also about mapping, describing and analysing the relational field in dementia care, exploring what facilitates and prevents
connection. It is also about mothering, understood in its broadest sense, the kind of mothering that involves reflecting on raw, sometimes unprocessed experiences that belong to individuals and organisations, working out how they may link, and finally reframing them – with the help of psychoanalytic theory – so that they may make a little more sense. By telling the story of two residential care homes, through the observations of older people, Dorothy and Daphne, and through interviews with staff and other residents, I hope to be able to say something about working and living in a care home and about the importance of these experiences. I want to consider what both helps and hinders ‘going-on-being’ (Winnicott, 1960) and working in such environments. How do groups of humans continue to demonstrate concern for one another when some practices and policies seem designed to thwart this aim?

**The Socio-Political Background**

There are 800,000 people in the UK living with dementia. The King’s Fund (2008, cited on Alzheimer’s Society online, n.d) projects the financial cost of dementia to reach £34.8 billion per annum by 2026, a 135 per cent increase from 2007\(^2\). In April 2012 the World Health Organisation pushed for dementia to become a global world health priority. *The Guardian’s* Haroon Siddique (2016) published statistics showing that Alzheimer’s disease and other dementias have now replaced ischaemic heart disease as the leading cause of death in England and Wales for the first time.

In terms of policy, the 17 recommendations in *Living Well with Dementia: A National Dementia Strategy* (DoH, 2009), emphasise better care in care homes and improved staff training. The first *Prime Minister’s Challenge on Dementia* (DoH, 2012) claimed that ‘Health and Care’ would be one of its main areas for action. In April 2013, NICE launched a new set of quality standards on care, ‘Supporting People to Live Well with Dementia’ (NICE, 2013). The *Prime Minister’s Challenge on Dementia for 2020* (DoH, 2015) highlighted the importance of care home research. Developments such as these place the question of dementia care and the quality of the caring relationship high on the agenda of policy makers. Or at least this is how it seems.

In recent years, however, social care in England and Wales has been increasingly subject to cuts, austerity and neoliberal reform\(^3\). As the Alzheimer’s Society points out:

Dementia care and social care are, largely, the same thing. Where other conditions need medication or devices to alleviate symptoms, the symptoms of dementia affect people’s ability

---

2 The number of new cases are 40,000 fewer than previously predicted (Matthews, FE et al., 2016).
to do day to day things – washing, dressing, eating. With no cure on the horizon and few treatments, people with dementia are relying heavily on care to meet the basic needs caused by the symptoms of their disease. Social care is the only treatment they have for their disease. Further to this, people with dementia are the majority of people receiving that care – they make up over half of people receiving care from paid carers in their homes, and are nearly three quarters of people in care homes. (2017, n.p.)

Recent reports also demonstrate that the care sector is routinely undervalued. Quoted in The Guardian, John Kennedy claims:

that managers are finding the role almost untenable as the complexity of their job grows and they face an external regulatory system increasingly adversarial and critical…they feel vulnerable and alone. The role of registered manager is a challenging one. Even a small care home will have a turnover in the millions, a significant workforce and more rules and regulators than you’d care to count. Even so typically salary levels are only in the mid £30k range. No other sector bestows so much responsibility on its management cohort with so little recognition or reward. (Sodha, 2016, n.p.)

Managers are under ongoing strain and we know that there is endemic abuse of the minimum wage laws in the care sector:

Data from the Office for National Statistics showed that between April and June this year [2016], about 113,000 of the 769,000 workers who provided at-home care for vulnerable people or were employed in care homes were on contracts with no guaranteed hours. At approximately one in seven, that total represents a substantial and rapid increase on 2015, when one in 10 care workers were on zero-hours deals. (Osborne and Duncan, 2016, n.p.)

Lay (2017) reports that social care cuts were linked to 30,000 excess deaths in England and Wales in 2015, based on findings from research conducted by the University of Oxford in collaboration with London School of Hygiene and Tropical Medicine and Darwen Borough Council. Professor Martin McKee, from the London School of Hygiene and Tropical Medicine, stated:

The impact of cuts resulting from the imposition of austerity on the NHS has been profound. Expenditure has failed to keep pace with demand and the situation has been exacerbated by dramatic reductions in the welfare budget of £16.7 billion and in social care spending. With an aging population, the NHS is ever more dependent on a well-functioning social care system. The possibility that the cuts to health and social care are implicated in almost 30,000 excess deaths is one that needs further exploration. (University of Oxford, 2017, n.p.)

Politicians’ statements and media reporting often collude to suggest there is an ageing population at bursting point, generating huge costs to our economic systems. For instance, a leaked memo from then Pensions Minister, Baroness Altmann, which was reported in The Guardian, talked of the ‘looming crisis (of social care) which has been left far too long already’, and pointed out that the government has not done enough to avert the ‘potential social and economic distress’ (Boffey, 2016, n.p). Her memo suggested that older people start to set up care-ISAs for their impending social care costs, since local authorities had no money set aside for
the demographic changes. Similarly, in 2013, Jeremy Hunt advised families to take in their loved ones in later life (Butler, 2013, n.p.). However, Manthorpe and Illiffe (2016, p. 14) claim there is a ‘high level of societal anxiety about dementia… (which) stems from the myth that an ageing population causes the costs of health care to rise dramatically’.

Appleby, Chief Economist at The King’s Fund, points out that the projected costs of a growing ageing population has been exaggerated:

The ageing of the population is also a factor, although of much less importance than is generally supposed: increases in life expectancy tend simply to delay the time at which the health care costs associated with death are incurred rather than increasing these costs per se. This is an important point as it challenges the conventional thinking that spending on health care will rise inexorably as the population ages. In fact, the pressure to spend more will largely be driven by other factors. (2013, p. ix)

He claims that long-term economic projections are riddled with uncertainty. To date such increases relate mainly to investments in technical and medicinal innovations, not necessarily in direct care.

Apocalyptic visions of an ageing population at bursting point (eg, the paralysing image of bed-blocking), are presented in policy and in the national media. It is as if there has been a move to stir up fear, and possibly hatred, of ageing populations – symbolising in the unconscious mind a drain on resources⁴. The metaphors and stories associated with dementia are often accusatory, persecutory. These narratives merge together, blindsiding the public and perhaps preventing it recognising that austerity measures and the adoption of a managerialist approach to welfare, lead to failings in the social care sector.

Relatedly, there are ‘new consumer expectations about better managing long-term and immediate care needs’ (Manthorpe and Illiffe, 2016, p. 14). However, with rising expectations, resources for health and social care have been systematically cut.

The gap between the expectation and the reality of service provision arguably creates a sense of deprivation. A consumer narrative within policy has part-fuelled this widespread sense of inadequate service provision, which appears all the more inadequate when spending isn’t forthcoming. There are, simultaneously, real and entrenched inequalities. The crisis is felt by all those no longer able to access services but in a sense the crisis is also exaggerated. This exaggeration relates to the managerial restructuring of welfare systems (Froggett, 2012), in

which the consumer/service user is increasingly set up, intentionally or not, to demand more in
terms of targets, timescales and outcomes. On a psychic level, people start to feel deprived by
the parental figures of government, which may mean that splitting, rivalry, and abuse become
par for the course in the public rhetoric around ageing. All of this is the result of a long-term
strategy, embarked upon in the days of Thatcherism, to shift radically the terms of sociality in
which the ethic of care for the ‘stranger’ is stripped away (Hughes & Lewis, 1998; Lousada &

In the care field similar mechanisms might be at work. The care home, after all, is a society, on a
micro scale. We have heard of abuse in residential care homes. A series of high-profile cases
have drawn our attention to what goes on when there are systemic organisational failings, where
we might surmise marginalised staff members in turn brutalise marginalised residents – the
latter raging against the former for reminding them of their own fragility, powerlessness. To
name a few, we have Hillcroft Nursing Home in Lancashire where residents were used for staff
entertainment (BBC online, 2014); hidden cameras at the Old Deanery Essex where staffing levels
were ‘woefully inadequate’ (Dugan, 2014) and abuse ensued; Purbeck Care Home in Dorset
where cruelty and neglect were widespread (BBC online, 2015); Keldgate Manor Residential
Home where Freda Johnson, 85, suffered regularly at the hands of the staff; and BBC Panorama’s
(2016) account of a nursing home ran by the Morleigh Group where a resident was left for forty
minutes stuck to a bedpan, where morphine was used as a patient cosh.

What I hope to consider in the unfolding of this work is how intimate, meaningful relating
nonetheless remains a possibility in an overarching socio-political context which attempts,
purposefully or not, to destabilise, or denigrate, our connection with one another on a basic
human plane in favour of a politics of self, of individual success (Layton, 2014). When dementia
care policies weave together voices from activism, advocacy and psychology with those from the
markets, big business and advertising which voice is in the end the most powerful? What is the
small daily revolution that allows people to show concern and make contact in an economically
driven care marketplace?

We have a crisis in social care and health care, where the cutting of resources leads to
inadequate staffing. Paradoxically, the quality of the caring relationship and a responsive
‘workforce’ is still a government expectation. What quality means within such relationships is
rarely defined, and care workers are asked to do something increasingly difficult: to be
compassionate with little compassion afforded to them; to be compassionate without time or
space to reflect upon what this means, to process the difficulties raised by the work.
Manthorpe and Iliffe (2016) make the important suggestion that the government’s over-focus on medical care and scientific research needs refreshing, and an approach that is ‘relational rather than technical’ (p. 14) needs greater investment.

This Project

Thinking about the relational, which Manthorpe and Illiffe (2016) highlight as an important omission in *Living Well: A National Dementia Strategy*, is fundamental to this thesis. The complexities of the professional dementia care relationship are manifold. Often, there is a disconnect between the ways in which the carer and the person with dementia experience time and their immediate environment. A professional carer of someone with dementia relates daily to a person who is experiencing the gradual dispossession of mind (Dartington, 2010), yet the emotional labour of the caring work frequently goes unrecognised.

It is this question of the quality of the caring relationship in a residential care setting that is at the core of this research. The work began with the idea of maternal subjectivity, a sense that it might have some useful applications to the field of dementia care. Maternal subjectivity is defined in relation to an-other, the infant, and vice versa: the relational is arguably written into the experience of mothering practice. As Donald Winnicott noted:

> There is no such thing as a baby... If you set out to describe a baby, you will find you are describing a baby and someone. A baby cannot exist alone, but is essentially part of a relationship. (Winnicot [1946] 2017, p. 98)

It was my experience as a mother, which reawakened my thinking about dementia care. When I held my second newborn and he cried, sometimes raging for milk, I began to think about pre- and then post-verbal experiences. The feeling of dread when we imagine that there is no one there to gather us up; of fragmenting into different pieces of existence with no recourse to being put back together; hungry in the belly and hungry in the heart. I started reflecting about myself, as a mother and earlier as a carer. What did this intense encounter with dependency stir up in me? I wondered what the post-verbal adult, unbecoming in his dementia, stirred up in the worker, expected to comfort and contain?

However, a person with dementia is in no way a newborn. Firstly, someone with dementia is moving in the opposite direction of becoming; people with dementia have had lives and experiences newborns have not yet encountered. Memory traces, from womb to old age, make us who we are and so, even when factual detail fails us, we continue to carry within some memory of being elsewhere. A person with dementia has known herself perhaps as a boss, an employee, mother, father, brother, sister, schoolchild; as stubborn, intelligent, joyful,
antagonistic, warm. These knowledges of self don’t shed themselves completely as dementia takes hold; a person with dementia remains, often holding on tightly and simultaneously slipping away. She remains in the sense that she meets with the world in familiar ways; tries to preserve whatever agency she has had as much as she can; wishes to be treated with a degree of respect as someone who has participated in the lives of others. Within her, she also carries the newborn, as we all do, and possibly the fears and desires of dependency and connection. What then goes on between the recipient and provider of care? This is what I wished to investigate. I wanted to understand if organisations have a way of supporting both the desires and fears of dependency/inter-dependency that seem to me to be written into humanity, our need to be with and to be supported by others while also wishing sometimes to be alone. I also wanted to find out how organisations deal with the experience of being cared for: what it is like to be looked after by another person and therefore vulnerable to him or her, however careful he or she is. How, I wondered, is expression given to this experience in a professional dementia care context?

My interest was initially in the subjectivity of the professional carer, potentially constituted intersubjectively between both parties. However, as the work progressed, the subjectivity of people with dementia and the life of organisations took on greater prominence and meaning. In fact, one without the other would have undermined the psychosocial, relational focus of the work. I also needed to think about these subjectivities and intersubjectivities in light of the way they are constituted in policy discourse. As Doutchit (2006, cited in Innes, 2009) highlights, in order to get to the ‘micro-level of care experiences, whether they be conceptualized as quality of life or quality of care issues, there is a need to engage with macro-level issues which shape the discourse of dementia care’ (p.44).

The project is limited since I visited and observed only two care homes, and interviewed only a selection of care workers and people with dementia. Generalisations that fix and produce truths are not possible with this small sample. The studies I conducted have nonetheless provided me with rich, in-depth material which offers insights into relating in care homes through actual interactions between people at specific times in specific places.

**Research question**

In essence, the research became an exploration of:

(i) The internal and relational experience of the carer and person with dementia, understood mainly through the lens of Kleinian and post-Kleinian object relations theory. Particular issues of

---

5 Also drawing on organisational theory and relational psychoanalysis, as well as the Lacanian psychoanalyst Bracha Ettinger (2006).
focus were whether or not the relationship between carer and cared-for mirrors qualities of the mother and child relationship.

(ii). The way (i) is informed by and itself informs and reproduces the organisational culture of the institution, focusing particularly on the way that the care organisation-as-a-whole thinks about the caring work. The research explores how paradoxes and splits form in the organisational mind, through a close reading of the data. The study also considers whether or not care practice has been distorted by the policy discourses that surround dementia, and whether something quite different is taking place between the people who live and work in the care home context.

With that in mind, my specific research questions were:

- How is dementia care experienced, consciously and unconsciously, by carers and those cared for?
- To what extent and in what ways is this experience relational?
- How does it relate to organisational culture and policy?
- To what extent does psychoanalytic theory illuminate the experience?
- To what extent does dementia care policy address this experience and what are the policy implications of taking it into account?

**Outline of Chapters**

In Chapter 1, Literature Review, I will begin with a theoretical account of the mother-infant dyad and how the figure of the mother and infant are constituted in psychoanalytical literature. To my mind, the representation of mothers to be found in this literature is not idealised but is, instead, textured, multi-layered and attuned to the emotional realities involved in the work of mothering.

I will focus on the mechanisms that underpin the affective flows that take place between both parties and demonstrate, where possible, how psychoanalytic ideas can provide further insights into ideas about relationality in dementia care discourse.

I have adopted a theoretically pluralistic approach to understanding this study, drawing on Melanie Klein (1930; 1937; 1952a; 1952b; 1952c), Donald Winnicott (1946; 1953; 1958; 1960; 1962; 1971), who developed clinical paradigms that contrasted with Klein’s, and post-Kleinian, Wilfred Bion (1959; 1961; 1962a; 1962b). My thinking is also informed by the relational psychoanalyst, Jessica Benjamin’s (2006; 2007; 2010) work on mutual recognition and Lacanian psychoanalyst Bracha Ettinger’s (2006; 2009; 2010) radical exploration of subjectivity. Her structure of the developing mind takes in networks of multiple subjectivities and traces of human
relationships, even in utero, which offer an exciting way into making sense of the patchwork of
dead and existing identities found in dementia care.

Chapter 1 is a review of the different and differing psychoanalytic theories I have drawn on. I will
concentrate on some of the processes involved in mother-infant relating that seem pertinent to
this piece of work, in particular, projection and introjection, containment, holding and play. The
second part of the chapter focuses on psycho-spatial concepts, such as the organisation-in-the-
mind (Armstrong, 2005), that may be useful in thinking about the dynamics and tensions in
organisational life and the capacity to engage with the work.

In Chapter 2 I give a detailed description of the research methods that I employed. The chapter
will consider the theoretical and epistemological assumptions of my research methods, as well as
demonstrating how they were used in this study. It will give particular consideration to issues of
psychoanalytic observation technique, ethnographic approaches, inductive research methods,
reflexivity and ethics, given the sensitive nature of the study.

Once the methodological frame is in place, I will present the findings from each care home site in
Chapters 3a and 3b. These chapters will introduce both homes, Winston Grove and Whittinghall,
and also some of the main participants (noted in the List of Participants at the beginning of the
thesis). These chapters will describe the three major themes of time, mother/s and death that
emerged from the data, including passages from the observations of everyday life and interview
material with participants. Although these are findings chapters, I hope also to convey the
emotional texture of life in the homes.

The three main themes are then analysed in detail in Chapter 4. Here my main focus is to explore
the main themes, through the lens of psychoanalytical theory, as described in Chapter 1.

Though the themes cannot represent the full richness of each organisation, they do provide a
means for thinking about the organisational culture of each site as well as some of the minutiae
involved in everyday relating. Chapters 3a, 3b and 4 draw on Armstrong’s (2005a) formulation of
the ‘organisation-in-the-mind’ which might provide an entry point to the ‘emotional experience
and meaning of the organisation’ (Lewis, 2009, p. 4) and a greater understanding of the care
home as a:

process of human relatedness in a context of specific roles, tasks, social and professional
identities and institutional norms of linkage and division among different units and
departments. (Lewis, 2009, p. 4)
Having heard from the residents and care staff at both homes, in the penultimate chapter, I will attempt to relate their understandings, and my own, to national policy. The chapter considers *Living Well: A National Dementia Strategy* (2009) in detail, since this is the policy that has had the most significant impact on day-to-day dementia care in recent years. The strategy will be situated alongside other pieces of policy, but particularly ‘Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care’ (2007). There will be some discussion of the neoliberal policy agenda, while also holding in mind that a babel of voices can be heard in the policy domain.

The overall aim of Chapter 5 is to pull out the central organising ideas of *Living Well: A National Dementia Strategy* to consider them in light of how they might animate the lived experience of dementia care and vice versa. The experience-near fieldwork I have gathered will be used as a tool with which to interrogate or reflect upon policy discourse and specifically how the relational field is conceptualised therein. Pertinent for this chapter is the question: ‘Would policy processes incorporating fuller, publicly observable, emotional engagement with the issues at stake result in more effective decisions and action?’ (Cooper and Lousada, 2005, p. 4).

Finally the thesis will draw to a conclusion, fleshing out further some of the main themes developed in the course of the research and situating them particularly in a staff development context. There will be consideration given to what can be borne in policy and what is also absent, perhaps too intolerable to give space to.
Chapter 1: Literature Review

Care of the very elderly, those so often lacking the capacity to speak, yet so intensely riven by extreme emotional states, requires a painful reversal of the original pattern of container/contained (very often the young now struggling to offer states of reverie to the old).


Introduction

The theory which frames this study is psychoanalytical, drawing on various traditions (object relations, the Independent School and relational psychoanalysis)\(^6\). The theoretical frame is a pluralistic one and, though the history of psychoanalysis has, at times, been riddled with ‘unhelpful splitting and polarised’ rivalries (Keane, 2012), it seemed to me that different aspects of psychoanalytic theory seemed to apply to the fieldwork data, to the experience of being in the care homes as cared-for, or as worker, and to the emotional atmosphere of care settings.

Borden (1998), struck by the way in which Winnicott guarded against the compulsion to make things known, both therapeutically and academically, writes:

> Winnicott, ever concerned about the dangers of omniscience, works to undermine ‘the impression that there is a jigsaw of which all the pieces exist’ ... More than any other figure in the Middle Group, Winnicott comes to emphasize the crucial functions of missing pieces, gaps, the "spaces between," and the areas of unknowing in our use of theory in practice. (p. 37)

Borden suggests that others, such as Bolaas, have also attempted to work in a way supportive of theoretical pluralism:

> Each Freudian should also be a potential Kohutian, Kleinian, Winnicottian, Lacanian, and Bionian,’ as each of these schools reflects a certain limited perspective. (Bolaas, 1989, p. 99, cited in Borden, p. 33).

This idea of drawing from multiple theoretical frames is inspiring to me. I also see the psychosocial milieu as one which conjures up notions of multiples in the sense that it is not a one-theory approach, not least because psychosocial endeavours try to create a bridge between two worlds – the psychic and social – which have been presented and treated by the division in

---

6 I am using object relations theory in relation predominantly to Melanie Klein’s work. Although she noted the developmental significance of the primary relationship, her work arguably over-emphasises internal mental states and perhaps the noisier bodily drives, such as hunger. The Independent School, also known as the Middle Group (used interchangeably here), is considered post-Kleinian object relations in its focus. This group highlighted interpersonal context, often observing real relationships, as seen in the work of Winnicott and Fairbairn, and possibly the quieter drives for soothing, holding, very much dependent on object-relating.
academic disciplines as if they are fundamentally different. Sociology and psychology attempt to capture aspects of human experience, and then proceed as if distinct. A psychosocial approach begins with the premise that the psychic and social are not distinct but are rather ways of seeing and understanding experience, which can be in conversation together.

Furthermore, the experience of dementia is full of moments of not-knowing. Using a range of theories is a reflection of my own not-knowing and the not-knowing involved in the work. Approaching the data in this way presents a counterpoint to the push – in current policy and practice – to get it right and to make certain the uncertain.

A pluralistic approach resonates with the work of David Armstrong (2005), whose concept of the organisation-in-the-mind has been invaluable in this study. In Organisation-in-the-Mind (Armstrong, 2005), it is clear that his model of understanding organisational cultures draws from the theories of Klein, Bion, from clinical psychoanalysis, as well as organisational consultancy. Some suggest (Hutton, Bazalgette & Reed, 1997) that the organisation-in-the-mind is a Winnicottian transitional object, which offers possibilities of understanding a client’s relatedness to an organisation through his me experiences in role and the not-me experiences of the consultant attending to the material.

Since I drew on Armstrong’s concept to make sense of the emotional relatedness of organisations, it stands to reason that I was automatically, yet indirectly, in touch with myriad disparate theories embedded in his model. Since this study involves the psychic life of the individual and the organisation I have made use of theories which are one-body, focusing on the individual and an emphasis on interior space, and those which deal with the intersubjective realm. The following quote from Armstrong (2005) relates to both dimensions.

Every organisation is an emotional place. It is an emotional place because it is a human invention, serving human purposes and dependent on human beings to function. And human beings are emotional animals: subject to anger, fear, surprise and disgust, happiness or joy, ease and dis-ease.

By the same token, organisations are interpersonal places and so necessarily arouse those more complex emotional constellations that shadow all interpersonal relations: love and hate, envy and gratitude, shame and guilt, contempt and pride – the several notes of Joyce’s ‘chambermade [sic] music’–a wonderfully apt phrase for the emotional choreography each of us weaves, consciously or unconsciously from our encounter with another, or with others. (p. 91)

Of course, dementia care takes place in an intersubjective space and in this study (see particularly Chapters 3a and 3b) it became clear that the nature of the carer (the external object) had

---

7 ‘Social’ being the domain of sociology and ‘psychic’ as the domain of psychology.
implications for the psychic sustenance of the person with dementia. However, I also had a sense that instinctual drives, particularly anxieties around living and dying, were often expelled into the care home atmosphere, and were – in a classically Freudian way – possibly related to the biological/neurological changes that people with dementia were experiencing.

Through this chapter, I make a case for choosing to apply certain theories to aspects of the fieldwork more so than others. I will explain why I used psychoanalytical ideas rather than general dementia care theories, demonstrating where the former can provide a richer account of human behaviours in the context of dementia care.

The reader will nonetheless see that much of the dementia care literature has offered an intuitive understanding of the person with dementia, from which some very important innovations have emerged.

To begin, I will lay out some ideas on relationality in dementia care discourse before expanding on them with the help of Ettinger’s (2006, 2009, 2010) work on the matrixial; Winnicott’s (1960, 1971) notion of holding and play; Benjamin’s (2006, 2007, 2010) formulation of recognition; splitting and mourning in the work of Klein (1937, 1946, 1952a, 1952b); and finally Bion’s (1959, 1962a, 1962b) concept of containment. One of the reasons why I explored a range of theories was to see if and how they applied to the affective realities of dementia, particularly given that there are at least three distinct phases from early and middle to late stage dementia (verbal through to non-verbal).

Psychoanalytic thinking concerns psychic development of the subject, from birth onwards. The experience of dementia is perhaps a reversal of the developmental trajectory of the infant, from dependence through to relative independence: I wanted to see how psychoanalytical thinking might help us to understand this reversal. Secondarily, the theories laid out here have helped me to explore the three major themes which emerged from the fieldwork, namely time, mother/s and death (Chapters 3a, 3b and 4).

This study is also concerned with how psychoanalytic ideas might usefully be applied to understanding the organisation, not as a fixed structure but as a dynamic process of interrelating. Armstrong’s (2005a) vivid concept of the organisation-in-the-mind has been helpful as an object of exploration. Finally I will say something about Britton’s (1989) triangular or third space while recognising simultaneously that other spatial terms are important, as per Benjamin’s (2018) thirdness and Winnicott’s (1971) potential space.
Relationality in dementia care

General themes

Though the literature on relationality in dementia care is relatively sparse, the following concepts appear, all of which provide some understanding of the (inter-)subjective experience: personhood, recognition, mirroring, embodiment, ethics and the senses. Those writing on relationality come from a variety of disciplines, from social psychology and psycho-gerontology to nursing and the behavioural sciences. Some, like Pia Kontos (2005, 2014, 2017), draw on philosophy, sociology and the arts. Paul Terry (2003, 2010), a clinical psychologist and psychotherapist, and Tim Dartington (2010), a former researcher from the Tavistock Institute of Human Relations, draw predominantly from psychodynamic theory and the lived experience. Others (Adams, 2005; Ryan et al, 2008; Nolan et al, 2004, Ellis & Astell, 2010) conduct practice-based research to formulate frameworks to help those working as nurses or carers. Much of this work has led to an exchange of important ideas, as well as some shifts in approaches to frontline care work and in national policy.

Many improvements in the field can be attributed to the work of psycho-gerontologist Tom Kitwood (1997). His work had a long-term, positive impact on dementia care practice, his focus was on the subjective experience of someone with dementia. Kitwood pioneered a person-centred approach in dementia care. One of his (1997) achievements was the development of Dementia Care Mapping, a practical tool used to isolate and identify harmful behaviours found in staff teams working with people with dementia.

The term ‘malignant social psychology’ (Kitwood, 1997, p. 48-49) was coined by Kitwood to describe the collective impact of a pervasive set of behaviours among staff teams in dementia care institutions that damaged the care recipient’s sense of self, personhood. These included objectification, infantilisation, invalidation and disempowerment (Kitwood, 1997, p. 47). Although Kitwood’s work has been foundational to improvements in dementia care, he does not explain how malignant social psychology might emerge. In line with Menzies-Lyth’s (1959) contributions, I would argue that psychoanalytic theory provides such an explanation, as well as further understanding about the intersubjective processes which lead to poor care. I would like to suggest that in deploying psychoanalytic theory, this study might help to fill the gap and to explain, at least in part, how such a malignancy might emerge.

In terms of ethics, Millet (2011) applied embodiment discourses and bio-phenomenological ideas to the concept of self and dementia. He argues that a person with dementia, although struggling cognitively, remains a being embedded in the social world, able to affect those around him.
Quoting Jonas (1984) Millet (2011) says: ‘The newborn is the perfect paradigm, literally the prototype, of an object of responsibility’ (p. 518), her mere existence places a demand on us. For Millet someone with dementia, like the newborn, is particularly vulnerable to harm from the world and there is an ethical imperative to care for and to relate to her.

At this stage, I wish to consider babies in psychoanalytic literature. In the literature there are different types of babies, though always assumed to be an object of responsibility. What differs among theorists is whether the baby is fundamentally pleasure-seeking (pain-ridding) or object-seeking from birth. From Keane’s (2012) account of different psychoanalytic traditions, we learn that the Kleinian baby is generally considered insatiable, riven with destructive impulses. For Klein, these destructive, or envious, impulses are rooted in the death drive, considered innate to human experience. The energy of the death drive needs to be bound with the forces of the life drive in order to mitigate internal conflict and tension. It is up to the mother to rid the baby of these kinds of frightening bodily discomforts, returning through her milk the experience of pleasure. Winnicott’s baby is also hungry, but his primary motivation is to form primary affectional bonds. A Winnicottian baby also displays aggression but this stems from frustration, when response from the primary carer is not forthcoming. For him, early object relations can produce gratifications leading to an internal state of tranquillity. This is not just a modification of painful states.

For clarity, I want to highlight a major difference between Freudian and Kleinian schools of thought and later Independent traditions. As Keane (2012) points out, there was a paradigmatic shift from Freud’s biologically determined theories based on drives and their transformations, over development, to an increasing emphasis on the structural changes in the personality which resulted from internalised object relations that took place externally. Klein fell somewhere between the two. She didn’t relinquish the fundamental drives of life and death, yet acknowledged that object relations are there from birth. Apart from the drive/object emphasis, a further distinction between Kleinian and Winnicottian theory relates to the assumption about the degree to which there is an ego that is to some extent integrated. In line with Winnicott’s interpersonal emphasis, Winnicott implies that ego integration is a developmental achievement, supported by holding, maternal adaptation and so forth. Klein says less on this subject, but proceeds as if there is an infant that has some level of integration, an ego of which often finds itself split.

The point of convergence, however – despite the difference in emphasis between ego integration or not, drives versus object-relating; or mother as shadowy external figure, simply modifying intolerable experiences in the infant, or mother as an object of attachment—is that the mother figure is nonetheless assumed to be responsible for the infant and for the development of his sense
of self, his ego strength. The mother-infant relationship is fundamentally asymmetrical, which is also generally true of the relationship between carer and cared-for.

Benjamin’s (2009; 2018) baby is also part of an asymmetrical relationship. However, this baby is beginning the process of weaning, an older baby. He has an increased sense of agency and independence. Benjamin’s theory of mutual recognition and thirdness revolves around the increasing separation of mother and baby. Finally, there is Ettinger’s (2006; 2009; 2010) foetus. Unlike other theorists, Ettinger highlights womb existence. Ettinger’s foetus is always-already an agential subject. This seems vital for dementia care because Ettinger assumes that all human beings, from conception to death, are both agential and social, collaborative.

Resonant of Ettinger, Millet (2011), indebted to Levinas, claims that there is an a priori ethical responsibility towards others which hinges on the fact that human subjective life is socially embedded from birth. Millet counters Davis’s (2004, in Millet, 2011) claim that dementia leads to ‘the very splintering of the sedimented layers of Being’ in which the ‘life-world dissolves into background meaninglessness’ (p. 518). For Millet, people with dementia need not experience a social death. When I considered the fieldwork data, the theme of death (including social death) appeared as a strong organising theme. Psychoanalytical theory – particularly the work of Bion and Winnicott – help us to understand the interactional processes which might lead to one party experiencing a social death. Here, Bion’s (1962b) notion of ‘nameless dread’ and Winnicott’s (1960) ‘going-on-being’ seem particularly evocative. I wish to make it clear, though, that these forms of psychic dying are related to two different sorts of caring (maternal) failures. For Bion (1962b) the experience of nameless dread comes about in relation to the mother’s failure to make meaning out of an infant’s projections of existential fear; for Winnicott (1960), the interruption of being takes place in the context of a mother whose holding, both in mind and in arms, function is shaky.

Returning to dementia care Ellis & Astell (2010) developed an intervention, Intense Interaction Therapy, in order to sustain someone’s personhood, to avoid a social death. This intervention involves interacting with people with dementia, often post-verbal. The therapy involves validating and mirroring the communications of the person with dementia. Ellis & Astell (2010) found that people with dementia had rich communicative repertoires that used sound and signal. This became richer when a carer reflected back the sounds, gestures, of the person with dementia. Although vital work, it does not detail the dynamic psychic processes encountered during such communications— communications that Klein (1946), Bion (1962b) and Winnicott (1960) so eloquently describe throughout their work.
The mechanisms through which people engage with and disengage from one another are barely sketched in much of the dementia care literature. Adams & Gardiner (2005) situate their work on dementia care triads alongside those who have critiqued Tom Kitwood’s (1997) person-centred care for failing to ‘fully capture the interdependencies and reciprocities that underpin caring relationships’ (Adams & Gardiner, 2005, p. 186, citing Nolan et al, 2002, p. 203). They see their work as offering a fuller picture of care exchanges and aim to minimise the polarised and polarising experiences of informal carers, people with dementia and professionals by paying closer attention to subjective experience. However, like many others adopting a relationship-centred approach (Nolan et al, 2004), the recommendations that stem from the research are often abstract.

Nolan et al. (2004) argue that ‘person-centred care, as defined in the National Service Framework, is not the panacea that it is held up to be’ (p. 46). They make a convincing case for ‘valuing interdependence’ (p. 47). Ryan et al (2008) point out that relationships are fundamental to good care, suggesting that six particular senses underpin good relationships for people with dementia and staff. A sense of security, sense of continuity, sense of belonging, sense of purpose, sense of achievement and sense of significance (p. 80) are listed. These are important aims, yet I am struck by two things: the research has omitted to consider how complicated processes of relatedness can be; and the six senses seem to be conceptualised as static once achieved, as if states of mind are never in flux.

Dartington’s (2010) exploration of Alzheimer’s disease is based on his wife Anna’s early (52 years old) onset experience of dementia. He offers an insight into dementia that is personal, political and psychoanalytical. He touches on the theme of recognition, writing: ‘It is our sense of our own self that is affronted. And we act as if the other has lost his identity, is not the person he was – a perception that is as true (or false) about ourselves as it is of him’ (p. 151). Dartington rages against a journalist’s lack of compassion when the writer claims that people with dementia are stripped of their ‘memory, their personality and eventually their humanity’ (p. 193). He is reminded, in the bleakest of times, of his wife’s humanity when she laughs at the Queen’s broadcast on Christmas Day. “What, he asks, are the ‘clinical signs of loss of humanity?’” (p. 193).

The way in which we construct ourselves in relation to others is as much a concern for dementia care as it is in infant care. Although someone with dementia might appear to be slipping away, advocates of good practice in dementia care suggest that the person continues to exist but in changing forms. Frazer, Odeboyde and Cleary’s (2012) discussion of women with dementia who live alone highlights an interesting phenomenon. They claimed that the women in their study, at least in the earlier stages, started asserting their identity as a past-life, at times forgetting themselves in the
present. Frazer et al. (2012) argue that now signifies incompetence and losses beyond comprehension. A return to earlier stages of personal history represents earlier competencies, a time which feels more recognisable perhaps. Recognising someone with dementia involves recognition of him in the present moment, of what is being lost and of the bewilderment that dementia entails, as well as the earlier selves that might come to inhabit him. In this context, Winnicott’s (1971) theories of play might be helpful, particularly in facilitating the possibility for someone with dementia to re-experience himself, or to experience himself, unjudged, anew.

Tim Dartington suggests that someone with dementia might use forgetfulness defensively, in order to split off depressing realities of change. He references music therapist Davenhill (2007, cited in Dartington, 2010, p. 151), who talks about the ego emptying itself out, as a way of understanding the emotional and physical deterioration in dementia. This psychoanalytic lens, based on Kleinian ideas, provides us with a way of thinking about how the person with dementia no longer seems the person we once knew. Dartington argues that without recognising these processes, it is possible that a mutually defensive interactive style, an avoidance of each other’s pain, begins between carer and cared-for whereby neither is recognisable to the other.

Kitwood undoubtedly felt it was imperative to reclaim personhood for someone with dementia, whereas others have wanted to acknowledge explicitly the importance of relationships in effective care. I hope that a psychoanalytic reading will be able to provide a further dimension to understanding the care relationship, the shifting subjectivities, the development and underdevelopment of mind, which Dartington (2010) and Terry (2003, 2010) point towards.

In her chapter, ‘My Unfaithful Brain,’ Anna Dartington writes about her experience with a plethora of different carers. With one carer, she might have an experience of her ‘choices becoming less’ her own (Dartington, 2010, p. 158), but with another she will have negotiated the world on her ‘own terms’ (p. 158), and found in a carer a new ‘mother’ (p. 158) able to inspire in her a more bearable mode of being.

It is interesting that Dartington speaks of carers as mothers because psychoanalytic theory assumes that the mother-infant dyad – notably from Klein onwards, is the foundation stone for all future relationships. What psychoanalysis might offer, which other theorists working on relationality in dementia care only hint at, is an understanding of the processes and mechanisms involved in such intimate relating. Psychoanalytic ideas help to disentangle what we imagine about other people

8 Freud’s tendency was to avoid situating the regulation of inner tension in an interpersonal context (ie, with mother/or father). Secondarily, fathers, grandparents, professional caregivers can also take on the role of primary caregiver in an infant’s life.
(how we construct them in our minds) from what might belong to us; how we transform others as much as they transform us. As Redman’s (2005) examination of transference and countertransference demonstrates, many psychoanalytic concepts also arguably provide ‘an inherently relational understanding of the unconscious dimensions of affective experience’ (p. 52).

**Mother-infant relationships**

*Ettinger: the matrixial*

I will start with Ettinger (2006), a Lacanian analyst whose work is at the intersection of clinical, maternal and artistic experience. What is striking about Ettinger’s work is its focuses on the growing foetus and woman growing into mother. It teeters on the philosophical in the sense that Ettinger makes the claim that, at base, a reliance on another is part of the originary make-up of human beings. Ettinger captures a primordial experience, less reliant on the notion of mental development than the other psychoanalytical thinkers I draw from. Her work resonates with aspects of dementia care, particularly because this can be a post-verbal time, where communications are embodied, and also a time of profound dependence.

Ettinger’s background is Lacanian, yet her interest lies in the pre-Imaginary and pre-Symbolic experience, the pre- or trans-verbal of the infant subject. For Lacan, language determined the order of the subject, enveloping him/her in a series of symbolic associations and signifiers. Human subjects ‘model their very being on the signifying chain that runs through them’ (Lacan, 1956, p. 21). Relating, at a conscious level, is made available through language, yet language also creates a distance between people. The process of intersubjectivity – and subjectivity itself – is an alienating one in which everyone is bound by the order of the signifier and signified.

Ettinger, though, is concerned with an experience that precedes language, which does not alienate. For her, there is an inarticulable residue of human experience which grounds us as subjects. This experience is always related to the site of the mother, a wombspace which leaves unconscious pre-verbal memory traces—an asymmetrical residing-in another, (m)other. The notion of asymmetry is also relevant for dementia care, since relating at this stage of life might stir up memories of asymmetries that characterised our earliest experiences, good and bad. For Ettinger, the foetus, relying on the ebb and flow of nourishment, via the umbilical cord, is a symbol of our originary experience of dependence, and of care. The baby is not without agency, however, as any mother would testify when she sees the outline of legs protrude from her extending stomach with each kick. Written into human experience is the sharing of bodies, psychic spaces, a pre-verbal co-
existence between two subjectivities-in-becoming who call the other into being (Ettinger, 2009, p.13).

Mother and foetus relate to one another in a sub-symbolic co-emerging, which Ettinger describes as trans-subjectivity (Ettinger, 2006, p219). The mother, in connection with the growing infant, distances herself from assumed earlier senses of self. Changes taking place in the growing foetus have an effect on the bodily and emotional experience of the mother.

Ettinger describes momentary encounters between two beings-in-becoming who experience in one another, at the deepest unconscious level, a simultaneous difference and sameness in a shared space. We might be reminded of Winnicott’s (1971) concepts of me and not-me. In Ettinger this holding-in-tension of neither subject nor object is experienced in the womb. This is interesting because this capacity to be neither fully ‘I’ nor ‘you’ has resonances with Winnicott’s sense of potentiality. In other words, perhaps our truest self involves an openness to experience, one which doesn’t foreclose on thinking by categorising being and identity into either me or not-me, a state of being that is not entrapped ‘behind’ hard (defensive) boundaries. There is an openness in this, which at the best of times might be seen in professional care when moments of co-affecting take place.

As Hollway (2011) highlights, the founding image of a life growing within a life-in-change is an experience that pushes at the ‘boundaries of available language’ (p. 24). Ettinger develops a new vocabulary in which concepts belong to a careful balancing of difference and sameness, which she demonstrates in her use of hyphenation (for example, ‘differentiating-in-jointness’; ‘encounter-eventing’). This hyphenation reflects her belief that the human subject is simultaneously touched by others and yet separate. Hers is an ontological language that resists splitting and makes space for collaborative contacts. Her subject is not alienated, tentatively moving towards and away from objects; rather her subject is implicitly capable of existing alongside other subjects and objects simultaneously.

This has resonance with Kristeva (1985), when she points to a form of maternal love, which gives the ‘speaking subject… refuge when his symbolic carapace shatters to reveal that jagged crest where biology transposes speech: moments of illness, of sexual intellectual passion, even death’ (p. 152). Kristeva reminds us that language acts for the speaking subject as a protective shell, an armour, out of which we construct notions of ourselves; that via language we engage with others as subjects who are never fully articulated. Kristeva speaks of the unconscious language of biology – an existential trace that rests in the body’s earliest experiences – which perhaps links to moments of the newborn’s handling. It is the maternal that Kristeva summons up, comforting in times of
discomfort, sexual union and even death. This takes us to the bewildering experience of dementia, where the symbolic often fails and when people are in need of solace, of a presence, sometimes outside language.

The feminine-matrixial resists both the narcissistic self (I/self), constituted through the language of self and object, and the forces of endless fragmentation experienced in a fused oceanic state (Ettinger, 2010, p. 2).

It is worth noting that Ettinger seems to be interested in borderspaces. Professional care work is very hard, and from my observations it also seemed very precarious, both psychically and in political reality. It was tempting for care workers to make their world feel more certain by polarising experiences and by applying neat categories and divisions to things and people. Ettinger might point to the usefulness of being able to encounter in one’s experience chaos and order simultaneously (the order of a bounded identity; the chaos of feeling what others feel).

In good circumstances the maternal subject in Ettinger neither returns to a fictitious autonomous pre-child self (Baraitser, 2009), nor does she lose herself completely to the infant. Rather she allows herself to self-fragilise (Ettinger, 2009). It is this idea of the self-fragilising mother which may act as a useful paradigm for all the caring professions: a process of opening up to the disturbances, joys, pains of the ‘client’ without entirely fragmenting in relation to another’s emotional realities. A professional able to self-fragilise is thus one who would not resort to rigid defensive modes (Menzies-Lyth, 1959) of functioning, neither would she be incapacitated by empathy. Encountering another person in this way in daily care work would most likely require a good deal of organisational support.

From this vantage point, Pollock (2008, p. 10, cited in Hollway, 2011) argues that the matrixial lays foundations ‘for our capacities for ethics, hospitality and compassion for the other in their otherness’ (p. 13) while also having a level of thoughtful compassion for ourselves.

Winnicott: holding and play

Although Ettinger’s conception of the matrixial is grounded in a time in utero, her work has some links to Winnicott. Ettinger’s matrixial thinking is complementary to Winnicott’s concept of primary maternal preoccupation (Winnicott, 1958). He describes an infantile experience before a singular stratum of individuality is acquired and when the infant needs an extension of the ‘compassionate hospitality of the womb’ (Hollway, 2011, p. 34).
Winnicott claimed that in the weeks after the birth, many mothers experience an unsettling mental state. The mother is closely attuned to the needs of her infant, by creating a near-perfect fit between demand and response. In this short time her infant’s demands take up the central place in her body and mind. Again the notion of asymmetry in the relational encounter is in play. If we are to apply this to Ellis & Astell’s (2010) research, mentioned earlier, we might expect the professional carer to make the effort to contact the person with dementia so that communication between the pair becomes possible. The carer brings the person with dementia to life, like Winnicott’s (1958) adapting good enough mother.

Winnicott (1962) used the word ‘matrix’ – the Latin word for womb – in his paper, ‘On the Capacity to be Alone.’ Ogden (1990) teases out the meaning of the term matrix in Winnicott’s paper, as the ‘silently active containing space in which psychological and bodily experience occur’ (p.180). Ogden is describing what Winnicott termed holding. For Winnicott, the infant’s psychological matrix is the maternal holding environment, and he views the infant as being highly sensitive to any changes in this environment. This holding environment provides a near perfect adaptation to the infant’s changing emotional and physical needs, but also to maturational ones. Winnicott’s matrix, resonant of Ettinger’s matrixial, has a womblike quality but is now external to the mother’s body. It is the responsive adaptation to the infant that provides this sense of continued womb space, of holding. Arguably, holding facilitates the experience of going-on-being, which in turn relates to a developing sense of self embodied in space and time. Holding is an important function in good dementia care, where a person may be calling out for continued being in the context of a shaky temporal and spatial frame.

Holding involves a process of highly responsive micro-interactions to ensure that the baby feels in control, omnipotent. He is fed when hungry, touched when isolated, warmed when cold – all of these sensitive moments prevent the baby from falling apart in panic, as if he is not surviving. This survival depends in part on his being in the mind of someone else. This is the complex work of being held in mind (thought of) and handled (practices of touch, feeding) that go into forming the earliest structures of mind: ‘yes, I exist’. Mother does this until the infant has developed his own internal psychological matrix, after which point the mother begins the process of weaning the infant from this consistent good-enough maternal provision of holding, handling and object-presenting. In dementia care, we are not talking about a movement towards integration, but rather the creation of momentary experiences of reintegration through holding. It is possible that Ellis & Astell’s (2010) Intense Interaction Therapy might provide the kind of illusion of oneness that helps someone with dementia to continue to exist in the social world.
Winnicott’s (1971) ideas on play are also helpful for the field of dementia care. Play is something that takes place between people, particularly small children and parents. Play creates a space (between the borders of individuals) in which nuance can be tolerated, where the conscious and unconscious sit hand in hand. Winnicott referred to ‘potential space’. This is an intermediate area of experiencing that lies between the inner world and external reality (Winnicott, 1971, p. 55). In the early stages of development the good enough mother helps to create in conjunction with the infant a potential space in which transitional objects (Winnicott, 1953) are used to quell the anxiety of disillusionment; the realisation that mother and child are separate subjects and not fused. Transitional phenomena, dolls and soft toys, can be brought to life by the child, acting and talking with them, investing them with certain qualities of me and not-me. This potential space is filled with the child’s imagination, stemming from his internal experiences. Play is not judged in a good-enough playful context, which helps the child to be in touch with parts of himself that are spontaneous, creative and, for Winnicott, authentic.

In play, the child achieves a sense of self and autonomy, watching her internal world outside in potential space, while also negating the ‘the idea of a space of separation’ (Winnicott 1971, p. 110) from her mother. There is a greater sense of self yet a continued connection with mother. Play provides an experience of passage, a bridge, between separation and unity, a jointness-in-differentiation that is crucial to making meaning as an individual, who exists alongside others. We shall see in Chapters 3a, 4 and 5 that play is vitally important in a dementia care context.

**Benjamin: recognition**

If we are to think of different psychoanalytic theories as dealing with different points on the developmental trajectory, we might think of Winnicott dealing with birth to weaning. Jessica Benjamin’s (2006; 2009; 2018) theory of mutual recognition, facilitated by the opening up of a Third, focuses on an infant’s journey towards greater independence and separateness from mother. The mother, in Benjamin’s work, begins to take leave of her infant and disclose her separate sense of identity. This marks the time when a possibility opens up for greater degrees of symmetry (or perhaps more accurately greater degrees of being seen and of seeing). She says:

> Mother, of course, ideally holds this awareness in mind from the beginning. But as time goes on each does something different to make it work. Mother is primarily responsible for making it work, for scaffolding the baby’s action, while baby ‘plays along.’ The differentiating Third refers to an awareness of the distinct part played by the other required for the coordination and resonance to work, the ‘something more’ than just us two matching even while we are feeling ‘at one’. This surplus attention to the other’s regulation based on recognition of difference characterises the mother’s asymmetrical responsibility. (Benjamin, 2018, p. 82)

Jessica Benjamin’s (1995; 2006; 2009; 2010; 2018) work on recognition has implications for dementia care. Benjamin argues that the process of recognition is central to intersubjective relating, in which both parties experience the other as whole, complex and separate beings. In dementia care the person with dementia will need much more from his carer than he is able to give back. Recognition permits us to engage realistically, and altruistically, with one another, as whole objects, which involves inequalities, as well as equalities, sameness and difference. In other words,
an ethics of care involves the recognition that humans share in existential experiences of dependency, interdependency and independence but that there are numerous individual differences in our abilities to care at different times across the lifespan.

Benjamin (2006; 2009; 2018) offers us a hopeful picture of the relational field, in which seeing, noticing, recognising acts as a counterpoint to entrenched power dynamics between people. Benjamin’s theory provides us with a way of understanding how we can go beyond a sort of narcissistic part-object form of relating, often at the basis of racism, sexism, ageism, for instance. As Benjamin (2018) points out:

Recognition involves knowing and being known, as in ‘moments of meeting’ when, as Sander puts it, ‘one individual comes to savour the wholeness of another’ (Sander, 2008, p. 169, cited in Benjamin, p. 77)

Neither party is therefore under the other’s imagined, and omnipotent, control. Winnicott’s ideas on play, where the parts of the self can be expressed freely and without fear, has some resonance here, too.

A process of differentiation is key to the production of subjective meaning for Benjamin (1995). The subject here is conceptualised as one able to manage difference and space in the context of a relationship. Benjamin takes a Winnicottian stance in so far as she believes that the infant’s capacity for empathy grows out of recognising that the very person upon whom he depends is not under his omnipotent control. For Benjamin, the mother’s departure from her infant signifies a crucial learning experience – thus reminding us of Bion’s (1962b) claim that we learn through a manageable level of frustration.

Recognition, from the perspective of the infant is quite complex – he recognises mother’s separate subjectivity through mother’s absences, and sees that this symbolises his limited sphere of influence over her. The infant also learns that mother also chooses to be there with him when she stays. Though the relationship – like an analytical one – is based on a form of ‘asymmetrical responsibility’ (Benjamin, 2010 p. 245) infant observation studies also demonstrate that the infant is able to communicate and make his desires known. What Benjamin describes is the possibility for greater symmetry embedded in a fundamentally asymmetrical caring relationship. I am reminded of the field of dementia care here. Although carers are ultimately responsible for residents’ well-being, people with dementia do at times recognise the needs of a carer and help out in whichever way they can. As Ettinger (2006) might argue, at base we all have the capacity to be collaborative.

In the interactions that Benjamin describes, both parties make self-disclosures. Intersubjectivity occurs when such self-disclosures are recognised, rather than distorted through the lens of
narcissistic desire, allowing for genuine contact to be made. Contact like this is considered a ‘shared third’ – both subjects have come to recognise interactively the other’s subjectivity. The ‘shared third’ (Benjamin, 2009, p. 443) is a concept that has vividly spatial connotations. This space provides the opportunity for each party to recognise difference and connection simultaneously. Arguably, this notion of mutual recognition (Benjamin, 2006; 2018) offers a more relational view of care and has the potential to be a guiding idea for the helping professions.

The logic of much of Benjamin’s work is that the infant’s capacity for recognising the distinct subjectivity of his mother emerges through a process of spatial and temporal distancing – there is a paradox here in that psychic closeness (understanding that others have separate minds to respect) is achieved through greater distances of a spatial and temporal nature. However, someone with dementia may find it hard to recognise a professional carer in this way, not least because increased withdrawal of care staff (breaks, absenteeism) is likely to lead to further disintegration in someone with dementia. Breaks and endings in this context, as with the mother-child relationship, must be managed with sensitivity and care.

Ettinger’s work on the matrixial, wherein the womb represents in our primordial unconscious the feeling of deepest security, and Winnicott’s notion of primary maternal preoccupation resonate here. Only from a place such as this one – in which space and time is shared, rather than fought over – can we gather ourselves up confidently enough to claim a space of our own. It is perhaps as true in organisations as it is in the family that a process of sharing and joint-meaning making is needed before we are able to recognise divergent approaches, roles and identities.

\textit{Klein: splitting}

Kleinian (1930; 1946; 1952a; 1952b; 1952c) object relations theory has been invaluable in this study. Klein often deals with the destructive feelings involved in the emergence of human subjectivity. One of Klein’s main assumptions is that the internal world of the infant is in conflict. The infant has tremendous difficulty in integrating innate anxieties about surviving. The Kleinian infant is one that tends to expel, or project, the bad stuff – rage, greed, hatred – and, all being well, mother returns something better for the infant to introject. If mother fails, then her dysregulation, or collapse, under the pressure of the baby’s destructiveness becomes internalised as a broken self, the infant either identifying with the mother’s collapsed state, or identifying with his own destructiveness. The external world becomes a precarious one, full of confused meanings.

\footnote{This sounds strikingly like Ettinger’s (2006) work, but also Winnicott’s (1971) ideas of me and not-me in the context of play.}
A similar process might take place between a carer and a person with dementia. The cared-for, by the very nature of the condition, may already be in touch with her own internal precariousness each time she notices the loss of a word, a memory, a thing, and, fearing break down, may project this outwards into the environment. In turn carers may become receptacles for destructive, angry, feelings. In essence, perhaps, an infant and a person with dementia might, at times of heightened primordial anxiety about survival, be calling out for rescue (see Chapter 4). In that moment, at a deeply ontological level, infant or older person is in contact with the sheer intensity of human dependence. Undoubtedly, then, when the calls for help are met with silence, raging distress is inevitably expelled.

Although ‘the struggle between the life and death instincts emanates from the id [forcing the ego into action]... the primary cause of anxiety, the fear of annihilation, of death’ (Klein, 1952a, p. 57) exist in the infant at birth, coming from within, and it is through identificatory processes with the mother that subjectivity is gradually structured and, in good circumstances, shaped to become less split. The tensions between the powerfully incompatible drives of life and death begin to lessen once introjections of a good object begin. A shift to a more ambivalent position – a fusion between life and death – allows for the management of the drives. A responsive carer able to think about the projections of a person with dementia might similarly be able to minimise conflicts in the person she cares for.

In Klein, the source of the ego is tied into the instinct for life and survival, the need to feel integrated; the id associated with the death drive and (aggressive) libidinal force. As she points out,

> Opposed to the drive toward integration and yet alternating with it, there are splitting processes which, together with introjection and projection, represent some of the most fundamental early mechanisms (Klein, 1952a, p. 57).

By projecting the instinct to survive outwards, ‘by turning outward libido and aggression and imbibing the object with them, the infant’s first object-relation comes about’ (Klein, 1952a, p. 58). Through the process of introjection this object\(^\text{10}\) becomes internalised. I am suggesting that processes of projection and introjection are taking place inter-subjectively between carers and people with dementia on a daily – and intense – level.

Like a dementia care worker, the mother, in Klein, is often under pressure to respond to violent projections. Although we have not come to him yet, it is important to point out that the mechanisms of projection and introjection were grounding ideas for Bion’s (1962a) theory of the container-contained. Although Bion details the function of the mother more comprehensively than

---

\(^{10}\) The first of these internalised objects is the part-object of the mother's breast (Klein, 1952b).
Klein did, he nonetheless built his theory upon these Kleinian mechanisms. Contrary to Winnicott, projection – the projection into – implies that there is never a period of a fused infant-mother pair in the work of Klein or Bion.

Klein’s work does not present us with the hopeful, creative narrative of Ettinger’s co-constructed emerging or with the ostensibly more gentle theorising of Winnicott. Klein shows us that the process of coming into being can be fraught relationally, and we might surmise that for many with dementia, the process of leaving existence, the relinquishing of self, is also unbearable, catastrophic. From Klein’s work, we imagine just how hard it can be to mother a baby. Extrapolating from this, and applying it to dementia care, we might also acknowledge how hard care work can be. After all, this is a job which involves responding to those who might be experiencing a deep, persecutory anxiety akin to the dependent infant’s fear of dying.

There is conflict in the interplay between the real mother and child, as there might be between the person with dementia and her professional carer. For Klein, however, this conflict is based in psychic fantasy and feelings of ambivalence perhaps more than in breaks in attunement between both parties.

Klein also helps us to understand some of the partly unconscious processes involved in harmful practices resonant of Kitwood’s (1997) notion of malignant social psychology in dementia care. Klein clearly fleshes out the mechanisms of projection and introjection which operate in all relationships. To return to the mother-infant pair, the mother-breast is experienced in object terms, something real while also constructed out of phantasis ed projection. A complex dynamic between the real external breast and the internal world of the infant takes place. The infant understands (unconsciously) the motivation of the part-object based partly on accurate perception (is the presentation of the breast responsive, withholding, anxious?). Mixed in with this is also what the infant is projecting on to it (gratitude, love, desire, rage, rejection). The infant introjects the experience of both the real breast and also her own feelings that have been projected into it. Internal objects are experienced initially as either good or bad/loved or hated, thus existing in the mind as part-objects. In part this splitting is a defensive psychic action to protect that part of the object which is loved: the loved untainted with the hated. As noted earlier, the ego, the internal world of self, is also split at this point. We might wonder how often a care worker takes on the projections of a person with dementia, left feeling that she is unable to provide satisfactory care. Or if the recipient of care takes on projections from the staff team, becoming a receptacle for disavowed feelings? How, if at all, do processes of splitting manifest themselves within the care organisation? This is something I will explore in Chapters 3a, 3b, 4.
The ‘paranoid-schizoid position’ (Klein, 1946, p. 2), is characterised by a dramatic alternation between love and hate. The internal objects are both loving and hating, as is the ego. Klein’s ‘depressive position’ (Klein, 1946, p. 14) awakens feelings of guilt. At this stage, somewhere in the child’s mind, he has come to imagine that he has damaged his love objects with an over-abundance of hate. The depressive position brings about the desire to repair the relationship with both his real external objects and the internal objects within. To attain the depressive position means that the child has understood that the hated object is also the loved object. To hold such powerful feelings in check with one another signifies the child’s capacity to relate to a whole human object, to show concern and to be able integrate apparently contradictory emotional states. At the heart of this process is a more rounded, ambivalent, relationship with the other (complex and paradoxical) and with the self. The Kleinian infant, having worked through the depressive position, develops a capacity for care and responsibility. This process might remind us of the ethical imperatives in dementia care noted in Millet (2011) earlier on. The Kleinian model of development suggests that human behaviour can be brought ‘back to oscillations between paranoid-schizoid and depressive positions’ (Keane, 2012, p. 9). Here we see a concrete difference with Winnicott, who resisted this explanation and formulated ideas which contributed to the understanding of playful and creative states of mind, which related, as I understand it, to the capacity for residing in paradoxical, and transitional, experience. Klein’s two positions are frequently used to understand the dynamics both in organisations and within dyadic encounters. The paranoid-schizoid position describes mechanisms at work when feelings are split off from one source and get located in another. The depressive position, thought of as a spatial configuration, can also be a useful paradigm for reflective practice in which strong feelings can be helpfully processed and reintegrated into the care work. Reparation, as Kosofsky Sedgwick (2007) points out, does not mean that the object is restored, as before, but a more realistic, integrated one emerges. The depressive position comes to represent a careful handling of hate and love, and it subsequently becomes ‘… a uniquely spacious rubric… (a site for) Klein’s explorations of intellectual creativity’ (Kosofsky Sedwick, 2007, p. 637).

Beyond this the act of reparation is often a motivating factor for doing care work, as we shall see in the course of this piece of work. I would argue that this latter position is also related to the process of normal mourning, of encountering the pain of loss, and working through conflicting feelings—an experience often defended against in care work, to be discussed in Chapter 4.

Bion: containment

---

11 Note the interview with care worker, Chaya, Chapter 3b.
The works of Klein and Winnicott address the way in which the human subject develops intersubjectively through the maternal relationship, setting the scene for a model of psychic development based on the experience of security. Bion (1962b) makes a further claim about the early relationship between mother and infant. He sees this relationship as integral to the formation of the thinking mind. Bion suggests that it is within this relationship that the infant-then-child learns how to understand his own emotional experiences. In his paper, *The Psycho-analytic Study of Thinking*, Bion (1962b) suggests that the process of containment involved in mother-infant relating leads to thoughts, thinking and finally to communication of an honest or truthful nature. There is something about the notion of truthful communication that resonates, for me, with Winnicott’s ideas on authenticity. Although Bion is concerned with the truthful naming of emotional experience, Winnicott is also preoccupied with the child’s capacity to express emotional experience, the self, in as truthful a way as possible. Although Winnicott was not primarily focused on thinking, it is possible to recognise that both men were trying to find ways – via different avenues – to understand how some achieve an experience of authenticity and others do not.

It was Bion who introduced the notion of the ‘container and contained’ (Bion, 1962a, p. 90). An early containing experience (offered by mother) was lacking in his psychotic patients, who relied on projective identification (in the paranoid-schizoid position) as a method of communicating their needs. Here we are reminded of Klein’s influence.

Bion believed that projective identification was an interpersonal process in which the person projectively identifying ‘engages in an unconscious phantasy of ejecting an unwanted aspect of him or herself… and depositing that part into another person in a controlling way’ (Ogden, 1990b, p. 145). The recipient of the projective identification is driven through interpersonal pressures to behave in accordance with the split-off part of the projector now located inside herself. If the recipient (mother or analyst) is unable to contain the projection and return it in a more manageable form for re-internalisation by the projector then the recipient becomes an external threat and the internal menace from which the projective identification sprang will remain unknown and unthought (in the projector). If the reverse happens, for the infant in the container-contained relationship, then thinking based on feeling becomes a possibility.

Bion’s (1962a) model for experiential learning hinges on the mother’s ability to act as a container for his projections and to make contact with the baby’s state of mind. The baby has a sense of falling apart when his needs feel overwhelming. Although distressing for the mother, all being well, she is nonetheless able to bear the full weight of what Bion (1962a, p. 6) calls beta-elements (pre-

---

12 In the sense of being ‘me’ in my own idiom, not in the image of my phantasised object.
symbolic signals of distress). It is her alpha function (her thinking mind)\textsuperscript{13} that processes them, returning them to the infant in a digestible form. This in turn helps the infant to begin to find ways to understand his own experience, arguably distinguishing between reality and fantasy, paving the way to separate out the conscious elements of the mind from the unconscious. The receptivity to being stirred up emotionally – what Bion would call reverie - is ‘the basis of our capacity to be responsive in all occasions throughout life when we are brought into intimate contact with someone else’s state of mind’ (Shuttleworth, 1989, p. 27). Organisationally speaking, the space for experiential learning is often unavailable for care workers yet necessary for people to do thoughtful work (Lowe, 2014).

The inability to digest our emotional experiences results in a minus K (non-knowing) functioning, in which we operate defensively in order to evade what can be the pain of experience and what we might come to ‘know’ from it.

Paul Terry (2010) likens the care worker’s role to the receptivity a parent might have in relation to the infant’s needs. Terry suggests that without the containing presence of a dementia care worker, the person with the condition can be disabled further. In other words someone must be emotionally available to the mind that ebbs away, to make sure the person concerned has an experience of being thought about while his mental processes are undergoing radical alteration.

In his seminal paper, ‘Attacks on Linking’ Bion (1959) argued that it was a failure in early containment experiences, and no chance of using normal projective identification, that left the infant devoid of a mind (minus-K) robust enough to process and join thoughts together in a cohesive narrative of experience.Containment helps us to reflect and learn from experience, which is important in the dementia care field because such environments can be rife with very highly charged emotional content.

**Organisational relatedness**

\textsuperscript{13} ‘It seemed convenient to suppose an alpha-function to convert sense data into alpha-elements and thus provide the psyche with the material for dream thoughts, and hence the capacity to wake up or go to sleep, to be conscious or unconscious. According to this theory consciousness depends on alpha-function, and it is a logical necessity to suppose that such a function exists if we are to assume that the self is able to be conscious of itself in the sense of knowing itself from experience of itself. Yet the failure to establish, between infant and mother, a relationship in which normal projective identification is possible precludes the development of an alpha-function and therefore of a differentiation of elements into conscious and unconscious.’ (Bion, 1962, p. 45)
I do not wish to over-state my use of Menzies-Lyth’s (1959) study. However, her examination of pervasive defensive practice, systematically assembled at the level of the organisational labour process, has been very influential in terms of understanding health and social care organisations at work. Her understanding has a distinctly object-relations quality to it, and though my work does not reference her study in depth, it is important to note her contribution to understanding organisational settings. Beyond this, Armstrong (2005), whose work directly informs my own, owes some of his thinking to Menzies-Lyth (1959), particularly in terms of identifying defensive organisational practice.

**Armstrong: organisation-in-the-mind**

Armstrong (2005) is interesting because his ideas span object relations, aspects of Winnicott, and also organisational consultancy traditions. His notion of the organisation-in-the-mind creatively bridges the gap between the internal world of the client and the external world – made of multiple internal worlds interacting – of the organisation at large. The notion of the organisation-in-the-mind as a psycho-social field (Armstrong, 2005 in Hoggett & Clarke, 2009, p. 246) finds echoes in Ettinger’s (2006) work on the matrixial field. Here multiple traces of identity meet with the multiple traces of identity found in others, forming new identities-in-process. Her matrixial field is understood as a psychic resonance field of multiples, all interacting and generating new sets of meaning. Armstrong (2005) does not cite Ettinger in any of his work. However, what both theories demonstrate is the level of complexity involved in human relating.

The nature of conscious and unconscious group processes is vital to understanding this piece of work because of its focus on organisational life. As Armstrong (2005a) points out, ‘emotional experience is very rarely located within a purely individual space’ (p. 32). If we relate this to organisational life, we come to understand that the organisation is bound up with the individual identities within it. How each one of us understands organisational life, its structures, routines and practices, is personal, tied up with our own emotional lives. The work of clinical psychoanalysis is the exploration of the phenomena that take place dynamically between the pair; in group work the object of study becomes the phenomena that take place between more than two people, also relating to both internal and external realities in dynamic interaction. By paying close attention to these phenomena, it is possible to begin to see the way that the group-in-the-mind or ‘organisation-in-the-mind’ (Armstrong, 2005a) is constructed between and within a membership. The emotional reality of the organisation as a whole is then registered within the individual in role. As Hutton et al. (1997) write:
Organisation-in-the-mind’ is what the individual perceives in his or her head of how activities and relations are organised, structured and connected internally. It is a model internal to oneself, part of one’s inner world, relying upon the inner experiences of my interactions, relations and the activities I engage in, which may consequently be influencing my own management and leadership, positively or adversely. (quoted in Armstrong, 2005a, p. 4)

What Armstrong’s work makes clear is that in order to improve organisational life, to allow teams to function with greater openness to experience, people need a ‘third space’ (Benjamin, 2007; 2018; Britton, 1989; Diamond, 2007; Lowe, 2014), or a potential space (Winnicott, 1971; Ogden, 1990) in which to think about the ‘organisation-in-the-mind’ of the team and of the individual. The process of constructing this third space often involves the complex coming together of different, sometimes tense, constellations of emotional experiences. It is also coloured by the various mechanisms, such as projective identification, introjection and splitting, that people use to deal with those experiences.

For Armstrong (2005b),

To work analytically in groups, or in institutions, is to use one’s alertness to the emotional experience presented in such settings as the medium for seeking to understand, formulate and interpret the relatedness of the individual to the group or the institution. It is understanding that relatedness, I believe, which liberates the energy to discover what working and being in the group or the institution can become. (p. 1)

Of the individuals he consults with, he treats each one as a person-in-role within the system. Armstrong seeks to understand this position as an expression of the individual’s relatedness to the organisation, as an expression of the organisation in his mind. This position is ‘a facet of the emotional experience that is contained within the inner psychic space of the organisation and the interactions of its members — the space between’ (2005b, p. 1). The organisation-in-the-mind is an object of exploration that, at times, might facilitate one’s understanding about malignant forms of social psychology, as conceptualised by Kitwood.

Britton: triangular space
The notion of a space inside and between minds is highly valued in psychoanalytical literature. Space allows the analyst and the analysand, mother and baby, the opportunity to do thinking work based on feeling work.

I will briefly consider Britton’s (1989) work on the relationship of the child to the parental coupling as a useful frame to think about the roles that people take up in organisations. Britton’s ideas draw from the Freudian concept of the Oedipal complex, and although others from different schools of thought write extensively about third/triangular/potential spaces (Benjamin, 2007; 2018; Diamond, 2007; Winnicott, 1971; Ogden, 1990; Lowe, 2014) Britton’s theory is clearly embedded within the ‘organisational’ frame of the family, moving out from the dyadic encounter. To my mind this is helpful since it links more closely with the broader group component of the thesis. That said, I do not dwell at length on Britton’s theory in the Analysis chapter, in terms of understanding the data. Rather his theory of thirds, as well as other conceptual approaches to spatially conceived thinking processes, is linked to my belief that the third space is one that ought to be a formally written in to organisational practice.

To return to Britton, he points out that a child needs to become aware of his role within the family constellation, and recognise that the parental coupling is distinct from parental-child coupling. The former is procreative and genital; the latter is not. The internalisation of the primal scene as a creative gift, rather than as an attacking presence, has, in Britton’s view, implications for the way we make connections and links as we move through the life course. The coming-together of the parents in the mind brings unity to a child’s psychic world. A link is formed which joins the parents, and two separate links connecting the child to each parent, a ‘triangular space’ (Britton, 1989, 1998, 2004).

Those links provide a mental space within the boundary of a triangle where separate relationships between different configurations of objects exist. Although in the primary family triangle, the parental link is at first experienced as excluding the child, if he is able to tolerate the link and become curious about it, he will find himself in a third position in which he becomes a witness to a relationship beyond him while also being witnessed himself from different vantage points and in different relationships. In this sense, the infant is making links and associations in his mind. Linking is also a feature of Bion’s (1962) work, as this for him is the bedrock of a thinking mind. There is also possibly some connection with Winnicott’s (1971) idea of the potential space here, in which associations can be made freely and spontaneously, where the infant can also experience the paradoxical components of himself. In Britton’s model, the child, viewing himself from different angles, might begin to see himself as made up of continuous and discontinuous aspects of identity,
although this is not stated explicitly. Finally, Benjamin (2018), whose conception of the Third is about the practice of relating rather than thinking, states:

Thinking of the Third as a position draws from and bears resemblance to Klein’s formulation of the depressive position, in which we can accept within ourselves a host of binaries including that of doer and done to. But in my usage it is meant to describe the state of the relationship, the stance towards real others, not to representations of internal objects... As form, the third position designates both a kind of relationship and its organising principle... The function of such a relationship... is to serve as the basis for lawful relationship to other humans, to enable recognition of the other, to move us out of tendencies to control and submission. (p. 78)

I wish to emphasise this quote because among analysts who make use of the notion of the third or a potential space, there are those who use it to make sense of the internal object landscape, and one’s role in it (Britton), and those who use such notions to describe a function of healthy and creative human relating to real persons (Benjamin; Winnicott). For the purposes of this study, I have at times referred to both ways of conceptualising thirds. From an organisational perspective, in terms of understanding oneself in role, Britton’s third proves most useful.

Applying his idea to the organisation, what we might be talking about is the capacity to stand outside of oneself to think about one’s role in relation to others. How am I seen and what can I see in myself? Such a position also offers a unique perspective for learning about oneself in the world or in the organisation. What are my particular emotional contributions to the organisational dynamic? What does the organisation put into me? The third space is a concept that has particular relevance for organisations, enabling professionals to make links between their own behaviours and their work, individually and collectively. If workers are able to think about themselves in these terms, there may be the potential for avoiding splitting off disavowed feelings and projecting them into others, a process which may lead to relationships which involve the power-play of subjugation and dominance.

As will be evident, this thesis is indebted to different strands of psychoanalytic theory, adopting a theoretically pluralistic approach. From Winnicott, I take, in particular, the notions of holding and the potential space that emerges in play; from Klein, the processes of splitting and rupture and repair; from Ettinger, the idea of a trans-subjective form of relating that precedes the verbal and which has paradoxically provided me with a linguistic frame to understand such moments; from Bion, his careful understanding of the need for containing raw emotion both at an individual and systemic level; from Armstrong the organisation-in-the-mind; and from Britton a conceptualisation of space which involves observing oneself in relation to others, learning about role and responsibility in the organisation. I will apply these ideas particularly to Chapters 4 and 5, the former of which analyses the fieldwork data and the latter of which examines policy in light of the
lived experience of care work. Chapters 3a, 3b and 4 will endeavour, in particular, to make use of Armstrong’s concept of the organisation-in-the-mind as an entry point into understanding the sites in which I carried out my field work, Winston Grove and Whittinghall.

Applying theory in this way has meant that the analysis of the data is unlikely to provide the reader with a conclusive and complete statement on what was happening in the care home sites of Winston Grove and Whittinghall. Rather, I hope that by employing this approach, there will be room for further thought – gaps which offer up a potential space not only for further thinking but also one which may allow those of us in the caring professions to recognise the inconsistencies and difficult paradoxes we may encounter in the work, as well as gaining some understanding of some of the causes of the malignant social psychology that Kitwood noted in dementia care.

As Winnicott states:

My contribution is to ask for a paradox to be accepted and tolerated and respected, and for it not to be resolved. By flight to split-off intellectual functioning it is possible to resolve the paradox, but the price of this is the loss of the value of paradox itself. (Winnicott, 1971, xii)

Now that the theoretical frame is in place, I will go on to discuss the research methods with which I engaged – psychoanalytically informed observations and interview-based research – and my rationale for choosing those methods. A particular focus will also be given to ethical issues and reflexivity in qualitative research practice.
Chapter 2: Methods and Methodology  As indicated earlier, this thesis takes as a starting point the psychic phenomena that exist both inside and between people, moving out to examine the convergences and divergences between such phenomena, organisational practice and social discourse. Consequently, the study is indebted to psychoanalytical thinking, which can provide ways into understanding the individual experience, dyadic encounters, organisational and social context. Using methods influenced by psychoanalytic theory and practice involves taking into account the subjective experience of the researcher. In so doing, the researcher reflects upon his own responses to what he is observing, hearing or reading, thus becoming an object of research himself. Psychoanalytically informed methods seemed fitting because many of the processes that they engage with (e.g., transference and countertransference, projection and introjection) imply a fundamentally relational understanding of pre-conscious emotional experience (Redman, 2005). As follows:

Psychoanalysis might contain useful resources for addressing affect, feeling and emotion in ways that do not reduce either to cultural inscription or to a notion of a self-contained bounded subject. (Redman, 2005, p. 53)

Though the study is not a clinical one, the methods have developed from ideas emerging out of therapeutic practice, a relational practice which involves processes of co-affecting.

The questions at the base of this study are about experiences of relatedness, as follows:

- How is dementia care experienced, consciously and unconsciously, by carers and those cared for?
- To what extent and in what ways is this experience relational?
- How does it relate to organisational culture and policy?
- To what extent does psychoanalytic theory illuminate the experience?
- To what extent does dementia care policy address this experience and what are the policy implications of taking it into account?

To get some purchase on the questions, I drew on methods which allowed me to a) explore conscious and unconscious processes involved in human relationships, in accordance with the dynamic operating between mother and babies; b) explore the person with dementia’s experience in relation to the carer’s and vice versa; c) understand conscious and unconscious dynamics between people-in-role within an organisation; d) explore the emotional atmosphere of the organisation as registered in its workers and residents and e) interpret critically important pieces of dementia care policy in comparison to the lived experience of care.
In order to examine the co-affecting processes that constitute the carer/person cared-for relationship, I used a psychoanalytically informed observation method. As a training for this method, I undertook a year-long infant observation, as pioneered by Esther Bick (1964). This training allowed me to get close to the forming of a mind in conjunction with an-other, to reflect upon the verbal, non-verbal and bodily mutual communications between mother and child, both conscious and unconscious. Data collected from the infant observation was analysed in fortnightly seminars led by a pioneer in infant observation: the material was interpreted through the lens of object relations theory. The analysis was often based on the seminar group’s countertransferential responses to the material.

Once the training was completed, I began two three-month-long psychoanalytically informed observations in two specialist residential dementia care homes. Though the observational approach had overlaps with psychoanalytic ethnography, especially in terms of the final write-up, it was strongly inflected by the principles of infant observation technique.

For instance, I situated myself in each care home as a quiet, non-intrusive observer for the first three months of the fieldwork, strictly adhering to the role of non-participant observer. My spoken contact with residents and staff was minimal once the observations proper were underway. The observations were intended to focus on a person with dementia and his/her keyworker. I had hoped this would allow me to investigate whether or not there is a replication of maternal practice in caring for someone who may be falling out of mind through dementia.

Being a non-participant-observer enabled me to attend to the micro-interactions involved in care relationships. By sitting apart as things unfolded, I could recognise when I was being stirred up by particular encounters in the field, noticing powerful countertransference responses in situ (recorded in a research diary). Although reminiscent of a non-participant ethnographic observation, the use of my own countertransference responses as a research instrument was arguably more systematic. Ethnographic researchers also draw on their own subjective responses as a tool, but this study’s link with infant observation technique meant that the analysis had very specific psychoanalytic sensibilities.

Sadly, I was not able to follow the psychoanalytic observation methodology as strictly as I had wanted, due to the fact that I couldn’t recruit members to join a seminar group. Also, outside the remit of a psychoanalytical observation case, I supplemented the observations with loosely structured interviews. Finally I drew on theories from organisational consultancy to understand the

14 Margaret Rustin, Consultant Child Psychotherapist at the Tavistock Institute and co-editor of *Closely Observed Infants* (1989)
interviews. During the study, it became clear that I was drawing on an eclectic, but possibly mutually reinforcing range of methods, which responded to the demands of the research question.

Although not a formal seminar group, I was able to meet with the infant observation seminar leader to reflect upon four challenging care home observations. I had several meetings with my psychoanalytically informed supervisors, and a subsequent discussion about the interviews with a former psychodynamic psychotherapist with whom I had trained\textsuperscript{15}.

Writing up the observational accounts, I noticed that they had an ethnographic narrative quality, though the psychoanalytical stance of the study meant there was a more focused attempt to convey the conscious and unconscious, affective, dynamics within the homes. Human contexts, in psychoanalytical observation, are assumed to be emotional interpersonal places. As a result, the ebb and flow between people – the psychic phenomena manifesting in speech, bodily gesture, involuntary sounds – were emphasised.

The observations were supported by a series of loosely structured qualitative interviews, which deployed some of the techniques adopted in psychosocial interviewing, and the assumptions underpinning them (see pages 61-2), like, for instance, the Free Association Narrative Interview (FANI) technique (Hollway and Jefferson, 2012). However, I did not follow this particular approach because the care workers – particularly at Whittinghall – were reluctant to talk at any length, so the depth of the interview material was not akin to accounts that a FANI study might generate. However, it was important that I use an open-ended question because participants could free associate, the interviews often unfolding according to the conscious and unconscious links participants made.

I also read respondents’ material beyond ‘face value’ (Gilmour, 2009). As Jervis (2009), like Gilmour, a psychosocial researcher, notes of her own study, it was important to consider ‘not only the manifest content of research data but also what might underlie it’ (p. 145). In order to investigate the meanings within and beneath communications, I drew heavily on my countertransference\textsuperscript{16}. As a psychodynamic counsellor, I had been trained to work with clients in this way, in a clinical setting, following the way that my feelings towards an individual in the room changed during the course of sessions, learning from personal affective responses as a way of understanding the plight of clients. As Laplanche & Pontalis (1973, cited in Jervis, 2009) note,

\textsuperscript{15} Jo Dickie, psychodynamic psychotherapist.
\textsuperscript{16} I am using the concept of ‘countertransference’ loosely to refer to the unconscious communication and emotional and embodied relating that are part of everyday interaction. This is not to imply that I am using it clinically, in the sense of the countertransference responses being embedded in an unfolding therapeutic relationship.
countertransference is ‘the whole of the analyst’s unconscious reactions to the individual analysand.’ (p. 92). As a researcher, I used my own feelings as part of the data, engendering the reflexivity that is vital for a psychosocial researcher (Jervis, 2009).

Throughout the observational study and interviews I noted potential unconscious organisational processes, how they presented themselves in relating, to make sense of the organisational cultures. At times, it was as if I became a receptacle to the organisation’s split off parts. As Jervis (2009) notes,

Contemporary understanding of the potential usefulness of countertransference owes much to Melanie Klein’s (1946) notion of “projective identification”; an unconscious process wherein unwanted parts of the self are psychically split off and projected into an object (often another person) which is then identified with those parts... (p. 147)

In terms of psychotherapy, a client may communicate his or her states of mind to the therapist who in turn might feel the raw experience of the client, internalising it, then finding enough psychic distance to be able to think about it with them. For this piece of research, the tool of countertransference – and the subsequent thinking about what might have been going on inside me as a researcher – was very helpful in alerting me to communications which may not have been articulated in words. Talking about the psychosocial research encounter, Clarke (2000) says, ‘...researchers are open to experiencing something that may feel “alien” to them, they can learn from respondents’ “otherness” and reach “that which is beyond words”’ (p. 149, cited in Jervis, 2009). When enhanced by clinical training, skills of this kind might be deepened. That’s not to say that skills such as reflexivity are not employed in other forms of research (eg, psychosocial ethnography) but that I adopted a specifically psychoanalytic framework, informed by my own clinical practice. I was also influenced by the organisational consultancy work of Armstrong (2005), employing his notion of the organisation-in-the-mind to examine the interview data.

Finally, given the need to situate dementia and dementia care in a historical context ‘of power, knowledge and subjectification’ (Hollway, 2001), I conducted an analysis of dementia care policy to examine how, and if, it relates to the lived experience of care. I focused on Living Well: A National Dementia Strategy (2009) because of its importance in shaping health and social care practice in recent years. The policy was interpreted comparatively against the fieldwork data. I also explored some of the ways in which dementia care policy inscribes subjectivities with certain meanings and produces subject positions. The approach implicitly involved triangulation, as I cross-referenced the data across several sources. The project involved becoming engaged with the research in experience-near (feeling) and experience-far (thinking) ways, which facilitated a further third space (Benjamin, 2007; Britton, 1989; Ogden, 1990) for learning (Froggett & Briggs, 2012; Lewis, 2009).
Methodologically this study is a psychosocial one. I am using the term psychosocial to refer to a psychoanalytically informed understanding of social interactions and processes (see Clarke & Hoggett, 2009). For clarity, this involved two three-month-long psychoanalytically informed observations in two dementia care homes (one social services-run; one private); a series of loosely structured interviews with 13 people with dementia and 17 professional care workers; and analysis of the National Dementia Strategy in light of psychoanalytic ideas and some borrowings from social constructivism.

Ethics and reflexivity

The ethical implications of conducting research with people with dementia are vast. There are issues around capacity to consent, the role of gatekeepers, protecting people from harm or accidental diagnosis, and reawakening difficult memories. I had touched on many of these issues (see also section on ‘informed consent’) during the ethical review stage of this study, which met with a favourable opinion from the Open University Human Research Ethics Committee (Appendix A). However, as Mertens (2013) notes:

> While qualitative researchers follow the same regulatory procedures for ethical review as all researchers, they situate themselves in consciously value laden territory in which human relationships and critical self-reflection loom. (p. 512)

Mertens (2013) implies that in a qualitative study ethics are likely to be reviewed on an ongoing basis. This was certainly true of this study.

Linked to ongoing ethical considerations, an overarching ethical concern has been how best to represent the voices of people with dementia and their carers, whose opportunity for sharing experiential knowledge on the wider cultural stage is minimal. This related to my anxiety about voicelessness and the difficulties of representation (Crociani-Windland, 2009)\(^\text{17}\). I feared, for instance, that my voice would overshadow the voices of the residents and workers; or worried about determining which stories most powerfully conveyed the themes that emerged, selecting and de-selecting narratives. In addition, I have posed myself questions around what it means to enter into people’s lives; establishing relationships that may not endure; appropriating the stories of others for my own research ends. Plummer (2011) sums it up: ‘What gives any social scientist the right to invade another’s life, gather up their tale, and leave... telling their stories to others?’ (p. 14).

\(^{17}\) Using intuition in the psychosocial research process is helpful in thinking about how to capture/represent non-linear, affective, unconscious experience, particularly relevant for dementia care.
Relatedly, it has been vital to approach the research reflexively. By doing so the researcher embarks on a continual process of self-analysis; checking and rechecking both the affective processes involved in making research decisions (choice of methods; choice of data selection) but also in her own motivations. The researcher becomes an indirect participant in the research, an object of examination, laying herself open to scrutiny. The distinction between research subject and object becomes less clear, and arguably a more democratic approach to the work ensues. I consider reflexivity to be an intrinsically ethical and intersubjective practice. May & Perry (2013, cited in Flick, 2013), adopting a feminist perspective to research, suggest that:

a critical and insightful gaze does not come from a position of disinterest, from which the researcher works but that the interest itself comes from the vantage point of being engaged. (p.112)

Engagement suggests that there is a relationship between the researcher and the subject of research, that an ethics of care, responsibility, is written into the reflexive process. This engagement involves critically reflecting upon the processes involved in such a relationship. As Hollway notes,

Identification also provides a useful starting point for conceptualising ethical relating, which should involve recognising others for what they are (not for what you want or need them to be nor for how they might want to be recognised)... (2008, p157).

For me, this relates to the honesty with which the data is organised, and the personal capacity in the researcher to allow its meanings to unfold rather than make the data fit in to a preconceived set of theoretical structures, and strait-jacket, in a sense, the voices of those I had worked with.

There has been a continual tension for me between presenting the data in interesting ways while also being conscious of making sure those who shared their insights with me, from which my further interpretations stemmed, are acknowledged. Individual and social worlds have been shared during the observations and interviews, and I have been privileged to encounter them. The dialogic nature of interviews meant that there was a co-constructive meaning-making process going on in the here and now; the observations, although often filled with silences, sometimes felt as if the participant and I were experiencing in situ together. In the present moment of experience-near work, the encounter did not feel cut off and scientifically objective. I would suggest that the affective hauntings that commonly occur in qualitative research were amplified. Feelings belonging to the participants and their environments frequently got inside me, provoking me into further thinking. Psychoanalysis offers a highly relational, co-affecting method of researching data, and I would argue that with a keen critical view of how the combination of accounts merge and separate, belong to both self and other, there is a possibility that research of
this nature can come to be partially representative of a particular social moment.

**Infant Observation**

**A training**

As already noted, I carried out a year-long psychoanalytically informed observation of a mother-and-infant pair in the first year of registration, as a training for the method of observation I would use in the care home study. The infant observation training allowed me to become intimately aware of my emotional responses and to seeing in action the oscillations that take place in human research between being practice-near during observations and becoming practice-distant during the more interpretative stage of understanding the material.

An infant observer makes every effort to stay in role, enabling her to perceive as much inter and intra-psychic phenomena as possible in the present moment. This focus on the present moment implies that the observer limits her desire to know or to make known – through reactive conjecture – what is going on. As Michael Rustin (1989) points out, ‘Theorising at too early a stage by the observer or seminar group is most likely to be a defence against the pain of emotional experience or ignorance than a means of real understanding’ (p. 52).

As well as paying close attention to the subjects of the observation, an observer attends to what is stirred up emotionally inside her. In this way the observer functions as a container to unwanted difficulties within the family that may be projected in order to avoid the associated intensity of feeling. This allows the observer to have a personal felt encounter, albeit one which is not discussed with the family. The nature of projective identification opens the way to a deep receptivity with the way that mother experiences baby or baby experiences mother. Staying in role without acting in the face of such projections gives the observer the opportunity to take in the different states of mind of mother (or father), baby, and the impact that each has on the other (Rustin, 1989).

My reason for choosing to collect data using a psychodynamic observation method relates to one of the key theoretical assumptions of infant observation methodology. As Rustin (1989) highlights, the main subjects of infant observations are:

relationships rather than separate individuals... What is described is not merely what the baby can do, or how the baby is, but how mother and baby are developing in relationship to each other (p. 63).

This study is also interested in the way subjectivities might be co-constructed in encounters between carer and cared-for. The dynamics between people at work and how these dynamics
feed into the establishment of an organisational culture possibly also mirror some of the inter-relational dynamics found in family cultures.

A further assumption of infant observation is that the ‘dense and subtle matrix of interaction between the internal and external experiences of mother and baby’ (Rustin, 1989, p. 64) allows the observer to witness the consequences of mother-baby relating for subsequent mental life. I hoped that by studying interactions in fine detail, I would see what the consequences of carer-cared-for relating were for both parties in a dementia care context, and what might be missing in the relating.

Infant observation studies are said to help observers to see first-hand a mind-in-development. In this piece of work, the focus is partially on the mind-in-deformation and how carers can support people to feel as contained as possible during the process of psychic fragmentation. One of the rationales for choosing to conduct a psychodynamic observation was because of this link between relating and mental life.

Infant observation techniques provide evidence about the social world. Sociological shifts are represented in infant observation material, such as multicultural family contexts (Hollway, 2007; Urwin, 2007). Elliot (2011) spoke of her experience as a research observer, emphasising the importance of learning about the research subject through one’s own encounter with oneself as a reflexive research practitioner, and also claiming that the ‘sociological lens offered by the range of observational material … (becomes) an adjunct to the psychoanalytical interior of family life’ (Rustin, 2009, p. 37).

There is some evidence that infant observation techniques provide interesting interdisciplinary insights that bridge the gap between the psyche and the social. I will now consider some examples of applying psychoanalytic observation techniques to a dementia care setting before detailing some important considerations of conducting an observational study in a care home site, namely access to the site, issues of informed consent and sampling decisions.

**Psychoanalytic observations in dementia care**

In conducting my research, I was conscious of the well-established method of organisational observation in health and social care settings (Hinshelwood & Skogstad, 2000), which expand on Bick’s methods. However, the observations I conducted were not strictly organisational observations because the initial focus was on the keyworker pairing, even though this changed

---

over time. As a result the organisational view further emerged during the course of the observations.

My work was perhaps more akin to Davenhill et al.’s (2003) psychodynamic observations which were used in the multidisciplinary training of health professionals working with older people in hospitals and nursing homes. They focused on the interactive nuances between professional carers and the cared-for subject. Davenhill (2009) found that the relational field was helpful in trying to map out good care with older people.

Datler et al. (2009) also conducted an observational study influenced by both the Tavistock Institute and Esther Bick, as part of a research project in an Austrian nursing home. The study examined how constellations of organisational dynamics fed into the relationships among the staff teams, which affected the well-being of the older people. A broad conclusion was that there was ‘little interest being paid to the inner worlds and emotional states of the people receiving care’ (Datler, et al., 2009, p. 78).

Liveng (2012) completed a series of everyday observations of trainee workers in a nursing home for older people. After analysing her data using psychoanalytical interpretation, she discovered that her own language became a hermeneutical key. Although jarring with much contemporary care language, Liveng repeatedly described the nursing home encounter in terms of mother-infant interactions. Through attending to her use of non-field specific discourse, she came to understand a series of paradoxical empirical scenes. Although care staff explained that the care relationship was central to their choice of work, Liveng systematically witnessed the withdrawal of staff from relating to the older people, particularly in the face of distressing situations. Liveng felt that care workers operated defensively in the face of resident distress because of the pain it evoked in them. Liveng’s work implies that the maternal figure might be one appropriate theoretical frame in which to think about the care home site, but also that psychoanalytically informed methods might help to tease out the multiplicity and contradictoriness in human behaviour. I will now turn to the observations which I conducted.

I made the first of the two observations in Winston Grove. This care home is managed by a local London borough council, a 45-bedded home, specialising in dementia care. Whittinghall, the second site, is a privately run home catering for 70 older people, with units for dementia care, elderly frail care and palliative care. I carried out the observations in the elderly frail care unit, Huntside.

Following the infant observation method, all observations were written up immediately after
visiting in everyday language, pseudonyms were given to participants, notes were held on a password protected laptop. In the final write-up of the observations, I attempted to present the social world in a naturalistic way, with as little theoretical mediation as possible. The narrative attempted to evoke in the reader the emotional texture and depth of each site.

The original chapter which emerged from this process was perhaps best described as a hybrid of an ethnographic narrative and psychoanalytical (based on infant observation technique) observation case study. Ethnographic writing is of course able to capture the experience of being in a particular setting, including the emotional range of a situation. However, in processing the material psychoanalytically – with the seminar leader on four occasions, with my supervisors, as well as through my own reverie and ongoing reflection – the writing came to embody analysis and interpretation that I would argue more poignantly represented the care-home experience with all its ambivalence, paradox and pain.

As above, I discussed four extensive scenes with the seminar group leader of the infant observation, noticing at times even somatic responses to the material. A particularly moving example of this was when we both found ourselves anxious in response to the material: Daphne, at Winston Grove, had returned to the home after a day out, and was gazing at the fishtank in the reception. This led to an interesting series of thoughts about weaning, separation and focal points (the fishtank) in the environment that might, at times of heightened stress, hold infants and older people together.

I also discussed the observations with my supervisors. The insights that emerged further demonstrated how nuanced the experience of being in a care home seemed to be. Sharing perspectives, by examining several sets of countertransference, provided some assurance that my thinking was not wildly off-kilter or fantastical. Part of my own ongoing thinking involved noting thoughts, feelings and sometimes dreams in my research diary. One particularly striking aspect of the thinking work involved writing poetry. Often I felt compelled to re-experience the care homes, in poetic form. In the end, I had a collection of poems which, I believe, expressed the confusion and depth of experience of those living and working at Whittinghall and Winston Grove. 19

I had written over 40,000 words in this hybrid infant observational/ethnographic vein, but limitations of space and the need to provide a rich psychosocial analysis, meant that less of this material appears in the final version than I would have liked. However, the process of writing like this informed my interpretations and the material that does appear. Vignettes from the original material are present in the findings, analysis and policy chapters, albeit in slightly submerged

19 I began a blog of the poems. https://dailyinfidelities.wordpress.com/page/2/
There might be a question at this stage about the nature of the study. Was the fieldwork ethnographically or psychoanalytically informed? Since I have laid out the bare bones of psychoanalytical observation methodology, I wish to say a little about ethnography. Though from my perspective, the study draws fundamentally from psychoanalytical thinking, there were overlaps with ethnographical studies. Nevertheless, two points should be made.

First, the observations in the care home sites strictly followed the methodology of psychoanalytical observation to the extent that I was situated in the field as an unobtrusive observer, in a state of reverie. Though tempted at times, I wasn’t a participant observer, an option open to ethnographers, nor was I simply a non-participant observer in the ethnographic mode. Second, the way in which the data was analysed involved paying careful attention to countertransference responses, although not through a formally organised seminar or peer group. Common enough in psychosocial research, this approach is not part of ethnography as it conventionally understood.

That said, it is possible to argue that the write-ups themselves were rich in description, with an ethnographic quality, reading very much like a collection of narratives. As Hammersley & Atkinson (1995) point out,

In narrating events, we show how people act and react in particular social circumstances. In doing so we reveal and reconstruct those social actors as “characters”… we can display the patterning of action and interaction, its predictable routines and the unpredictable surprises or crises. (p. 199)

I had wanted to tell the story of Daphne and Dorothy, coming close to ‘storying other people’s stories’ (Hammersley & Atkinson, 1995, p.199). I took note of jolting moments in otherwise routine, mundane everyday encounters; and I was interested in the sometimes ‘messy and unruly experience’ (Woff, 1999, p. 355) of the human condition.

There were further similarities between my research approach and ethnography that are worth mentioning. For ethnographic, and psychosocial, research the principle of reflexivity runs through the encounter with the subject/s of study. I also noted the ways in which I as researcher was both influenced by what I had witnessed and yet also influenced, by my presence, those I observed. Similarly, like ethnographies, this study is not one that is easily replicable because of the uniqueness of sites and social actors that contribute to them.
Additionally, the analytical process was slow, unfolding and iterative and, as noted earlier, the write-ups were often thick with description. However, differing from ethnography, one of the main areas of interest here was to find ways in to the intra- and inter-psychic fields of the social worlds under investigation. Of course, I was interested in the way that such spaces, and those within it, were constructed and how people constructed themselves, but I was also focused on the interior spaces of individuals in relation to one another, as well. This could, in my mind, only have been reached through an engagement with psychoanalytical methods.

Nonetheless, as I have said, in the end I adopted a mutually reinforcing range of methods to respond to the study as it developed. The observations were supplemented with loosely structured interviews, in order to develop ideas around the organisation-in-the-mind and, in the event, the original write-up was a hybrid of ethnographic narrative and the observational case.

**Winston Grove**

My entry into Winston Grove was smooth. I knew Winston Grove. From 2003 to 2008 I had worked there in several different capacities: as a carer, as a senior carer overseeing a dementia care unit, responsible for the supervision of six permanent keyworkers. The home’s status then changed – it became a specialist dementia care home. The manager at the time was keen that the home practised person-centred care in line with the National Service Framework for Older People (DoH, 2001), and that there were increased activities. I became the home’s activities co-ordinator, offering group activities alongside arts therapists. I also encouraged staff to engage residents in the routine tasks of the home. Since leaving, I had kept in contact with the assistant manager, Elaine, who now runs the home.

When I asked Elaine if it would be possible to carry out the observational study, she invited me in to discuss the idea in greater detail. Elaine acted as the ‘gatekeeper’ (Hammersley & Atkinson, 2007) to the setting.

I spent some time with her, explaining the work and the rationale behind it. She was open to my observing and interviewing residents and staff, but needed to think a little more. I gave her the information sheets about the study. She would speak with some care staff about which residents might be happy to be observed. Given the fact that we had worked well together, I sensed that she wanted to help me in my research and that she felt the home might benefit too.

As Hammersley & Atkinson (2007) point out, negotiating access can inform the researcher about the field of study. The fact that I was making arrangements with a former working colleague meant that I did not feel alien to the organisation, or that I was being treated as a critical figure.
coming in from the outside. Elaine was curious about the study, and I sensed that, although she wanted to have some input into the process of selecting residents, she also trusted me to be able to work with staff and residents.

We scheduled a further meeting a couple of weeks later. Elaine explained that there was a couple of residents – both female – who, along with care worker feedback, she thought might be happy to participate. She felt it would be appropriate for me to spend time in the home just getting to know people, telling them what I was doing, especially the residents she had suggested. She thought I should reacquaint myself with any staff I knew and the routines of the home, before embarking on the study.

For one month, I visited, half a day at a time, spoke with people and noted the movements of the home, yet none of these visits were considered part of the formal observational fieldwork data. I had managed to establish tentatively a relationship with the two residents, Margot and Daphne, whom Elaine had suggested. I decided after a month had elapsed to speak with them about the study.

Informed consent

In line with the Mental Capacity Act (2005), I started from the premise that every individual had the capacity to decide whether or not he participated in the study. Simultaneously, recognising the changeable nature of capacity in the experience of dementia, I also took seriously the Act’s requirement that research involving adults with questionable capacity must potentially benefit the person without disproportionate risks and must not interfere significantly with freedom of action or privacy.

The Mental Capacity Act (2005) is a vital piece of legislation. However, it considers capacity within the frame of the rational subject able to make logical decisions based on factual detail. I would argue that human beings also have capacity to make sense of things at a more primordial, instinctual level. (This meant that there was an ethical duty to be particularly attuned to how someone was feeling during the process of discussing the study.) In other words, it is possible to ascertain whether someone wants something or not, by paying close attention to responses outside language. In terms of dementia care, a trusting relationship can sometimes support the decision-making process; or can allow people to feel safe enough to do/choose something.

Building on guidance received from DeNDRoN (Dementias and Neurodegenerative Diseases Network), which I had contacted about my research aims, the informed consent forms were in straightforward English rather than in psychoanalytical jargon. I wanted possible participants to be
aware of what the study entailed but not bogged down, or alienated, by too much detail and theory. I did not want to evoke in people with dementia a sense of failing at the first hurdle because the information sheet itself was too confusing. I used the sheets mainly as props, tending to talk through the study. There were two lots of information sheets (eg, Appendix B), one for the observational study, the other for the interviews. The consent forms (Appendix C) contained six statements, which ensured people had understood the information sheet and felt no obligation to be part of the study.

*Margot and Daphne*

The first lady, Margot, became nervous when I formally presented her with information about the study. Once I had stepped into the role of researcher, providing documentation, it became clear that Margot wished to withdraw from me. It seemed that she felt I was in some way testing her, her anxiety manifesting itself in a fidgetiness that hadn’t been present before. Margot did not formally say ‘No’ to being part of the study, but as I talked to her she kept looking in her handbag, mentioning her sons. Having made a lot of eye contact before, Margot seemed unable to look me in the eye. It was as if her handbag were a shield, a barrier, to protect against my intrusion; as if she were summoning up her sons as a reminder to herself, and to me, that she had people who could look after her. I thought about what Margot was communicating to me and expressed my concern that she was not keen on talking about the project any longer. She politely said she would rather not. It is hard to know what was making Margot worried, but I imagined that she felt there was something official, potentially critical going on. She had quite possibly been subjected to tests in the past from health and social services, which had changed the course of her old age. My information sheets mentioned dementia but did not focus in great detail on the condition. Nonetheless I wondered if Margot was reluctant to be reminded of her diagnosis and felt uneasy about being thought of, albeit indirectly, in this way. I wanted to ensure that no undue stress was placed on any residents. I reassured Margot that she wouldn’t have to participate, but that I would make sure I said hello to her when I visited.

Gaining informed consent for this project was a key guiding principal, but making sure this was watertight was not without its challenges. As with Margot, I wondered whether my explanation had sounded too complicated, whether the written documents were necessary. Perhaps her reading abilities were diminishing and she would have better processed what I was saying pictorially on an iPad, for instance. Would consent have been better gained in conjunction with family members, her sons, a trusting bridge between her and the researcher? There are, of course, ethical dilemmas in pursuing informed consent from people with dementia, who may not
understand the full implication of what is being asked. I felt that it was vitally important to attend as fully as possible to the conscious and partially conscious communications, the bodily gestures and tone of voice, in order to ascertain whether or not a resident was at ease with the process. I wanted to avoid a situation in which a resident was verbally agreeing yet contrariwise expressing discomfort. As a researcher, I seemed to have some power of setting the research agenda and of how I might order the findings, but I was very conscious of needing to recognise, and avoid, those instances in which I might establish ‘power over the researched’ (Sapsford, 2011, p. 310) through the gaining consent of reluctant individuals.

As Hammersley & Atkinson (2007) suggest in relation to ethnographic research, there is a danger that the information on which the future consent is based might change the behaviour of participants, indeed deterring them from participating. Although I was clear that a covert form of research would feel ethically uncomfortable, particularly because I envisaged a project involving some co-constructive processes, I could see that in some instances this approach might provide valuable insights into the mundane everyday experiences of people.

I met with Daphne the following week. Daphne had a different demeanour. Immediately she wanted to talk about the project. She expressed an interest in wanting to help. She was very taken with the idea of being involved in a piece of work that might lead to improvements in places like Winston Grove. In that first meeting she expressed her thoughts about how it would be better if people did more things together. She enthusiastically read the information sheet, asking me where I had come from. Daphne had a background in education and was interested to learn that I had come from a university. There was no sense that Daphne felt under pressure or that I was a persecutory figure. Daphne presented herself as someone who could consult, be of use. She wanted to share her stories, even though at this point I had made it clear that in the beginning I would just be ‘coming to see how she spent her mornings.’

I left Daphne with the information sheets, explaining that I would return after she had had time to think. When I went back, Daphne was in a different chair but had the sheet with her. I asked her if she remembered what we had spoken about and, though she was vague about the detail, she remembered me and the idea of working on a project to help the ‘older people.’ I went through the details once again. I showed her the consent forms which she signed once I knew that she understood that she could leave the project any time she wished to do so. I explained I would ask her each week if she was happy for me to observe her experience in the home.

The process of gaining entry into Winston Grove was relatively straightforward, as was finding a resident to work with. Elaine had enabled me to re-familiarise myself with the home and to
establish relationships with residents. There was something open about this process, and I was able to take up my own authority. I am sure this was in part related to my having worked there before, as well as a combination of organisational factors which I will consider in Chapters 3a, 3b and 4.

It was not hard to find a keyworker. Erica, a carer who had worked in the home for some time, and whom I vaguely knew towards the end of my working life at Winston Grove, offered to be part of the project. She had heard informally that I would be conducting research in the home. She was happy to be observed with Daphne and seemed at ease. There was one nagging issue, which I could see physically: Erica had back pain which would intermittently come and go. I had no idea that the back pain would shortly become so intolerable that Erica would take extended sick leave after our first observation.

In pragmatic terms Daphne was without a formal keyworker for the duration of the observations. In Erica’s absence it was impossible to maintain the basic frame that they were due to take place in. This may in part explain why observations with Daphne were often full of movement: her keyworker – who may or may not have been like an anchor to her – took leave.

**Whittinghall**

Finding a second site proved more challenging. I was in contact with clinicians at DeNDRoN who signposted me to their ENRICH (Enabling Research in Care Homes) project. A research worker at ENRICH introduced me to a charity care provider that was considering being involved in research. Having liaised with the Head of Research there and having provided information, consent sheets and evidence of HREC ethical clearance, no offer was forthcoming. I was wished good luck and advised that this was an interesting project, but that the charity wouldn’t be part of the project itself. I wondered about the reasons behind being refused access to the setting. As I understood it, the charity had a Christian ethos and I wondered how in this context psychoanalytic thinking might be understood, what the associations and fantasies might be. I also wondered about the competition between theoretical models: I was suggesting the use of a psychoanalytically informed understanding while the charity’s practises were based on a person-centred model. Alternatively, perhaps the charity, well respected in the field of dementia care, felt it had nothing to learn from this piece of work; that they were already providing excellent care and therefore had no need of another ‘expert’.

After this, I contacted someone in my neighbourhood who worked in a senior position for a privately run care home provider. His response was positive. He introduced me to a manager of a
large care home, within easy travelling distance. He suggested that I meet with the manager to
discuss my proposition. After several emails, mainly focused on when and whom to contact, he
handed over all communication to me and the manager, Amy, who acted as the immediate
gatekeeper to the setting. We met several weeks later. Unlike my effortful attempts to access a
home through DeNDRoN, in this case an opportunity seemed simply to fall in to place.

Amy was amenable to the project. I gave her all the documentation and, ending our meeting, she
said that she already had a resident-staff pair in mind. She said that she would speak to both of
them. Amy quickly took control of managing the ‘sample’, the keyworking partnership. Like Elaine,
Amy limited the lines of enquiry (Hammersley & Atkinson, 2007). However, there was a subtle
difference: Elaine invited me to get to know the residents she suggested so that some rapport
could be established, which allowed me to see how someone felt in relationship to the study.

Amy wanted to present the project to a monthly relatives meeting to make sure there were no
objections from visiting family members, alerting them to my presence within the home. She
would also do the same at the staff team meeting before I visited, though she made no reference
to a resident meeting. Elaine had made no reference to holding formal meetings with family, staff
or residents, suggesting I speak with people during my month in the home. There was a distinct
difference in the way the managers chose to convey information about the study to those living,
working and visiting the home. I imagined this also reflected something about the cultures of the
organisation (formal/informal, residents-in-mind/residents-out-of-mind). We set up a preliminary
first date in the home.

Dorothy and Nancy

On the day of the first observation, Amy explained a little about Dorothy, who was willing to be
part of the project as was her keyworker, Nancy. Amy had spoken with both, using my
information sheets to describe the study and what it entailed. Amy also said that she had
informed the resident’s kin and that they were aware of my future visits. Amy had selected both
the case (the unit, Huntside) and the sample (keyworking pair). For me, this raised ethical issues
around the process: conscious that Amy hadn’t mentioned the need for a resident meeting in
conjunction with a family and staff meeting before the study commenced, I had to be clear that
Dorothy had been fully informed and was able to consent to being part of the study. I was anxious
that Amy may have exercised too much control over Dorothy, since she had a diagnosis of
dementia and was also a resident in the ‘elderly frail unit’. Although I knew that ‘elderly frail’
usually signified that residents had nursing needs, I could not shake the feeling that this was
possibly where the most psychically (as well as physically) in need and vulnerable residents were
housed. I was concerned how much time was given to the process of discussing the project, and wondered how any fears might have been processed.

I was introduced to Nancy and Dorothy, speaking with them for some time to make sure they were comfortable with my making observations. There was no overt or covert distress for Dorothy, who said that it would be ‘fine’ for me to see what her days were like. She seemed to be very comfortable with Nancy, and perhaps being with her keyworker provided her with a sense of security in my presence, a stranger. I noticed Dorothy repeated words, but this didn’t seem to stop her from being coherent about knowing what she wanted. As with Daphne, I explained in detail what the project was about and said that neither she nor Nancy had to be part of it. Owing to the fluctuating nature of capacity in people with dementia, I was clear that I would ask each week if I could watch what they did in the morning and if Dorothy had changed her mind I would leave. I explained how long I would visit for, making sure there was a clear boundary around the observational session. Nancy looked engaged, sharing some of her thoughts on dementia care.

Thereafter I visited Dorothy and Nancy (who was there for most observations) over the course of three months. I saw Amy once again on the last visit.

Although in some ways Amy had set me up as a visiting expert, from whom the organisation could learn, she tightly and hierarchically managed my entry into the home, only asking about the study on my final day. I sensed that there was some anxiety about how I might judge the performance of the home, particularly since it had a good reputation.

At Whittinghall I did not know anyone. I came to the home with no pre-given sets of knowledge, apart from my general experience of dementia care. It is possible this meant that staying in role as an observer was easier. However, I was concerned that I hadn’t experienced the same slow way into the organisation to establish relationships. As Flick (2011) notes, particularly in terms of generating verbal data with old or unwell people, a ‘central matter in this context is the relationship to the interviewee we need to build up’ (p. 8).

Sampling for observations

Flick (2011) states that ‘sampling requires prior knowledge of the phenomena’ (p. 20). My experience of working in a care home provided me with certain types of knowledge: I knew that caring responsibilities were often organised around keyworking systems; that there were often small hierarchically structured teams covering different units within care homes; and that relationships and attachments were likely to be important in dementia care. However, I didn’t have knowledge about the experiential and affective realities of the particular residents and staff.
in the homes at that particular time. Given my more general knowledge, though, I was able to propose certain sampling decisions.

Firstly, in order to explore relationships between residents and staff, I felt that the keyworking pair would be the most effective sample. Owing to the aim of the study, I did not attempt to select for potential differentiating factors in such relationships (illness progression, ethnicity of the pairing, gender), although I was sensitive to such factors in the relationships with which I worked. This was a small sample, largely determined by the aims of the study to explore information-rich, in-depth relationships. Though there would have been advantages to sample in breath and to conduct wider, organisational observations (Hinshelwood & Skogstad, 2000) across both sites, resource constraints prevented me from doing so. The sample was a means to begin to explore the research question: it was ‘illustrative not definitive’ (Patton, 2002, p. 236, cited in Rapley, 2013). My focus was to reflect carefully on the relationships I observed, allowing me to draw reasonable inferences about what was particular to them and, extrapolating from this, what was likely to be common to the experience of giving and receiving care. Arguably, the small sample size allowed me to concentrate intensely on fine, observable detail that helped to provide texture and ‘shape … to the emergent categories and substantive theory’ (Rapley, 2013, p. 54) in the final analysis.

The sampling criterion was also necessarily tied up with issues of informed consent: the person with dementia had to have demonstrable capacity to be able to understand the research project and to be able to agree to my visits each week. Careful consideration had to go into finding participants who were cognitively shaky enough to show signs of dementia, yet cognitively able enough to say ‘No’ to being a participant. Conscious of repeating power dynamics that might exist in the care field, through the researcher-participant relationship, I had no intention of observing a resident for whom my presence would stir up anxiety.

At Winston Grove, the initial sample (Daphne and Erica) came to an end after the first observation. The consequences of the keyworker’s absence at first felt detrimental to the study as I no longer had access to the phenomena that would have emerged in a dyadic encounter. That said, Erica’s absence meant that the carer component of the sample came to be made up of multiple people with whom Daphne interacted. This raised problems in terms of informed consent, since gaining informed consent from everyone was simply not possible (Hammersley & Atkinson, 2007) yet by this point people knew who I was and what I was doing, and outside of the observations themselves, I had established many informal, though limited, contacts with most people in the

---

20 Possibly a clearer sense of the range of carer-cared-for relationships and the differences between them.
The change in the sample proved to be fruitful: by adjusting my focus at Winston Grove from the dyadic encounter to more group-wide phenomena new analytic issues surfaced. At Winston Grove, the organisational view became more pronounced, which allowed me to develop my thinking around the interview component of the research. In other words, I became interested in finding out about a wider relational field, from managers to staff; residents to staff; policy to organisation and so forth. To be able to get at the way this relational field was conceived in the minds of the carers and older people, I would need to find an expansive interview question which could lead down all sorts of avenues of association. It seemed important that I added to my theoretical repertoire in sympathy with my observational findings at Winston Grove. The mother-infant frame of reference still seemed applicable, but I also needed a tool of thinking through which the imagined organisation (of staff and residents) could be explored. Armstrong’s (2005) notion of the organisation-in-the-mind seemed to be a helpful place to start. This was one example of how the study took on an inductive quality. I will now move on to consider the sampling considerations for the interviews before describing the interview process itself.

**Interviews**

*Sampling for interviews*

The first consideration in sampling interviewees was to find out from as broad a range of people as possible what it was like to live or work in the home. The second involved finding out from workers what the organisation-in-the-mind (Armstrong, 2005a) looked and felt like. I thought that I could reasonably achieve this by speaking with people who might offer a variety of perspectives as people-in-role (ie, in terms of jobs and what they might have represented unconsciously for the organisation). Another driving factor in the sampling process was a resident’s capacity to verbalise, even if this verbalisation was often more metaphorical than literal. There were other considerations which meant that the samples were smaller in one home (Whittinghall) than the other because participants were self-selecting; staff being particularly reluctant to speak there. Nancy (Dorothy’s keyworker) introduced me to four residents, all of whom wanted to talk. Sadly when I came to interview Dorothy, she became sleepy, which may have been her way of withdrawing her consent. I therefore spoke only with those who seemed interested. Samples were therefore part-purposeful; part-convenience.
To interview someone who was not comfortable participating would have involved extracting meaning from him rather than it being shared, co-constructed\(^1\). This in itself would have replicated practices of institutional abuse, which safeguarding policy exists to protect against.

Though the staff team and residents whom I interviewed were not typical representations of the make-up of the two sites (no cleaners or a manager in Whittinghall), I was able to note rich emergent themes (sometimes by their omission) and patterns of understanding that characterised each site. Such themes – time, for instance – are likely to manifest themselves in many care homes.

At Winston Grove, I interviewed 13 staff and at Whittinghall, four. I interviewed nine residents at Winston Grove and four at Whittinghall. All interviews were audio recorded and transcribed, ranging from 4-33 minutes in length. Consent was achieved in a formal way with many of the participants, residents and staff, but with a few the issue of mental capacity was particularly pronounced. I wondered if one or two residents, such as Ellen (see Chapter 3b and 4) and Dirk (see Chapter 5), really understood the detail of what I was saying. They seemed to recognise that they were being invited to be interviewed, and appeared to be making choices on the basis of feeling at ease with me, as if I didn’t present a threat. They signed the sheets with something approximating a signature, but I doubted that they recognised that I was doing a research study looking at the experience of dementia. Other residents, such as Daphne, and Dr Jesmond, whom I describe in Chapter 5, conveyed a belief that they could help make sense of the homes, consultant-like, and in a co-constructive manner. For both residents, my attentive presence as an observer/interviewer had a positive impact, enabling them to take up an authority (known to them, I imagine, in former careers) as individuals with constructive things to say. With Dr Jesmond, I wondered if he felt I was conducting a market research survey, and that his input might lead to some kind of improvement in the service. During interviews (and observations), I reflected upon my presence as a researcher and how it impacted on the data. I also noticed times when my own thoughts and feelings about respondents had an influence on the quality of interviews.

Residents such as Ellen at Whittinghall and Dirk at Winston Grove left me with a particular ethical dilemma – did I include them in the study, given their willingness to spend time talking to me, or explain that this might not be appropriate. I opted to include them because, at an emotional level, I felt that failing to speak with them might leave them open to feelings of rejection, further

\(^1\) I tried to note the impact of researcher-participant interactions on the way the data unfolded. My ‘use’ in people’s minds sometimes offered insights into the wider context – ie, Nancy, Dorothy’s keyworker presented herself as an impossibly attentive keyworker initially, anxious perhaps that I was a figure of surveillance.
confusion. Even if the interviews were not entirely on point, Ellen and Dirk were nonetheless inviting me to share their experience. Dirk had occasionally used me as a sounding board to talk about his day or past life. Ellen was someone who stayed in her room, but during the interview, she expressed gratitude for my having been with her. It seemed important to sit with her with minimal intervention, as if I were bearing witness to her experience, rather than opening her up and perhaps leaving her more harassed in the process. Whether to engage or not mirrored something of the difficulty that carers may have faced on a daily level of making contact and then leaving at the end of a shift. Although Ellen let me leave her room, thoughts of her lingered in my mind – such a meaningful encounter left me thinking about the importance in dementia care of simply ‘with-nessing’.

Interview method

I conducted a series of loosely structured qualitative interviews that borrowed some techniques from psychosocial interviews, such as FANI (Hollway & Jefferson’s (2012)). As explained, I posed an open-ended question to residents and staff, ‘Tell me what it’s like to be here’. I hoped this would ignite associations of being in the home, elicit personal stories so people could talk about their experience in their own terms.

Choosing an open-ended question was guided by principles of free association, perhaps the ‘central methodology in the psychoanalytic toolbox’ (Clarke & Hoggett, 2009, p.16). A free association response follows an emotional rather than cognitive logic (Hollway & Jefferson, 2012, p 141). This approach seemed well suited to interviewing in an emotionally charged context such as the dementia care field. There is an increasing recognition (Balfour, 2006; Dartington, 2010; Davenhill, 2007) that, though people with dementia might be in a state of cognitive decline, there is an ongoing emotional awareness that may be conveyed in stories, memories, and bodily and unconscious expression.

I also used a high degree of researcher reflexivity in making sense of the data. Although this isn’t a substitute for theory, it can ‘strengthen theoretical conviction or alert to a misreading’ (Hollway & Jefferson, 2012 p. 62). This is because the researcher herself notes moments of intensity stirred up by the material. I was also interested in a main assumption of FANI, that a psychoanalytically informed technique leads to a more ethical view of the human subject in the sense that she can emerge in a more complex, nuanced way than in ‘rationally driven’ accounts (Hollway & Jefferson, 2012, p. 22) of the unitary subject.

Additionally, work of other psychosocial researchers, such as Jervis (2009) and Gilmour (2009)
lends support for the stance I adopted towards the interviews. Both researchers describe the experience of interviewing from a position of reflexivity. Jervis (2009), also a psychodynamic counsellor, relied heavily on her countertransference responses to the interviewees in her study, and to the material they generated, as a form of knowledge production. I would argue that my approach to understanding the communications of individuals and their material was similar. As noted, I also discussed two very long interviews with a former colleague to unpick further some of the dynamics at play within the interview material. The learning and analysis was iterative and ongoing during and after data collection.

Gilmour (2009) also makes an interesting point about fear and anxiety during the process of interviewing, shedding some light on techniques which move away from the certainty of structured interviewing techniques. For me, there was always the anxiety that the residents with dementia would say little, if nothing at all, and an anxiety about how to contain their fears if they arouse. It was sometimes possible to notice this anxiety in the material when, for instance, I might find myself asking more questions than I usually did and moving towards something more directive.

Gilmour (2009) discusses the power dynamic in interviews. She suggests that the interviewer has power over the question – although the more open the question, possibly the less power – but that respondents have a power to select and de-select what they share. Although my research hasn’t focused in detail on the power dynamics at play between me and the respondents, there is some investigation of this in terms of class and race, found in Chapter 4.

**Interview spaces**

At Winston Grove, most interviews were conducted in the activities room with a sign saying ‘Private’ on the door. There were still regular interruptions, noted in Chapter 3b. Interviews with residents were occasionally conducted in individual bedrooms out of the residents’ choice, but despite these spaces being personal there were frequent knocks on the door.

At Whittinghall, all interviews took place in individual’s bedrooms, mirroring the time residents spent there. Staff used the lounge area, which was never inhabited, leaving me wondering about community. All interviews were audio recorded, which raised no concerns among interviewees, and downloaded on to a password encoded laptop.

I was only able to interview participants once and, though some of the material was particularly rich, and I would have liked to have visited them to focus on particular strands of narrative. Time was a prohibitory factor, though. A wealth of data was generated through the interview process,
which became clearer during the transcription phase. As Kowal & O’Connell (2013) note, ‘sampling in interviewing not only refers to finding and selecting people to interview but also to finding the right parts in the material’ (p. 71). This is both relevant for transcription, and for analysing the content as a whole.

**Transcription**

As Kowal & O’Connell (2013) point out, it is often beneficial for the researcher to transcribe and analyse the data. Chafe (1995, in Kowel & O’Cowell, 2013) states, ‘One cannot fully understand the data unless one has been in on it from the beginning’ (p. 61). I listened multiple times to each interview in audio and carefully noted both the prosodic components of speech (way it was spoken) when noticeable, and paralinguistic components (laughter, coughing). Transcription therefore was a laborious process, since I transcribed all accounts in full. This was because I did not want to make decisions about what was important and what was less so before I had consciously began to analyse the data. Despite the time it took to transcribe the data, I nonetheless felt that this was very fruitful in terms of thoughts percolating in an ongoing way.

Equally I did not filter out poor or garbled speech since I was concerned I would lose vital evidence for interpretive purposes. Dementia often leads to confusion in verbal communication, and I wanted to capture this. I did not correct the spoken word for grammar. As much as possible, I wanted to present a close correspondence between the spoken discourse and the written record, although this is always partial. I included happenings in the environment to provide further insights into the social worlds of the organisation.

I often returned to the audio recordings to verify them, eventually reading them against the recordings in full. When I was grappling with the analysis of the interview data, I returned to the audio recordings to examine my interpretations in case there were counter-indicators to my interpretations.

As you will see in Chapters 3a, 3b, 4 and 5, I did not apply a standardizing transcription system to the data, to maintain the narrative flow of what I had heard.

**Data Analysis**

*Grounded theory*

Although I did not opt to employ a grounded theory approach (Glaser, 1978) to the collection and analysis of the data from both the interviews and observations, I attempted to derive insights
gently, as they unfolded (during the fieldwork, during transcriptions and more consciously during analysis). Like ethnography, grounded theory refers to a methodology and a product.

Although starting from a psychoanalytical orientation, I sought to avoid imposing a set of preconceived theoretical categories and notions upon the data. Rather, ideas and categories of understanding emerged from the data to explain the processes which I observed in the care homes. Resonant of grounded theory, as I collected data I was simultaneously analysing data (as noted in continual countertransference understandings). The concepts that I used to make sense of the data came directly from what had been gathered during the fieldwork. This meant that the themes were often undergoing modification and were open to negotiation (O’Reilly, 2012, p. 3). As a result the process was not a linear one, involving a sort of to-ing and fro-ing between data sets, between present thoughts and past experience, which almost mirrored the experience of dementia itself.

As Strauss and Corbin (1999) would argue, theory which comes to light in this way is ‘more likely to resemble the “reality”… than is theory derived by putting together a series of concepts based on experience or solely through speculation.’ (p. 12).

Barnsley (2016) speaks of Strauss and Corbin’s work thus:

...the essence of grounded theory is that concepts emerge from the data rather than being forced onto it, a process that requires sensitivity to the “aha moments” that result from the interplay of the data with the mind of the researcher. (p. 113).

This approach to the data resonated with a psychoanalytical approach to observational material. We might remember that theorising at too early a stage anxiously forecloses on an understanding of the situation, and the human dynamics therein. What seems to be important to both a psychoanalytical approach to analysing data and a grounded theory one is that there is an implied patience, a waiting for ‘non-coherent data to make itself a little more coherent’ (Barnsley, 2016, p. 121).

The data was subject, as per inductive theorising, to constant comparison (interview with interview/interview with observation). From this clusters of codes emerged which began to fit into superordinate categories (themes). Take for example the major theme of Time, which also included themes of ‘austerity’; ‘bullying and abuse’; ‘dependency’.

*Psychoanalytic analysis*

When I began analysing the themes in more detail, particularly through the analysis of my own countertransference, I had a lingering anxiety about imposing meanings on the material. It was
important, resonant with grounded theorising, that I drew from my own position as a researcher, constantly comparing my own pre-conceptions and knowledge in order to scrutinize what would be helpful for inclusion in the ever-emerging theories and concepts.

I hope also that by discussing the data with other psychodynamically informed practitioners/academics, and in transcribing the interview data as fully as possible and in capturing the observational material in narrative form – the voices of those I encountered have been brought to life in the mind of the reader. As noted earlier, I also spoke confidentially with a psychotherapy practitioner to discuss in depth two unsettling interviews. Opportunities for discussion meant that further meanings were evoked through processes of co-construction, helping to find meaning in the ‘irrational phenomena… by going beneath the surface’ (Willig, 2013, p. 140). These meetings also acted as a checking-in process of wild countertransference responses.

Although Willig (2013) suggests that psychoanalytical interpretation takes a ‘suspicious’ stance to the data because the approach implies that it can extract deeper meaning from the surface of the material, I would argue that the approach holds within it an empathetic stance, too. Psychoanalytic approaches to research, as Froggett & Briggs (2012) discuss, require that the researcher gets close to the subject of research through felt-experience. Equally the phenomena under investigation enter into the researcher’s psychic space. It is the interpretative phase that takes on a more ‘suspicious’ (Willig, 2013) – if this is the right word – quality. The interpretative phase is at a distance and involves drawing out meaning based on a theoretical frame, a particular language with which to contain and think about the feeling (a return to closeness) involved in the research encounter. Froggett & Briggs (2012) make clear the possibilities of psychoanalytic interpretation:

if psychoanalytic forms of attention and interpretation are brought to bear on the research object, a subtle intertwining of near and distant perspectives becomes possible. This opens up unconscious dimensions of experience in observation or interview based texts, in ways which enable the researcher to get close to the puzzling or provocative situations of practice. (p. 2)

I wish to highlight the empathetic aspect of the psychoanalytic approach because it ties in with my ethical position towards the research work. I hope that through identifying at a deep level with the experience of people in both homes, disclosing something of my own viewpoint and internal landscape, I have shown that reflexively oriented psychoanalytic approaches to interpretation do not reproduce the power relations of knower and known of which they might be accused. For me, the psychoanalytic approach begins with a curiosity towards the subject of research, leading to incremental learning; rather than being a wholly theory-driven exercise which colonizes the world
view (Plummer, 2011, p. 24) of the subject, forcing an analytical fit. The researcher in this context is not elevated to the position of all-knowing expert, whose interpretive reality is privileged (Mertens, 2013, p. 4) over the reality of those being researched. Rather, it seems to me, that theory helps to understand the lived experience but that it can also be disrupted by experience, too. As noted in Plummer (2011), there is a ‘need to see experience and life as a fluctual praxis, always in flow and ever messy’ (p. 8). I assumed that the psychoanalytic theory I applied would only partially be able to explain the myriad phenomena I witnessed yet would help to examine some of the ‘mess’.

With the interview data, I also drew on emotional responses both to the respondent in the interview room, noted in diary form afterwards, and also to the transcribed material itself – noticing specific instances that jarred. This helped me to examine contradictions, alerting me to any unspoken communications. This was helpful in gleaning something about the mechanisms at work in the organisation-in-the-mind, also demonstrating how the individual part-experience fitted with the whole.

The interview data specifically was trawled through in great detail in order to note repetitions of themes. The themes that recurred in the data most frequently were also analysed psychoanalytically.

The final methodological component of the study was the analysis of policy (Chapter 5), in particular on *Living Well: A National Dementia Strategy* (selected because the breadth of policy documents that intersect with issues related to dementia care was too vast to cover in this thesis). This was analysed psychoanalytically and compared with the field notes. Given the social component of this research, it was important to explore the ways in which dementia care policy constitutes subject positions and inscribes subjectivities (workers and people with dementia) with certain meanings that relate to wider cultural and ideological systems.

A trope for our times, dementia arguably represents a far-reaching anxiety around dependence and failing. The policy analysis part of the study sought to investigate if and how dementia care policy turns a blind eye to the relational field while (possibly) simultaneously affecting the relational by the way in which it positions professional carers and people with dementia. The analysis also highlighted the polyvocal nature of the document in order to pinpoint where paradoxes and continuities exist.

It is this combination of the psychic life of the residential care setting, coupled with a broader investigation of the social field as it is represented in policy, that I hope to have made some sense
of in terms of the lives of professional carers, those they care for and the institutions they work in. In conjunction with a key concern of psychosocial research, my aim has been to work with and through the psyche/social binary (Froggett & Briggs, 2012, p. 13) and to capture something of the quality of subjective experience without losing critical rigour.
**Chapter 3a: Findings**

Articulating unbecoming through breathlessness,
Shuffled feet and heads bent down at floors cleaned
Tirelessly by proud people tired by cuts.
Swallowed up by velvet chairs and foreheads leaning
Into cold toast on tables with wheels.
Noises in the background, antiques in attics
Discovered by loud voices and celebration
While we sit on, blankets covering legs with muscle waste.
‘I need a wee,’ we hear you but we cannot help.
Someone in uniform, gloves on
And ready. After doing one, two, three, four already.
Trolleys feeding numbers with false teeth
And changing tastes. No wine now.
Cabbages, cabbages, cabbages
But we are not that. Articulating our unbecoming
We say, ‘Take a seat with us and share
The silence that welcomes us in.’
Dog howls and rushes through
In chase of pigeons or slippered feet.
A balloon is batted past our heads and kicked
By someone younger. This is play
Still for us in chairs.
‘What is this life, if full of care,’
She mumbles, ‘We have no time to stand and stare.’
‘No, quite right,’ he laughs, ‘Sit down.’

Research diary, 3 February 2015

**Introduction**

During the months that I sifted through the observational and interview material, I was regularly taken up with the need to put some echoes of the work into poetry form. Being compelled to write like this seemed to be instinctual. I understood this process as a response to being stirred up by the experience of being with the people in these homes, reliving the experience through the material. Individual residents came to mind, as did members of staff: the smells, sounds, bodily gestures, as well as stories of past and present. The poetry attempted to make sense of what I had witnessed, creating a patchwork of memories, stringing events together, reconstructing and reconnecting time and space, even if in reality they didn’t unfold like that.

I say this because what follows is the attempt to produce something more orderly from the data, a thematic narrative, coherent and analytical. To articulate what was going on organisationally through individual and collective minds is a difficult task; the more you feel you begin to know, the more questions arise, the more the knowing feels out of reach. It was this not-knowing that
drove me to verbalise the experience poetically. It spoke to the muddle, confusion and non-linearity of being in care homes for people with dementia. That is not to say that it was impossible to isolate certain qualities of care but rather that extrapolating clear themes does not do full justice to ‘being there’ and ‘speaking with’ because being there and speaking with also allowed me to see where paradoxes and contradictions existed, where omissions occurred, and why it was so hard to make claims to truths.

Observing Daphne at Winston Grove, and Dorothy and Nancy at Whittinghall, meant sitting and walking, experiencing with them. Although I was seeing their lives and relationships through my own eyes, there were times when the full weight of pain or joy that they encountered felt as if it had penetrated my own psychic skin. These were moments when my identification with either Daphne or Dorothy allowed me momentarily to forget my own identity as a younger person, with children, in a relatively healthy body, and imagine myself in their shoes.

Interviewing staff and residents did not lend itself to the same depth of identification – words perhaps, and the perceived formality of an interview, the taking up of the ‘researcher’ role, gave me less scope for ‘self-fragilising’ (Ettinger, 2006). The reliance on language perhaps, a system that interprets and abstracts feeling and lived experience, meant that I felt more distant.

In observations, with Dorothy and Daphne, discoveries were often made through an attunement to moods, flows, sound, rhythmical movement– through the unspoken, pre-symbolic. In interviews, an increased focus on words, and the cognitive, sometimes led to an engagement of my thinking mind more than my feeling one.

That said, there were stand-out incidences in interviews where feelings were powerfully communicated: Sue, at eighty, trying to return to Bangor on the bus to get to school; Ellen struggling to match up her shoes, claiming my foot as her own; Diane likening care work to the relentless brutality of the Holocaust and other forms of racism, and Sophia trying to come to terms with death. These interviews slowed me down, opened me out to the speakers’ lives. But relationships are funny things and one major component of them is time. I wondered how much more I would have learned if there had been more time to interview everyone again.

The interviews complemented the observations: sometimes, particularly with the residents, they highlighted the muddle of dementia. Since words are at the basis of an interview, the semantic losses of older people showed up time and time again, interviews occasionally became more like puzzles. During and afterwards, I felt I had to fill in gaps to create more recognisable meaning. How hard it must be to live with, or work with, the puzzle and its ill-fitting pieces. The process
reminded me of the meaning-making that can go on between an infant, ‘before words’, and a mother. In a dementia care context, the maternal figure – if we are to call it that – helps to hold and to define meaning when someone is communicating ‘after words.’ This involves being attuned enough to another human being to be able to express what that ‘inexpressible’ thing might be.

What I was trying to do, especially with the voices of the people with dementia, was to create a coherent narrative where sometimes such a narrative was elusive. This involved a ‘holding’ together of strands. I think of Winnicott (1960) and ‘going-on-being’; how a relatively continuous sense of self is central to our lives; how, with dementia, meaning might escape us and we may need help to reconstruct it. It was a great privilege to have these conversations with residents and staff, and to find a shape, together, to the organisations they worked and lived in, and which simultaneously inhabited them.

The daily grind of the work was thoughtfully spoken about: the pressures; the ideals; the austere regimes. For some, words seemed to allow them to mask some of the hardships of care work. Nancy, who at times struggled with Dorothy, resisted thinking about her ambivalence. One or two gave glossy interviews, containing ‘advertising speak’ of the kind we might find in marketing brochures for care homes.

The interviews with staff were more self-conscious, processed, whereas material from the observations involved more leaks and slippages. Movements into the unconscious were present in the interviews through involuntarily bodily movements, coughing, laughing, and staff members sometimes used powerful images to convey ideas about the care homes.

The residents with dementia seemed less defended. Protective defences, perhaps assumed to be part of ‘sane’ adult subjectivity (Phillips, 2005, p. 69), seemed to be diminishing. Interviews were often raw, capturing emotional realities rather than factual ones. This mirrored the material from observations, particularly when residents searched for mothers on difficult days.

**The interview question**

As noted in Chapter 1, each interview opened with ‘Tell me what it’s like to be here?’ The idea was to see which versions of Winston Grove and Whittinghall were in people’s minds, and how such conceptualisations related to my observations. I hoped that through interviewees’ associations an understanding of the organisational cultures would emerge. A conceptual starting point was Armstrong’s (2005a) ‘organisation-in-the-mind’, discussed in Chapter 1. As a reminder:
Organisation-in-the-mind' is about what is happening inside my own head—it is my reality—and has to be distinguished from any other reality 'out there'. It is the idea of the organisation which, through experiencing and imagining, forms in my inner psychic space and which then influences how I interact with my environment. (Hutton, Bazalgette & Reed, 1997, p. 2)

Attending to the organisation-in-the-mind involved being present, as far as is possible, to a) the subjective experiences of interviewees; to b) the emotionally laden intersubjective experience between researcher and interviewee; and finally to c) the countertransference responses of the researcher to the interview material. Analysing these three areas in which the organisation-in-the-mind manifested itself allowed me to distinguish sometimes between the idiosyncratic and individualised responses to the organisation, based possibly in part on the person’s family-in-the-mind and her position therein; the dynamic interplay between members of staff and residents, and between staff and residents, and the modes of interaction used to sustain or to undermine relating.

It is also the case that the observational study, vignettes of which are included in this chapter, extended beyond an observation of dyadic encounters between a keyworker and resident pairing. As noted in Chapter 2, this resulted in some rich material revealing what it was like to be there, in both homes. This chapter is completely organised around the two sources of data that I collected, which has allowed me to see Winston Grove and Whittinghall in different, complex and nuanced ways.

**Winston Grove: an introduction**

Winston Grove is a 45-bedded dementia care home situated in a prosperous ward of a London borough. Very few staff live in this ward. Average house prices are just under one million pounds. The area has a village feel, occupying a meander on the River Thames. Residents at Winston Grove mainly come from outlying wards in the local borough. Many have not come from affluent backgrounds, though Daphne, whom I observed, as a former teacher, lived and worked here. She still recognised the area when she went out.

The home itself could be found on the corner of two main roads, opposite a children’s play park. To get there some staff would walk past the health centre that the residents use, others would come past the supermarket, past the pub, past the road where the day centre for older people used to be, now closed, empty. Some would get off the tube and make their way across the green, past the occasional dog walker or the adolescents chatting on a bench in front of a line of red-brick Victorian terraces. It is a lively area.
Inside the home, there is laminate flooring throughout, with darker wood panels on the outer parts to give people with dementia a good line of vision through the corridors. Toilet seats are navy blue, and there are homemade signs labelling bedrooms, toilets and kitchens. Walls in the home are pastel, and two bathroom walls have murals on them painted by residents: Cary Grant is on one; an underwater scene on another. There are two memory walls with artefacts from the 1940s and 50s dangling down, and outside in one courtyard there are chickens with very ostentatious plumage. Upstairs on the roof garden there are four rabbits. The manager’s dog is a daily visitor.

The staff team at Winston Grove have, in the past, received a considerable amount of training. In the Autumn of 2007 the home opened its first dementia unit for older people, the ribbon cut by a local and renowned actor. With this new status came person-centred care training programmes from the Alzheimer’s Society. One or two carers even embarked on dementia care diplomas which involved hard work, observations and essay writing.

Latterly, the training budget has been cut. Training is in-house, quick and focused, often through video instruction. Nonetheless, Strategy Four of the borough’s Joint Commissioning Strategy for Older People with Mental Health Problems (2011 to 2016) highlighted the need for training of all staff so that residents could remain ‘independent’.

There are five dementia care units at Winston Grove, headed up by senior care workers, although the staff team at the time of observations was not complete. Two seniors had left and the deputy manager was replaced by a deputy acting up from another home. All residents had a diagnosis of dementia. Most were born in and around London, but a few were from different parts of UK or from other continents. The staff came from the UK, Europe, Africa and Asia. During the course of observations, I discovered that some floating shifts had been reduced; the home was downgraded by CQC from good to inadequate and the local day care centre, which had historically fed into the home, had been shut down.

Whittinghall: an introduction

Unlike Winston Grove, you could not reach Whittinghall by public transport. There were no tube, train or bus links here. Along windy country roads, over bridges across the River Thames, past at least one stately home, an herb garden and several pubs serving home-cooked locally sourced food, Whittinghall could be found on the outskirts of a pretty village in Middle England on the boundaries of an Area of Outstanding Natural Beauty. Close enough to commuter towns for workers in the City and far enough away for once weary Londoners to drop down to a
slower pace, the surrounding areas of Whittinghall were in the main conservative and very green.

Whittinghall was not close to shops, restaurants, art houses or businesses. It could be found to the right of a cul-de-sac with a street of several modern red-brick houses. Whittinghall was also a red-brick contemporary home, large enough to accommodate 70 older people. An extensive lawned garden went all the way around the house, and two Juliet balconies at the front of the home gave residents the opportunity to watch the comings and goings.

Part of a large private care home organisation, Whittinghall provided a combination of residential, nursing, palliative and specialist dementia care. The organisation, Wellbank Homes, prided itself, according to its promotional literature, on having its own dementia care strategy. In recent times it had received a dementia care award. Whittinghall had received ‘good’ in its recent CQC inspection. It had input from some of the best minds in dementia care design: fabrics were warm and bespoke, carpets and wallpapers offered comfort and luxurious design. Walking into Whittinghall was like walking into a four-star hotel. It made you want to sit down, have a coffee and read the paper. Smells of urine, bodies, disinfectant were absent. Residents were not conspicuous at reception. There were just some small telling signs that alerted you to the true purpose of the building: photographs of older people playing a quiz, a notice about an upcoming relatives’ meeting and the many signs on toilets, clear and in bright yellow, and on corridors, categorising spaces, and the memory boxes on the front of bedroom doors. These were the dementia-friendly signs that any good home would have, the acceptable faces of frailty – degrees of frailty. Instead of reading ‘nursing’, ‘dementia’, ‘palliative’, units were given names that might be found on any home in any street: ‘Huntside’; ‘Appleyard’; ‘Berryhill.’

There was a permanent receptionist who greeted visitors on arrival, directed them to the signing-in book. The staff team at Huntside, the unit in which I observed, were young, in their twenties, some from the UK, Europe and Asia. This was interesting because the unit was for elderly frail people, and cases were regularly palliative. The residents were all from the UK.

**Themes**

A wide range of themes emerged from the corpus of the fieldwork. During observations I noticed certain repetitions, patterns, as the weeks unfolded. I began to notice a strong presence of certain themes in one site, and stark absences in another. In interviews, themes emerged because they were frequently discussed, not always directly or in all interviews. Some interviewees touched on only one or two whereas others brought multiple themes into focus.
The themes had different meanings to different people. For instance, the theme of time was regularly addressed, though time for a carer was not necessarily conceptually equivalent to the notion of time that a person with dementia might indirectly refer to.

For the purposes of creating a general thematic landscape, which drew on both the observational and interview data, the following themes were identified. As you will see, the emboldened, underlined categories are those which emerged directly from the material, often used by the participants themselves in interviews in order to understand their own experience. The subset of categories that follow are those which I have developed – some borrowed from theory, some implicit in the material – to make further sense of the overarching first-order categories.

**Time**
- Dependency
- Play
- Bullying and abuse
- Splitting of good and bad care
- Disconnection and connection
- Austerity

**Mother/s**
- Lost objects
- The Matrixial
- Holding
- Reparation
- Interruption

**Death**
- Aliveness, mania, control
- Mourning
- Occupation and social death
- Anxiety
- Absence
- Regulation, policy v. play

*The data*

At times, the thematic picture that evolved through the interviews overlapped neatly with the observations. At others, the reporting seemed to be in disconnect with the observations. This was rare but noticeable. The disconnect itself perhaps spoke to something at play in the organisational culture itself. I will describe in this chapter and the one that follows the three significant themes, noted as observer and as interviewer, which take us to the heart of the experience under investigation: time, mother/s and death. I will explore these themes using vignettes from the observations and quotations from the interviews. Time, mother/s and death.
were strongly present in both sets of fieldwork. As a result, I believed they would be a useful way to organise my thinking about the experiences of the staff and residents as members of the wider organisations.

Time was ever-present in my observations at Whittinghall. I noted myself studying my own watch there. Dorothy, whom I observed in the home for three months, was seated opposite a clock. The long hand of the clock felt as if it were barely moving each week. This focus on time related to the overall, sometimes paralysing, sense of waiting at Whittinghall. Ironically, the staff team never seemed pressed for time. Time was heavy and available yet the availability of time was not necessarily used in service of the residents.

In Winston Grove, there was little evidence of staff breaks. In every interview staff spoke about the lack of time. This mirrored the observations, in which staff seemed to be permanently busy doing one thing or another. They needed more time for dressing, more time for playing and feeding, time for training and reflection.

In both sites, the residents were observed existing out of linear clock time, revisiting earlier periods of their own history. In interviews, residents often tried to bridge the gap between the present and the past. The future was never thought about. Mother/s emerged as a strong category because in observations at Winston Grove, residents sometimes looked for their mothers around the home, particularly when they felt overwhelmed with powerful feelings. Staff also connected the care work they provided with imagined informal care that they might have wished to offer their own mothers (and sometimes fathers). However, at Whittinghall, the mother figure was noticeable by her omission, in observations and in interviews. This present-absent divide acted as a provocation for further thought. It introduced interesting possibilities for understanding the overarching ‘quality’ of care in both organisations. That said there were other important figures (familial objects) that featured in interviews and in the daily life of the care homes. In Chapter 3b, I will expand upon the category of mother/s and think about the homes from the point of view of a matrixial field (Ettinger, 2006).

Finally, death, the impact of loss, was pronounced at Whittinghall. The theme of loss – missing people and objects – was a recurrent theme, taken up in two interviews from the staff team and one resident particularly. I was struck by this because the interview material from the staff at Whittinghall was generally at odds with what I had observed. However, on death, the observations and interview data married up.

For Winston Grove, death was shut off behind closed doors and the push towards life and living.
Activity generally took precedence. Although Daphne’s (the subject of my observations) long-term partner, Benjamin, died towards the end of the observations, no one spoke with her about him despite her palpable pain. Even his funeral was resignified as a regular day trip out. Similarly, a death in room two, on the first day of my observations, went unremarked: I never discovered who had died or how. Again the interviews bore out this organisational denial. Although the physical death of residents was never acknowledged, there was a sense within the organisation that a different kind of death was being lamented. Some members of staff seemed to imply that, over recent years, they had experienced an occupational death. In the context of austerity politics, their work as carers had been systematically undervalued. Corners had been cut which made it hard to do the work; it was less rewarding and more rushed. These differences between the two homes raised questions, of which I will try to make sense in this and the following two chapters.

In this chapter, I will consider the findings for the theme of time. This was a very strong category, and a large amount of data was gathered on this theme. I had hoped to bring the themes of time and death together in one chapter, since arguably there is a relationship between the two. We are temporal entities; our finitude written into our very existence. There was also a clear link between the conceptualisation of time-as-brutalising and the sense of an occupational death as a symptom of austerity measures; and for the residents there was a need to access time to do some gentle mourning in the presence of a responsive other. However, for pragmatic reasons, owing to the amount of material gathered on the theme of time, I have decided to make this a stand-alone chapter.

I will therefore discuss the theme of mother/s and death in a separate findings chapter (Chapter 3b). Mothers were important in the internal worlds of staff and residents, and in the interpersonal spaces at Winston Grove, and seemingly absent at Whittinghall. Beyond this, the maternal figure has an especially pertinent link with the psychoanalytical literature, which helped to frame this study. Though the link between time and death, in my mind, was a more obvious one, I did wonder whether mother becomes re-imagined, and yearned for, as we get closer to death and dependency.

To note, each interview participant will be introduced with text given in italics.

**Time**

During observations it became clear that competing notions of time often caused organisational tensions. This was particularly evident when residents’ needs, many immediate, were at odds
with the home’s routines, time-tabled according to linear clocktime. In Winston Grove, there was a greater rebellion against time constraints. Sometimes carers, particularly in Daphne’s unit, seemed to slow it down deliberately. I witnessed this a few times during lunchtime. This seemed to suit the staff more than the residents, even though staff reported in interviews that going slow benefitted residents. At Whittinghall, time was generally more available, owing partially to the greater number of staff on shift. Staff took more breaks from the work, and were often seen drinking from their own bottles as if refuelling. This availability of time, yearned for at Winston Grove, did not mean that staff at Whittinghall made more contact with residents. On the contrary, the staff took the opportunity to congregate together around the nurses’ station, as peers.

At Winston Grove, references to time and its significance in and for care work were frequent. A common association was made between good care and time-spent with residents or time-given to staff. Many carers talked longingly about ‘one-to-one’ time; a short-hand for a form of rewarding relating where both parties could exchange personal details. These almost sacred encounters were considered scarce and in counterpoint to the general busyness of care work and its associated tasks. At Winston Grove, carers were saddened by the reality that time was becoming increasingly stretched: at least one floating shift (covering breakfast) had been cut, leading to what they described as ‘conveyor-belt care’. At Whittinghall, time was not mentioned by staff in the interviews.

The experience of linear time was shaky for all residents. The fact that, at Whittinghall, the staff team had placed a ‘day of the week’ sign up for Dorothy demonstrated how precarious temporal markers were. People with dementia seemed to exist in the moment without an external temporal frame; time was internally defined and as a result many retreated to times that had long since passed.

**Staff experiences of time**

The following interview material on time is mainly from Winston Grove; only Nancy’s is from Whittinghall. This is because she was the only staff member there who talked about time. Observational vignettes which relate to time are from both sites.

**Bridget**

*Bridget, a long-standing member of staff, doubles up as a cleaner and a breakfast assistant. She is in her early fifties, a vocal woman, often prompting carers to respond to residents. After she has done her breakfast shift, she is able to speak to me for over half an hour.*
I talk to her in the activities room, a colourful space in the home, at the end of the ground floor corridor. There are paintings on the walls. This is where the activities co-ordinator, Gemma, runs craft and ball groups. Bridget is happy to talk to me and on the surface shows no anxiety, smiling and laughing throughout. I wonder if her laughter masks some nervousness. She had known me many years before when I was an activities co-ordinator in the home; I wonder what she makes of my return, coming back as I do, with recording equipment, paperwork.

Bridget imagines herself as holding a privileged position within the organisation, as the breakfast work affords her a slower pace, the chance to be with the residents. Here Bridget talks about her perceived place in the organisation, and how it relates to time.

E: Please tell me what it’s like to be here...

B: It’s nice. Residents are nice. A lot of the staff are nice. Um, I do enjoy it. There are different aspects to my work that (a resident walks into the room, standing behind her, mumbling something. He moves from one foot to the other) I do. (She smiles, noticing him standing behind her. He then leaves). So I spend a lot of time with the residents in the morning and then during the day I’m just doing my work. I sit, chat, laugh, joke and we sing sometimes (breaks into laughter). It depends how somebody’s feeling and... so this is all happening while we’re doing breakfast (laughs again)

...

E: Is that quite a privilege getting one-to-one time?

B: It is (very forcefully) cos they don’t get it during the day cos obviously there’s lots going on during the day and it can get overlooked.

...

E: You say you spend one-to-one time with the residents, does that mean that you have relationships with some people?

B: Yeah very much so. Yeah, I can get someone to do something that you can’t (laughs). Cos I have more time cos obviously carers are busy... they’re doing the basics whereas I don’t have to do the basics.

E: When you say the basics you mean things like...

B: Personal care whereas I don’t do any of that. I would call a carer to come and do that...
And I don’t do medication, anything like that, that a resident is going to associate with a carer. I have the nice bit. I’m going to give you something to eat and we’re going to have a laugh and a joke whereas a carer doesn’t have that time cos they’ve got 8 to 10 residents on their unit that they need to be giving personal care to...

(The activities coordinator’s puppy is in a cage in the room –squealing).

B: ...I’ve got the fun bit really (lots of laughing).

E: Do you think that, how do you see it, do you think the fun bit allows you to connect with people?

B: Yeah because, although some people may not be able to string a whole sentence together (dog squealing) if you listen carefully and you’ve got one-to-one with somebody who can’t string a sentence together you can make sense of what it is they’re trying to say so you can work out what it is they want and you get that smile at the end of it rather than an aaargh (she enacts a kind of roaring)... Which some residents do and I think they must find it frustrating as much as we find it frustrating... and that’s why I think it’s important if you can spend time with residents... I think it’s great even if they don’t make sense but neither do we at times.

(The puppy is squealing. A male resident has wandered in, muttered, and left).

B: Oh, it’s knowing the little things... and I know little things because I’ve seen somebody kick off and it’s like ooh, now, why did that happen? And I can take time to retrace why... I might have said something wrong or I’ve said yes when they’re trying to tell me no so you think, oh fine, that means no then...you pick up on how they’re trying to tell you.

(Interview, 3 March 2015, Winston Grove)

As will be evident from the preceding material, the organisation-in-the-mind for Bridget is one that is hurried, in which carers find minimal time to spend with the residents, yet fun and understanding is available, at least in her role. The one-to-one possible at breakfast gives Bridget the opportunity to engage in play, laughter, singing with residents. Time is seen as a way into connection.

Despite her formal working role as a cleaner, Bridget conveys a sense of authority. Her formal role might have been associated with a lack of education, with a lowly position in the organisational hierarchy, but during the interview, I had a sense of Bridget’s agency. She makes
claims to know the residents and to be able to work with them in a way that others could not (she knows more than ‘you’). It is as if she has to assert her position. Perhaps beneath the voice of authority, she is regretful that she is a cleaner. She seems to have more to offer. I wondered if her nervous laughter communicated something about the riskiness involved in stepping out of role, yet simultaneously her assertiveness seemed striking.

It seemed that her sense of authority related to her ability to claim time within the organisation, and to know the residents well. The time which was available to Bridget also linked with her desire to be considered, I thought, superior to carers. I wondered how issues of race and class featured in this quiet jostling for position. I certainly had the sense that Bridget wanted me to see in her a breadth of capacities which weren’t commonly associated with cleaning. That said, from my experience of working in different care environments, I have often noticed that people conducting domestic duties are able to make genuine, and important, contact with ‘patients’ when nurses or carers are busy with other tasks.

At Winston Grove, I also witnessed moments of pleasure, nurture and play – the spontaneity Bridget alludes to – as part of the culture of the home. For Bridget relating like this, supported by time, facilitated knowing and discovering. There is an association between meaning-making and time in her interview. The home is a place in which coherence is sometimes out of reach, where residents are not able to string sentences together. Bridget believes she contributes to meaning-making through attending to, and accepting, the unlinked communications from residents in play.

The way that Bridget sees her privileged position vis à vis the carers is also indirectly a reference to some of the organisational splitting among the staff team. Carers saw things very differently and did not feel excluded from intimate encounters, in the way that Bridget imagines. I wondered if Bridget was demonstrating some kind of inverted snobbery, elevating her on-the-job know-how above those paid and trained to care; above people like me, formally researching the care context. I wondered how she felt in relation to the carers, to others working in higher status roles, a matter I will discuss further in Chapter 4. Bridget’s superior position in her mind might have referred to an organisation-in-the-mind, conceptualised as divided, competitive. However, although there was evident competition within the organisation, this usually played out between temporary and permanent workers. For instance, there had been a difficult relationship between Zalee, a temporary carer, and a permanent worker, who had to step in to rescue a difficult pre-lunchtime shift. (This scene will be discussed later in the chapter).

However, observations of Bridget also suggested that she collaborated with the care team to
provide support for the residents. Here Bridget helps out unquestioningly, noticing that the carers were limited by time.

Bridget joins into help, sensing that lunch is on a go-slow. There is a conversation about the woman with the bright light near her. Bridget asks her what food is going to be appropriate, soft food. She suggests that they give her chips to suck on for now.

*(Observation, 27 January 2015, Winston Grove)*

Bridget represented something about Winston Grove’s adaptability. However, the spirit of mucking-in that Bridget embodied was a capacity shared by other staff, even though she had more time to muck in than others did. This access to time seemed to offer her, and staff like her, a protected space within the organisation. This was linked to a belief that those with time at their disposal could achieve greater connection through play, the social, than those hurriedly on-task. Being able to play, to engage socially with residents, was considered a privilege. Of course, Bridget made an important case for human contact in a care environment, and it did seem a reality that she was not as rushed as carers. Nonetheless, Bridget seemed to align herself with workers like Gemma, whom I will discuss in a moment, educated and senior to carers.

Gemma, the activities co-ordinator at Winston Grove, also presented herself as someone able to create connections, in contrast to the rushed care staff. There were some overlaps with Bridget’s material, an agreement that time afforded a better quality of relating. Gemma, however, was a graduate and, despite her formal education, she seemed less confident in her role within the organisation than Bridget did.

**Gemma**

*Gemma likened herself to a ‘nanny and granddad’ because she had the time to have ‘fun’ with the residents. We are in the activities room. Gemma is in her mid-twenties. She has worked in home care, nursing care and residential care since university. She does not often do the ‘basics’. She takes residents on local trips to the shops, cafes and parks. She speaks to me after her morning group activity for over half an hour.*

*I had worked as the activities co-ordinator many years ago. Gemma sees me as an ally. However, she stops the interview midway fearing that she is not responding ‘right’. I wondered if she felt I might be critical of her way of doing the job, as if I were more experienced; Gemma was still relatively young. I also wondered about her formal education and whether,*
organisational, doing-the-work in a hands-on way was valued over formal qualifications.

In this extract, Gemma talks about a successful example of her work, taking time to get to know a resident in preparation for a celebration. In counterpoint, she presents a picture of heavy daily care work.

G: ... We did some research with her daughter... we got the family involved ... the lady who was Chinese ... really enjoyed that day and her family actually came and enjoyed it with her.

E: Yeah

G: Joined in which was nice... it gave us activities and like arts and crafts ... we made a Chinese dragon. We looked into how... what Chinese dragons look like and how they were decorated, and the colours... painted dragons and put them up. It was quite good. So all the residents got involved in various different ways... And then people were experiencing... that they may not have experienced before...

E: Um

G: ... and because it had food involved it went down very well. (Smiling, and breaking into laughter). It was, like, something for, um, all the senses.

(A male resident, fond of Gemma, walks in, stands behind her coughing. He leaves when he notices that she is doing something.)

G: (wanting to say more). And some people just don’t realise that... They think, Oh I’ve done my job... they’re dressed, fed, watered ... we’ll just leave them in front of the TV. (Brief pause). What kind of a life is that really? They may as well... just existing.

E: You said earlier that if you were a carer full-time it would be hard.

G: I think it is back-breaking work... not enough carers, even in a care home that’s fully staffed... I don’t think there’s never enough ... People tend to run around and pass people in the corridors, say hi as they’re going past...as a carer they always seem, it’s that side of them... Oh they’ve not got up, they’re not dressed and they’ve not had their breakfast. Their concentration is doing that side of it. I think they need to have more concentration ... with people ... stimulating them, talking to them, making them feel special, making them feel like they’re wanted.
... they feel they have hardly any time to get things done.

-------------------------------

G: Yeah, because in a care home you only have so many staff that are allocated to so many residents and people try to (muffled word)... and cutting costs and things like that... um, where am I going with this now? ...it gets a bit more regimented so you have lunch at one o’ clock. Now you don’t have to have lunch at one o’ clock but people make them try to have their lunch at one o’clock cos it makes it easier. And cos there is a lot... there are like 43 people in this home... so 43 people and you’ve got two carers per unit, which is what two, four, six, seven, eight carers and you’ve got your domestic staff on top. It’s pushing it... because there are high levels of needs, you know. A lot of people aren’t able to... put on their own clothes and give themselves a wash

E: Um

G: You know, we’ve got people who are hoist dependent... completely dependent on you to.... You know... carers are running round, trying to tidy their bedrooms as they go... make sure they’ve eaten, make sure they’ve had a drink, they’ve had their medication... (short pause). It’s hard. They need someone who can just be around to ...a member of staff available so they can get that person up with no rush. So that time’s not rushed...

(Interview, 3 March 2015, Winston Grove)

-------------------------------

Time is associated with pleasure, and activity. In Gemma’s mind, she is involved in a form of relating that is relatively free from conflict. On one level, Gemma expresses real empathy with busy carers. She talks of the back-breaking work (reminding us of Daphne’s former keyworker, Erica). They are positioned as task-driven and time-impoverished; up against a clock. On another level, she is quietly critical of carers, imagining them forcing time on residents for their own convenience. Again we see an organisation-in-the-mind imbued with splitting and division – a psychic and relational process organised by the structuring of tasks by time.

These distinctions were sometimes observable on visits, but there were many examples that challenged the neat split that Gemma perceived. During one exercise activity, Gemma herself was outpacing the residents, jokingly calling them ‘wet lettuce(s)’ for their slow movement, as we see here.
Gemma begins marching quickly, the residents march slowly. Gemma starts making scissors shapes with her legs; the change of pace is too much. Gemma gets out a small plastic basket of beanbags and hands one at a time to each resident. She asks them to move them from one hand to the other. Only one resident copies her. Daphne is holding her beanbag and rubbing it between her fingers, looking at it as if it holds some kind of magic. ‘Oh dear, everyone’s a bit of a wet lettuce today,’ says Gemma.

*(Observation, 30 December 2014, Winston Grove)*

Contrary to Gemma and Bridget’s representation of carers, I often saw evidence of carers slowing down time to accommodate the needs of residents, where there was a careful pacing that mirrored residents’ experiences. In the following vignette, Bridget, the deputy manager, Lynn and a care worker, Erica, stop to make time for an encounter with Daphne that, though brief, is meaningful. This vignette, along with others scenes that I witnessed, provided evidence to suggest that the splits around time were not as entrenched as Bridget and Gemma imagined.

Bridget smiles almost as much as Daphne does and the two have a brief but warm exchange. ‘Thank you for your help earlier, Daphne,’ says Bridget. ‘You’re so helpful.’ Daphne laughs. ‘Oh yes,’ she says. ‘Always smiling. Easy to make you smile.’ Bridget thanks Daphne for putting the wires away. ‘Hey ho, the Barley Mow,’ says Daphne. The cleaner laughs and bends back down to finish putting the hoover away. This is one of those encounters where people, in spite of their differences, see each other.

In slippers today, there is no sign of a trip out. Daphne is wearing a long navy skirt and a cream patterned blouse with a grey cardigan. On top of that, she has a blue floral short-sleeved top. She is comfortable in her ensemble, looking at ease in her body as she walks through the corridor, smiling. Daphne, we might surmise from the layering, has dressed herself. On either side of Daphne are lilac walls and beneath her slippered feet laminate. Ahead the corridor looks busy but Daphne is walking on assertively. She stops behind two carers, who are spilling out of the senior care office. As if coming to attention, Daphne stands behind them.

Some days there is a lot of smiling. A carer, Erica, is smiling at Daphne right now. ‘Hello, Daphne,’ she says, taking care to name the old woman. Daphne stands so very still and makes a salute, raising her right hand to her head, bringing her heels together as if she is a soldier. ‘Hello there,’ she says. Erica is laughing with Daphne, mimicking her movements, bringing her right hand to her head and her heels together. ‘Good to see you,’ she says. Watching this
scene, you’re reminded of mirrors, of play, of seeing yourself in others, of pleasure. Erica is Daphne’s current keyworker and possibly knows her better than some of the other residents with whom she works. It would have been up to Erica to settle Daphne into the home; to make an inventory of her clothes; to make sure her toiletries are replenished; and to plan her care notes.

‘Always smiling faces, how very nice. Good good fun,’ says Daphne.

Daphne has a knack of making friends. Now the temporary assistant manager, Lynn, comes out of the room. Like Daphne she seemed to make friends easily.

‘Hey ho the Barley Mow,’ says Daphne at the top of her voice, repeating one of her favourite expressions.

‘Hey ho the Barley Mow,’ says Lynn. ‘Hey ho the Barley Mow... You know Daphne, I can’t stop saying that. It’s really stuck in my head.’

You might think Daphne would be pleased to hear that she, or her saying, has found a home in someone else’s mind, like a song repeated on the radio. But this kind of spotlight might be too much for Daphne. She looks more serious now and, making eye contact with Lynn, ‘I am sorry. I am a silly sausage, I know.’

Lynn is moved, and so she does move... closer to Daphne, putting an arm gently around her shoulders. Their heads almost meet, touching. ‘No you’re not, Daphne, you are so much fun.’

‘With the bum, bum, bum,’ says Daphne, trying to rhyme. Hearing this play on language makes us think one of two things. Daphne is either living up to her name as a resident who has fun, or she is enjoying the freedom and spontaneity she finds in words. It’s no surprise that Daphne sometimes quotes WH Davies or Shakespeare as she walks around the home.

Daphne laughs and Lynn does too, still hugging Daphne. ‘I think we have an awful lot to learn from you, Daphne. I really do.’

‘Thank you,’ says Daphne, recognising the kindness. ‘Every loves.’

(Observation, 29 October 2014, Winston Grove)

Although Gemma bemoans the fact that carers are too rushed to take an interest in the residents, scenes like the one above countered this. There was also the day Daphne had a chill. That day she had felt neglected by Gemma. It was a carer, mother-like, who had made time to
fetch her blankets and tea.

‘You have a chill,’ says the carer. The carer leaves the room and returns with a fleecy blanket and another larger one. She asks Daphne if she would like them. Daphne smiles, ‘I would, yes please.’ The carer places them over Daphne’s legs and up to her waist gently. ‘That might be nicer,’ she says. ‘It’s cold.’ ‘It is,’ says Daphne. ‘Thank you very much.’ The carer offers Daphne a cup of tea and Daphne says that she would really like one. She puts her arms under the blankets and her body begins to relax.

(Observation, 23 December 2014, Winston Grove)

Nonetheless, for Gemma time is understandably written into the kind of practice that allows residents to be treated well, as special. Gemma talked about working in home care where she stretched time, sacrificing her own time, fighting quietly against service-provider timetabling. Choosing time becomes an ethical dilemma, one that can lead to worker exploitation. Other carers at Winston Grove talked about their mini-revolutions against time constraints. This ethical stance means that carers feel they are doing the right thing for residents, but organisationally might be doing the wrong thing.

Ending the interview, tape off, Gemma takes me aside to tell me how she would love to be in closer communication with her work colleagues. Gemma worries about being alienated and having to pull the psychosocial weight of the organisation. She did have a generative role within Winston Grove and sometimes active engagement with residents got located in her. However, carers also reported having meaningful encounters with residents, yet they approached intimacy in different ways. In actuality, Gemma was rarely alone, running the activities groups.

It is interesting to note that Bridget and Gemma’s interviews were the longest out of all the members of staff. This seemed to indicate that carers were generally more hard-pressed than Gemma and Bridget were, and that the care workers did not always have time for slowed-down human interaction. However, as indicated, my observations suggested that the distinction (in terms of having time to relate) between their roles and the carers’ was over-drawn.

There was one carer, April, who stood out, giving the longest interview of all carers. She was also the longest-serving member of staff at Winston Grove.

April
The activities room was being used for staff training. April and I had to use an empty bedroom. April is given clearance by the senior to be interviewed. She takes a chair in the sparse bedroom and I sit on the edge of the bed to speak to her. A power dynamic already in play?

We had worked together in the same unit, both as frontline carers, many years ago. She had taught me the nuts and bolts of care work. (I wondered if she remembered teaching me, especially when she talked of training temporary workers on the job.). My memory of April was that she took a lot of pride in her work. Though she was strict, particularly with making sure residents were clean, dressed well, I admired the way she believed the work had to be done with great care. Although she had seen many changes in the home, appearing exasperated by many of them, her attitude to her work and to the residents had not altered much.

A: You give him a drink and he will calm down because he doesn’t say oh I’m hungry I want something to eat but he is like the same person. When I went to the new unit, to this one, all the handover was, ‘didn’t eat his lunch, didn’t eat’ so I was under the thing of observing this situation then I observe, ok this man is coming down at 11am, washed and dressed, because of his meds he tends to sleep late and I’m not one for waking people up because what’s the point of waking them up because they get all agitated. Let them sleep, give them whatever medication and then eventually get them up. This person comes down at 11am and that’s where I talk about this hotel-model care, everything is done in this block of time. Hotel-model, that’s what I call it. Or what happens in the hospital. Personal-centred care is not based on this. I observed him at 11 o’ clock and then comes dinner at one and you sit him and give him his dinner, and he’s not eating his dinner and they hand over ‘such and such didn’t eat.’ Well, 11, 12, 1 would you go and eat (astonished) after having had breakfast at 11?. Go having a big dinner, it’s common sense. Stagger it.

E: Stagger it.

A: Give it a bit later... Common sense has to kick in. So yeah.

E: But I suppose, on one level you’d like to give everyone person-centred care but there are these limitations at the same time.

A: Staff. That’s the issue. It’s the staff... in this unit... don’t have like before a domestic that would help with the breakfast. I get in in the morning, we set up the tables, you get everything ready, porridge, then before you could go off. So for me one is up and one remains in the event of anything, one goes up to the residents, up, and one has to be down.
A: I don’t mind that to a point, you know if you’re not certain just ask to ... You know it’s just you find yourself going and going and going all the time. Aahhaaaaaahaaa (as if in pain). It has its challenges, challenges in its own way. But what we need is continuity of staff and I think maybe it’s all to do with them at the top and their finances but make us work on a lesser staff ratio and don’t expect the same because something is going to fall short. And if you are going to be on people’s cases people won’t be doing things the way it should be done. And um I don’t know about conveyer-belt care, I know about person-centred care and that’s what I’m going to do because I like to treat people the way I want to or would like to be treated if I cannot do things for myself any more. You know, so... I can’t do it differently. If I go into help someone it has to be properly done. I don’t do shortcuts.

E: No

A: So when somebody going to be taking ten and I’m taking 15, 20 because I’m allowing you, I’m showing you which one would you like to wear today? I’m not choosing that for you... And these things take time... Not you just rushing them. Let her do what she wants, wash here five minutes, let her get on with it, maybe that’s how long she took to wash there. I cannot change because oh you want this done in this time when the person wants this time. No I can’t do it.

(Interview, 24 March 2015, Winston Grove)

April points out that one of the reasons that there are more time pressures on her and other permanent staff is because the floating domestic shift that helped with breakfast has been removed. Getting the residents ready in the mornings feels like a production line (which she calls ‘hotel-model’ care – everything done in designated ‘block[s] of time’). In order to provide the person-centred care (synonymous with empathy, attunement) in the way she would like, she makes the decision to resist hurrying the residents. There is a painful recognition that the practice of care is being distorted by economising, and relatedly increased demands on workers’ time.

April has a sense of her practice being driven by an ethical imperative, which involves working at residents’ pace and knowing them. This sits in tension with what she sees as the current demands on care workers, and ‘splits’ from the temporary workers.

In the following observational vignette, we see evidence of the staffing issues that Winston
Grove faced. April suggested that the number of temporary workers in the home affected the consistency of care provided. It also meant, for her, that the effort and time that permanent carers had spent getting to know the residents was undervalued organisationally, as if temporary workers could do the care in the same way, without the intimate knowledge of the residents’ experiences. Here we see, Zalee, a temporary carer unaware of and apparently unconcerned about Suki’s needs.

Next to the entrance is Suki, low down in the chair, with a wheeled table over her legs. ‘I need a wee,’ she cries out. She repeats herself again, stuck. She shouts again, as if in panic. We are all urging someone to come.

Daphne looks at her and sighs. It is true that Suki has a tendency to shout out into the lounge. ‘Help me. I need a wee.’ A carer has entered the room, but she is standing over two residents deep in conversation with one another. The carer is unfamiliar, perhaps a temporary worker.

Another carer, with a headdress, walks in, notes in hand, swiftly followed by a male senior carer. Suki calls out again. The senior carer goes directly to the woman, next to Daphne, sleeping in the corner. The carer with the headdress stops by his side, as he bends down towards the woman. As soon as he kneels, he turns to the carer in the room, who is standing by the two residents in conversation, ‘Zalee, please take Suki to the toilet, she is in need.’ Despite his assertiveness, the carer walks reluctantly, without urgency, towards Suki.

The carer with the headdress asks Zalee why the tables are not laid for lunch, highlighting her failures. ‘It is 1.05 and lunch is supposed to be at 1,’ she says. She mumbles something about having to stay with the two women. It is not clear why. The permanent carer shakes her head, not buying it.

Zalee moves the table away from Suki, bringing the zimmer frame to her. ‘She can walk to the toilet or do I need a wheelchair?’ she asks. There is a conversation about Suki’s mobility, a sort of on-the-ground care planning. Zalee asks Suki to stand. Suki is not able to do so. She starts to tell the carer that her ‘son is a doctor’ and that he knows what is best for her. She says that she needs a wheelchair. The carer shrugs her shoulders and shakes her head. ‘Stand up,’ she says, exasperated.

‘This isn’t good,’ says Daphne. Consultant-like and examining, Daphne notices so much at Winston Grove.
The male senior asks the old woman, who is waking from her deep sleep, if he can take her temperature. She nods, half-asleep. He takes her temperature by gently placing a thermometer in her ear. ‘She isn’t well,’ says the carer. ‘She is wheezy. Listen,’ she says asking the male senior, an authority, to listen. He explains to the woman that he is going to listen to her chest. He places his ear above her chest and listens. ‘I don’t think she sounds too bad,’ he says, contradicting the carer but careful not to humiliate her. ‘Let’s keep an eye on her, you are right, and we will call the doctor if you think we ought to.’

Daphne watches Suki who has forced herself up to standing, sensing the imperviousness of Zalee. But she falls back down. ‘My son is a doctor,’ Suki says again. Zalee tells her that she can stand.

‘Oh dear,’ says Daphne, shaking her head. It seems impossible to make sense of a place like Winston Grove through these two very different scenes of caring.

‘This is bad, very very bad,’ says Suki.

The other carer returns with the wheelchair and starts to park it up. All the while Daphne is watching. She has both hands clenched tightly, the scene she is witnessing seems to make her tense. It is a sort of will she, won’t she, get to the toilet in time. She releases them momentarily and brings both hands up to her cheeks. ‘Life goes on,’ she says.

The carer with the headdress turns to Zalee, rescuing things, ‘I will lay the tables and get everyone to the table.’ The partnership is a frosty one.

(Observation, 6 January 2015, Winston Grove)

April’s relationship with time gives her a unique platform among the interviewees. She has worked in the home for over twenty years, experiencing many changes around care policy and practice. For April, working in older people’s care had become increasingly difficult, in the face of resource cuts, more paperwork and frequent changes of staff. Having survived the changes, her voice is forceful and knowing. Her time in the home offered her a different sort of expertise to other carers I spoke with; I noticed myself hanging at times on her every word, as if she could tell me all about good and bad care. If we are to think about Winston Grove through the lens of April’s organisation-in-the-mind we see an organisation prone to splitting.

There is a divide between the good old days, where work was perhaps more rewarding, and the present, a rushed, corner-cutting version of care. April’s account no doubt had a rational, objective basis because she, like others, had witnessed funding cuts, poorer care, and a move
from person-centred to more regulated forms of practice. Other distinctions were powerfully drawn, between temporary and permanent workers; hotel-model care and person-centred care. However, I also wondered if the splitting, evident in her material, was in some ways a retreat from thinking about the sadesses that April might have been experiencing in terms of her own personal loss, having once had a valued occupational role. Her anger about the situation – as seen in these divisions into good and bad workers, types of care – nonetheless seemed to be an important position to hold on to. By feeling justified in her position, she was able to stage a daily protest against the time pressures she believed were eroding good care.

There were many other examples of splitting at Winston Grove. As well as splits between staff who ‘have time’ and those who ‘do the basics’, which I have already discussed, there were splits among residents as if some had a sense of the organisation as benign; and others a sense of it as being bad. (For instance, there was Ann who raged against the ‘kids’ activities during a painting group and Daphne who wanted to express some gratitude for it.) It was possible that these tensions were symptomatic at times of a pervasive organisational paranoid-schizoid functioning (Klein, 1952), about which I will save a theoretical understanding of for Chapter 4.

April had the confidence to buck what she saw as the current system – hotel-model care wrapped up as person-centred care – in which carers were under pressure to ‘do’ people in ten minutes. Cutting time was related to the wider austerity agenda. April represented a quality of worker delinquency/rebellion that seemed part of the home. This was something of which workers and the manager seemed proud; equally, they consciously associated this stance as having an ethical underpinning. It was about making human lives better.

It was curious that April had talked about the notion of hotel-model care because Winston Grove was nothing like a hotel. Whittinghall, however, could be placed in this category. I often observed how time there related to service, rather than connection. In the following vignette, the tea-and-biscuit waitress stops: time supports something transactional.

A young girl dressed in black trousers and a black waistcoat with a white shirt walks past with a trolley. ‘Dorothy will,’ says the girl about the biscuits on her trolley, a foregone conclusion. She offers the plate to Dorothy who looks at the tray of biscuits and chooses two malt biscuits. ‘Oh two,’ says the waitress. ‘Of course.’

(Observation, 10 June 2015, Whittinghall)

April, in contrast, positions herself as a person-centred carer, who takes extra time to fulfil her responsibilities and to offer choice. April’s longevity in the home seemed to give her a strong
sense of identity as a carer; she inhabited the role with self-possession as if she would not be beaten. Time was linked to wisdom, to identity.

April’s voice was politicised. At a later stage in the interview she says, ‘You cannot rush care; you cannot compromise care.’ April implied that good care involved engagement, which was either restricted or supported by the availability of time and funds. When time is short, she argued, the quality of relating between carers and people with dementia is compromised, leaving both parties dissatisfied. It was black and white: good care seemingly couldn’t be efficient and kind simultaneously.

I will now introduce you to another long-term carer, Diane, who also discussed care work within the context of the wider political scene. Diane was also regretful about the way care was being organised in austere times. She makes associations between the economic situation and the development of conveyor-belt care, which is personally burdensome, leaving her feeling unacknowledged in her work. Again the considerable time pressures are experienced as annihilating, as a factor in a sort of occupational death.

Diane

Diane has worked at Winston Grove as a carer for over six years. She is around fifty years of age. Watching her work, she moves slowly, unhurried, sometimes for her own benefit and sometimes for the residents. I interview her in the activities room. Diane has arranged cover after the morning shift. Gemma is running a bingo session. Diane seems to want to speak to me, but is conscious that she does not present an idealised picture. Like April, Diane talks about the home while also situating her work in a wider context: the current economic crisis.

D: It’s okay... but you’ve got to understand the hierarchy and how it can affect you. Um. I enjoy working with people. I enjoy working with the elderly but it’s a trend at the moment in the current economic crisis that they expect you to get somebody up out of bed, 20 minutes to half an hour, and washed and dressed and down to the breakfast table. I can’t always do that.

E: No

D: What I will do, I will go to one. This person might tell me to pee off not getting up now. I might be able to persuade them to have a biscuit and their medication, go to the next one. Next one might be the same. I have days when I go to two three four of them then I go back to the first second third one. They might be more approachable, put them on the commode,
give them a cup of tea. Make them comfortable go and do that with the next one. Then you might have someone who you can’t put on the commode and you have to wash them on the bed, (resident in background, agitated, Diane says something I can’t hear). The bed might not be appropriate, it might be a back-breaker. You have to wash them dry them clean them look after them sort them all out make them comfortable. Get them in a wheelchair, get them downstairs. You’re expected to do your quota. Many a time I’ve been pulled up on it, but I don’t take it personally. Because it’s not all about conveyer-belt care. It’s about a quality of life that person has, it’s about making it as pleasant and nice as possible for that person. It’s about them, it’s their time. So this is the problem that I have. Many a times I’ve been called into the office and given a bollocking. You can explain to them but they don’t care. They’re not interested. You’ve got to get a person down, 20 minutes to half an hour. What do you mean you spent 15 minutes and in that time you could only make someone a cup of tea and give them their medication, if they were willing to have. If they were not willing to have their medication, so what, I’ll give it to them later. It’s their time.

E: But you feel you are constantly under pressure?

D: We’re all in the same boat. You get some girls, whether they want to or they don’t want to, washed dressed and brought downstairs. It doesn’t matter if they can’t wash them properly, it doesn’t matter if they can’t cream their skin properly. For me these people are very vulnerable if I look after them and if I look after them well they’ll last a bit longer and have a good life.

E: Yeah. And how do you get your head round the kind of idea that you’re getting a bollocking from time to time and the needs of the residents...

D: How do I get my head round it? Quite easy, quite easy. I’m not the only one (breaking out with laughter). I’m not the only one (laughs). You get some of these super super people inflict their way regardless of how that person feels. You’re getting up now, come on. Then they’ll come and say ‘D, I’m not like you, I got six up this morning and you only managed four’. And I think shit only managed four. Didn’t hurt anybody, didn’t bully anybody, didn’t ride roughshod over anybody’s needs... Treated them the same as I would treat my own mum or my own dad. They tell me to piss off or I’m not coming back to this hotel. Would you like a cup of tea? Cup of tea don’t solve everything, huh but I try anyway, try to make it as nice as possible.

‘Sorry.’ (A man walks in).
D: As calm as possible and sort it out. But you constantly feel from the office of no value, constantly feel as though you are going against the grain. But for me these are human beings. When I get to 94 and I don’t want to get out of bed, I won’t get out of bed.

*(Interview, 17 March 2015, Winston Grove)*

Diane points out that time belongs to the residents; carers should be sensitive to their pace. This bears striking similarities with mothering – the extra time it takes a toddler to sit in a car seat when he or she wants to do it themselves; the time it takes a small child to use a spoon at mealtimes... Who takes ownership of time, and the sequencing of daily life?

In the way she talks, without pause, Diane conveys something about the non-stop nature of the work, which can feel hurried, factory-like. The content of her interview contrasted with the way in which she speaks demonstrates powerfully how the treatment of time is divided: organisationally, there is a requirement, explicit or implicit, for speed; but for residents (and staff) this approach doesn’t work.

What follows is an observation of Diane slowly offering up food to Gaynor, who had had a recent stroke. Gaynor recovered very well, which we might assume was testament to the time taken to care for her, as Diane notes above.

Diane, sits down next to a woman who has a glazed look on her face. She may have had a stroke. Very slowly the carer cuts the woman’s fish and slowly brings it to her mouth. The woman opens her mouth and takes in the piece of fish, chewing slowly. ‘I’m glad you’re eating, Gaynor,’ says Diane

*(Observation, 16 December 2014, Winston Grove)*

By holding time rather than speeding it up, Diane acknowledges that a greater amount of human agency can be encountered in the person with dementia. Diane firmly situates herself among the carers who revolt against time pressures. A troublesome individual (Symington, 2003), Diane has a rivalrous relationship with the ‘super super people’ (the efficient carers) that reminds us of April.

There were undoubtedly real differences between staff who prioritised human contact and those who were more instrumental, or compliant, in relation to management procedures. These differences had a footing in reality. However, the extent to which April and Diane
seemed to conceive of the differences as entrenched and immovable also suggests a degree of splitting. This split meant they were able to deny their own task-focusedness, locating it fully in others. The situation was more complex than this. For instance, all staff I spoke with at Winston Grove spoke fondly and in detail about individual residents in their care, suggesting that relationship was important to workers across the board; equally I had seen Diane avoid making contact with people as she filled out care plans or stacked dishwashers. In other words, the split was not as fixed as either woman imagined.

As other workers had done, Diane expresses a real capacity for empathy. Diane puts herself in the shoes of someone at 94, who doesn’t want to get out of bed. She recognises that people do not always wish to fit into routine temporal structures and are entitled to say ‘No’. Diane, in turn, is saying ‘No’ to those in the ‘hierarchy’. Diane encounters herself as both victimised and agential. She also sees the residents in this way. Time is central to the argument: it can either become a persecutory object or a helpful one.

Later in the same interview I returned to Diane’s remarks about being in trouble with the manager for failing to get enough residents up in the designated amount of time. This fits with the idea that time can be used against care workers, as a way of judging their performance. Diane feels penalised by these judgements, linking in her mind such a ‘bollocking’ with abuse. Diane suggests indirectly that time needs to be available, particularly in difficult, emotionally intense, situations. She references concentration camps and remembers racist notices posted on shopfronts. It is possible that Diane is capturing something that could not be thought or spoken about within the organisation.

D: Never by the residents always by the manager. You know you only got four people up this morning and what do you think you were doing? Some of them have got dementia, some of them have got different mental problems. Some of them have different psychoses. Sometimes I might go into one resident, ‘You black bastard you killed my mother you killed my father you killed the children I could have had. Don’t touch me.’ And you start and calm them down and try and give them a cup of tea. But because of the way they feel you don’t know if they might have had someone in a concentration camp, you don’t know what the problem is, I’ll take them out of their bedroom, take them to the dining room, ask the housekeeper, give them a cup of tea for their breakfast, please. And once she’s calmed down I will try again or I’ll get another carer and say if you get her washed and dressed for me I’ll do one of yours.

(It is very noisy, a carer and an elderly gentleman have come in; the dog is trying to get out of
its cage, jumping up and down.)

D: ...I am not going to do anything that makes me feel uncomfortable and make someone feel like shit so I can say hang on I can score a brownie point. So, Esther, I don’t know if I am the right person to be speaking to.

E: I am thinking about you being on the receiving end of someone calling you a black bastard when they’ve just woken up.

D: Well yeah I don’t know what that’s all about. But I know I didn’t do it whatever crime has been done. But I grew up in the 60s, 70s, and I remember notices being up, not going in. She’s a bit older than me and it’s possible she has had family that have been in the worst situations. Sometimes it’s her worst nightmare and she worries about everything. Sometimes this lady can be sitting down eating her dinner and she says she’s not eating, and she says, ‘What is this? I’m surrounded by blackies.’ And so I say to the activities co-ordinator, please sit down with her, chat to her, talk with her have a dinner with. It’s not my place to give her her dinner, chat to her, make her feel good. We’ve all got something in our cupboards that frightens us and it’s a very lonely sad place to be but when I speak with my manager she says, well next time it happens go and get one of the managers or the seniors to come and witness it but where you gonna find them. If there’s a carer I’ll say you hang on you’re a white one I’ll relieve you but we can’t do our jobs.

E: I suppose in that moment it’s quite difficult to do your job.

D: Because if anybody comes in they might think you’re abusing her, doing something you shouldn’t be doing, so there might be a problem with safeguarding. I don’t expect the manager to understand or even give me any support. So I have to cover my own arse and protect myself

E: So sometimes you do feel pretty alone.

D: Yes sometimes you do feel very vulnerable.

(A senior walks in and it all becomes too noisy – we have to stop.)

(Interview, 17 March 2015, Winston Grove)

Diane relives being ‘bollocked’ and positions herself as an organisational trouble-maker, resorting to a split between those who are compliant and those who are not. As a result of her perceived status as, so to speak, an anarchist, she wonders whether she is the ‘right’ person to
give this interview, aware that she is not going to provide an idealised picture of the care context that others might (which in fact nobody did). I wonder if she is expressing something about an organisational fear (her regular bollocking) of really articulating the frustrations of not being able to do the work as she believes it was intended to be done (in former times).

Although Diane reports that the work is enjoyable, her enjoyment is marred by the perceived deprivation of time and concern. Diane’s picture of daily care work is bleak. She talks about being called a black bastard, remembering excluding notices on shop doors in the 60s and 70s. She associates the racism she endures at work, and as a younger woman, with the anti-semitism of the Second World War, of concentration camps. Diane appears to be conjuring up an unremittingly brutal world, in which humanity is absent and people are treated as part-objects (Klein, 1952), receptacles for raging aggression and hatred.

If we track Diane’s argument, she begins by talking about being chastised by the management. Sometimes a resident is very agitated, and Diane finds herself subjected to racist abuse. She is nonetheless able to recognise in the residents’, and in her own, experience a pain that is individual and also shared. In doing this, Diane expresses a deep empathy with a resident’s distress, imagining where this might come from in the past. She says something about the gruelling reality of day-to-day exposure to racism and how she finds ways to respond. She goes on to describe an organizational culture that has little response to these daily encounters with racism other than through formalities and procedures drained of both practical effect and of the awareness of human suffering. Her interview is a powerful example of someone struggling to make space to think about her work in a context where the capacity to do so is, at the very least, under increased pressure.

It also seemed to be worth considering whether Diane is simultaneously speaking about something else, below the surface, even harder to articulate at an organisational level. Diane talks about a set of experiences that seem to be characterised by systematic and extreme persecution (concentration camps, overt racism, exclusion); by the indifference of those in authority who ought to do something about it (but deal in formalities), and individual isolation and vulnerability in the face of this. This is not to say that the home itself was characterised by systematic persecution. Despite occasional glimpses of something sadistic, it was not a brutal place. However, the content and emotional tone of Diane’s comments was shocking and raw, alerting me to the more aggressive feelings which were part of life and work at Winston Grove. Quite possibly this reflected something in Diane’s own history and inner-world, but I also wondered whether these were the kinds of feelings that were left unprocessed in the
organisational culture. Speculating, this might have been about the intense anxiety felt in the face of human decay and death, and relatedly the aggressive feelings that such anxiety evokes.

Beyond this, Diane also seemed to make an indirect case for locating human pain in a wider socio-historical context. Her pain is current – she feels abused within the home – yet it builds upon past pain, which evokes the history of racism in the UK.

There is some confusion in Diane’s account – a switching back and forth about who is the one doing the ‘bollocking’ and who is the victim. Although Winston Grove did not strike me as being a site of abusers, and of victims, perhaps what Diane flags up is one strand of the experience there: that human suffering, and the consequences of history and social circumstance on human suffering, could barely be acknowledged.

Indeed, care home life often seems disconnected from the outside, from the current and past historical context. People with dementia rarely know which year they are living in. In that sense, perhaps Diane’s narrative says something about human pain, and also about the cut-off experience of living in a care home, where one’s identity might be viewed at times one-dimensionally as a subject of daily routinized organisational life. In such a context, people are never fully seen.

There were a couple of instances at Winston Grove, which unsettled me but overall I did not experience the organisation as a brutal place. There were two unnerving observations: when Zalee kept Suki guessing about whether she would get to the toilet on time (on page 89), as we have already seen; and then again, as follows, when an older woman at 94 was ‘walked’ to the dining table, by a carer holding her precariously as if both were dancing. Both acts were thoughtless, imbued with a streak of sadism.

One of the residents is shouting, asking that the carers leave her be. They are explaining that it is lunchtime, and that they don’t want her to miss her food. One carer walks past holding the woman in front, as if the old woman is learning to walk. The carer is making dancelike movements behind, as she holds the woman’s arms in front, but they are too jerky for the woman who shouts out, ‘No, stop it.’ The carer does. The old woman puts her hands in her pockets. The permanent carer, Diane, says something about the old woman being ‘My adolescent with her hands in her pockets.’ The old woman is angry. She doesn’t know where the seat is and what she is doing. She can barely see. Daphne’s face grimaces.

The woman is shouting out. There is discussion about her being blind. Daphne’s lips open then tense together. She looks directly at the scene to the left of her. Another resident
passes comment about the shouting, and about a special light the woman has at the table. There is conversation about the old woman. Diane says that she’s entitled to ‘style something out’ and that ‘at 94 she can do quite as she pleases.’

Eunice says something about being fed up here. The residents have been waiting at the table now for 20 minutes. Waiting like this feels heavy, and made more unbearable because of the scene that has been unfolding around them.

*(Observation, 26 November, 2014 Winston Grove)*

Returning to Diane: for her, Winston Grove could be relentless and inhuman. Working there makes her angry, delinquent and vulnerable. Diane’s organisation-in-the-mind is characterised by a complex web of persecution and revolt. Even the dog is attempting to uncage himself during her interview.

Work stirs up anxieties, reminding her of ‘things that frighten us in cupboards’, of unprocessed memories. It is not a homely, safe place. Here time is taken away, through psychic and/or physical death. We are reminded by Diane that in its wake death leaves us with hauntings and haunted people. Unlike Gemma, who represents the aliveness at Winston Grove – the sometimes manic, triumphant, fight against dying – Diane seems to capture not just death but the cruelty of ending here.

The lack of safety Diane depicts is associated with the mean distribution of time. Where time could support greater humanity for those who are dying; instead it is fought over, a site of one-upmanship. Diane bemoans the fact that her explanations, which take time, are not taken up and thought about organisationally. The leadership, in her mind, does not care about her or the people she looks after. Time, or its absence, silences feeling.

Speed and efficiency, concepts often found in new managerialism, and often used as measures against which carers can be assessed, are linked for Diane with bullying, ill-treatment. Her story relates to how she feels those above her do not take the time to listen to her difficulties. I wonder whether Diane feels I am listening to her, and where I might belong in this system? Her protestations are not heard in the same way that the residents who are speeded up are not heard. From her perspective, the care field is riddled with layers and layers of top-down objectifying practice that filters all the way down to the residents.

Given the general thread of Diane’s argument, it is symptomatic perhaps that a senior carer interrupts her interview, stopping speech, marking the end of Diane’s attempt to be heard.
Diane’s interview was painful and, though it was unclear whether she experienced me as someone able to take in the pain, I did see that the interview allowed her to express her vulnerability in her role and in her life. This interview, I think, provided evidence for the need of staff teams to be given access to a third, reflective space (Britton, 1989) to process their experiences of the work.

In contrast to Diane, April, Bridget and Gemma’s interviews, the organisation-in-the-mind which Ursula depicted provided a modified, less impassioned account, less split in its representation.

_Ursula_

_Ursula is a part-time carer in her mid-fifties. She seemed neither keen to speak to me, nor resistant to it. Her physicality and speech seemed to communicate something measured about her. She was statuesque, articulating her words in a considered, unhurried way._

_I interviewed Ursula in the activities room at the end of her shift. Time was present in the interview in a different way from others I had conducted, and perhaps the ending of her shift (as well as her part-time role) acted as a boundary for the interview and for the content._

_U: What it’s like? Well as I’ve told you I only work here part-time... so the reason I chose actually to be here part-time is to enjoy it...I have noticed that I can actually be a lot more patient than I thought I would be... which has surprised me I have to say because I didn’t think I would be able to be that patient._

_......_

_U: Not really then because things change all the time. You get to know a person and you know roughly how they are, what they like, what they don’t like. But then again it’s all a process. They are going through a process in their mind and it’s not always the same, but that’s the same with us we are not always the same._

_E: Um._

_U: But with someone with dementia it is probably more so._

_E: Um, yes perhaps it’s more noticeable. So how do you adapt to all of those changes?_  

_U: Um, just take it as it comes really and try and not get set into my own ideas. So yeah if I’m flexible enough that helps. If I think it has to be done there and then because it’s half eleven it might not work._
E: So time is quite important – how you relate to time?

U: Time is important in a way because it is important in the setting of a care home to a certain extent, but then again it shouldn’t be that important to let everything else revolve around a certain set pattern. That is sometimes difficult but there are ways around it.

... 

U: Yes, it’s the polarity between getting satisfaction of working with people and it being a big challenge at the same time. That’s there everyday, it’s a challenge and also really getting a lot out of what you are doing. If it all goes well and you have a feeling that you have done your best and you have tried to make their experience as positive as you can then the positive side outweighs definitely everything else. But that’s not always possible. That’s just reality. On a day to day basis that’s not what you’ll experience everyday. When there is a shortage of staff and you can’t do as much as you would like to and you go home with a feeling that it’s not quite that satisfying. But uh that’s reality.

(Interview, 17 March 2015, Winston Grove)

Ursula recognises the frustration that timetabling and rigid institutionalised routine bring, but suggests that there is some freedom to bend time. Ursula derives pleasure from her job, partially because she works part-time. Perhaps this protects her from the relentlessness of the care work: she implies that she gets time to recuperate from the emotional labour of the work. It seems that this might enable Ursula to manage the uncertainty of working with people with dementia. She neither idealises the home nor does she denigrate it.

Ursula reflects a little on how the work has changed her, and what she has learned from being a carer. Overstretched, as many are, there is undoubtedly less time to be able to reflect like this for full-time workers. This is an interesting formulation because it demonstrates that with experience and time, she has become more patient and understanding of those in her care. So ‘time-in’ work is experience for Ursula. Simultaneously, ‘time off’ work, through part-time hours, makes it possible for her to consider the care work. Time here relates to space for reflection. Time is about movement and change: she sees the minute-by-minute changes of people with dementia. Ursula does not feel persecuted by the institutional time frame as Diane and April do. She seems to tolerate the routines as a marker of contextual reality, while feeling she has enough agency to manipulate time when necessary.

Being pushed for time was not a theme that emerged in my talks with staff in Whittinghall. The
ratios between care workers and residents were better. The staff team did not seem to challenge the way the home was organised as they did at Winston Grove. At times the interviews idealised the home, as a family place, and seemed in disconnect with what I had observed during my months there.

All members of staff asked whether I had ‘enough’ material, which I was curious about, given that interviews were much shorter than those at Winston Grove: this was resonant of the way staff had taken breaks, as if they had had enough of the caring. The longest interview was 13 minutes. My feeling was that the team was more guarded. The time spent in interviews also reflected something I had observed. The organisation shied away from in-depth relating and intimacy. However, the residents at Whittinghall, spoke at length, which demonstrated, I thought, their need for companionship. I will now introduce Nancy, Dorothy’s keyworker and senior carer, whom I was able to talk with briefly. As a theme, time was absent in staff interviews at Whittinghall. As a result I will draw on observations in support of my discussion.

Nancy at Whittinghall

Nancy is Dorothy’s keyworker, a senior carer in Huntside unit. Nancy is no more than 25. She has been in the home for four years, part of a long-standing team. She worked in another care home before this one, but didn’t feel as comfortable there because she felt the team didn’t care as much.

No private room is available for interview. Nancy suggests we speak in the lounge. No one is there apart from the stuffed white tiger on top of the baby grand piano. The doors are shut and there are no interruptions.

N: …and then like there is a set routine but if the routine changes, the staff, we are happy to do whatever here… We all like have our own little jobs so we don’t need to say oh you go in and do that resident, stay with that resident or this resident on that day. We all know who to help and who to go to at that certain time.

E: Which helps…?

N: Yeah cos if we’re confused they’ll get even more confused… So they’ll all be running round not knowing what’s going on so we all know what’s going on…There are four of us that are always here. (She lists the names of the staff and the days of the week they each work, almost going through the rota, there is always a permanent person on shift). Four of us are permanently here and the nurse all the time.
N: We, like, control the unit. (She lets out a laugh).

E: It’s hard to talk about?

N: Yeah. (Laughs.).

E: ... there is a clear structure and you know what you are doing.

N: Yeah we know limits, when to have fun and when not to like be serious and things like that. And we have fun with the residents and they join in... Like when... It’s Christmas Day and we all sit down with them and get the Christmas tree out and we open presents together. At least then they know what they are doing. What’s going on.

(Interview given 11 August 2015, Whittinghall)

Nancy and the senior team seem to be in ‘control’ of the unit, and the way time is ordered. Nancy is not at the mercy of time; she is a time-manager. This bore out in the way that the care staff ensured they took breaks. During the three months of observations at Whittinghall, it became obvious that Nancy made sure that she was refuelled, removing herself from the unit during the morning shift. I wondered whether she needed distance in the face of Dorothy’s need for proximity.

Nancy announces that she is going on her break. She says it has been a very busy morning. She puts on her hooded top behind the nurses’ station. Dorothy glares at her. She smiles at Dorothy and walks into the lounge. She speaks to two of her colleagues and they all walk around the corner, like friends breaking up after college.

Dorothy looks in that direction then looks back at the nurses’ station. She starts pushing herself forward in her wheelchair, unstable. ‘I want my hair done, my hair done, my hair done,’ she shouts. The repetition, loud, forceful; her frustrations; the staff’s imperviousness.

‘She always wants her hair done.’ An activities co-ordinator, in burgundy pink, walks past and laughs. This feels cruel.

Dorothy moves closer to the station, precariously. The nurse walks towards Dorothy. ‘She is busy right now,’ meaning the hairdresser. She wheels Dorothy back into her position and puts the brakes on.

But Dorothy clicks the brake off and starts pushing forwards again. ‘I want my hair, hair, hair,’ she is pointing to the top of her head. Another carer appears, placing her hand on Dorothy’s
arm as if to settle her. ‘You will have it done, I’m sure.’ The nurse walks out of the hairdresser’s room and says that she will have it done in the afternoon. ‘What does she say?’ asks Dorothy. ‘I can’t hear a thing, I can’t, I can’t.’

The carer strokes Dorothy’s arm. The nurse also bends in closer to Dorothy and strokes the top of her head, smiling. Dorothy puts her head back into her hands, closing in and away from the two women who are attempting to calm her. She pushes them away, showing them what it feels like to be ignored.

Nancy walks past with her two colleagues, and walks as close to the wall as possible as if she is trying not to be seen, stealth tactics. Only she’s not going in, she’s going out. She needs to get away.

(Observation, 30 June 2015, Whittinghall)

Time was about order and structure at Whittinghall, something that perhaps helped staff keep some distance from the confused temporal spaces of the residents. It is resonant of mothers who find it comforting to create rigid routines for newborns, possibly fearing the pull to slip into baby time. In the following vignette, Nancy asks me to step in as a surrogate carer because there is no one else in the unit available. This was striking because it demonstrated the exasperation of carers, never broached in the interview material. This scene also expressed something about how burdensome contact with residents was; as if residents were an imposition on staff. Dorothy is, after all, ‘dumped’ on me. My time as an observer is undermined and the staff’s time takes precedence. At that point, I felt like a mother to a teenage child (Nancy) and a carer to an older relative.

Nancy appears with a sandwich in one hand, a fizzy drink in another. She stands in front of the nurses’ station. Dorothy puts out her hand, ‘There she is, there she is. Who is she?’ she says, as if Nancy is both remembered and forgotten simultaneously. Nancy doesn’t want to engage. ‘I’m going on my break but I don’t know where anyone is. I hope you’ll be able to find someone if you need someone,’ she says.

Some needs are overlooked. There is no one around. The phone starts going at the nurses’ station. ‘No one anywhere. No one at all,’ Dorothy says. Evie is calling out ‘Paddy, Paddy.’ She looks distressed in her chair but there is no one around. ‘Help me, help me, help me.’ No one comes. Does the researcher take on the care work? It is becoming ever more tempting.

(Observation, 14 July 2015, Whittinghall)
During the interview, Nancy had talked about Christmas. Arguably this symbolises the compartmentalised nature of Whittinghall. Fun is reserved for specific events. Nancy’s organisation-in-the-mind is rational, unconfused, neat but lacking in spontaneity. It is as if the uncertainty that dementia arouses doesn’t have a place there.

This mirrored the staff’s response to Dorothy, who had a clear physical space in the organisation between two red velvet chairs in the corridor, but whose complex, muddled needs were sometimes painfully overlooked. Although the home had won accolades for its dementia care, the staff team was young and, in a manner that was perhaps developmentally appropriate, took more time to relate to one another. Sadly this often meant avoiding the residents. The split here was between the staff and residents, rather than within the staff team.

Behind Dorothy two men in black waistcoats and black Dickie bows have come into the room with a drinks trolley. They are chatting. Dorothy says there’s too much noise behind her. The activities assistant goes to join in the chat, telling them about her new tattoo. Dorothy tries to turn her head but she cannot twist it around enough to see what is going on. She makes another effort to turn her head, but gives up. When she looks up she has tears in her eyes.

*(Observation, 12 May 2015, Whittinghall)*

**Residents’ relationship to time**

The residents at Winston Grove had very poignant relationships with time. Generally residents tended to consider time from the point of view of past lives, trying to integrate former senses of selves with the person now in the present moment. The interviews with the residents alerted me to the real need to spend time bearing witness to their stories, often evoked with an emotional eloquence.

The theme of time appeared differently with residents from how it was discussed by staff. As I have detailed, staff at Winston Grove were preoccupied with time constraints. These time constraints were linked to the austerity agenda and the cutting of resources, which in turn generated a sense of disappointment about changes to care practice and in working conditions.

The residents, on the other hand, did not seem harassed by linear clock time and therefore, interestingly given the diagnosis of dementia, their time-related talk was not characterised by pronounced splitting as it was among the staff. Maude, who I will shortly introduce, used the time to play; and Sue used the time to mourn. In other interviews time was used in similar ways: Maude and Sue, though, are most illustrative of this particular theme.
The interview with Maude, an 82-year-old woman, who had enjoyed being a musician, takes place in her bedroom because the room allocated to interviewing is being used for staff training.

Maude surrounds herself with all manner of cuddly toys – large Teddies to small bees and ducks, and her favourite, Rupert the Bear. Maude introduces me methodically to every toy. She says at the end of the interview, ‘Oh I’m delighted that you have taken an interest in the little things, you know.’

M: Everyone that comes in, you know, they’re all young children and I let them just say hello ... and all the rest of it to enjoy the short time they are here with you.

E: So do you feel at home here?

M: I do actually. I don’t pine for, you know, or wish I was where I had been so... what was this one? They all have a bit of character.

E: They do all have a bit of character

M: It’s so silly but I can’t think. I know that’s Rupert. There is a story about Rupert, a book, so that could be of some interest.

E: Yes (laughter both of us).

M: Now I don’t know what I’m doing actually.

E: But you remember Rupert the Bear

M: He seems very familiar to me... (Looks around.) Oh excuse me.

... 

M: Oh you clever girl, you. I want it to go all the way down here.

E: All the way down here. Shall we give it a go?

M: Yes. It’s a bit hard that.

E: I bet it is. Is that better?

M: That’s my photograph. These are all my little precious things. They’re nice for... if children come in I let them play with them for a little while.
E: You’ve got an interesting collection.

M: Oh yes individually they are quite interesting. That’s Scotty. This is Quack Quack.

E: Hello Quack Quack.

(She repositions Scotty and Quack Quack so that they look like they are talking).

M: There they are having a chat.

.....

E: You like having all your things around you?

M: I do. I feel that they all belong. .. I don’t know if you want a chair or something.

E: I could sit here next to you.

M: Oh thank you, (she smiles). I’d be honoured. I got a bit sniffly (she sniffles).

E: Yes you have a bit of a cold.

M: Yes... So may I ask you a question?

E: Of course.

M: Are you (coughs) excuse me. Are you indulged in the place?

E: Well I’m sort of because I’ve been coming quite regularly now, getting to know it better. So I’ve sort of come along to find out what other people think and not just what I might be thinking,

M: Yes, and I agree with you... I’ve been collecting those little things that are on the windowsill there... they... they open and you can put something in. It’s interesting.

.....

M: Yes, I’m free to come and go which is very nice. That’s Rupert there.

E: He is. He’s looking right at us, isn’t he?
M: Oh yes, I’m dedicated to them... it’s lovely going around saying, oh you know, the time I
looked after you and you were almost talking to me.

*(Interview, 31 March 2015, Winston Grove)*

Maude’s interview was baffling because it didn’t follow the unfolding of a linear narrative. She
flitted, or free associated, from one significant object in her room to another. Beyond this the
emotional content of the interview told a tale about what it was like to be at Winston Grove for
Maude in that present moment.

She had a warm, welcoming room, filled to the brim with friendly faces on photographs and on
soft toys. It was as if this environment fed into a secure internal structure, or bolstered one,
already at home where Maude could be Maude. I wondered how her organisation-in-the-mind
mirrored the family structure in her mind, which reminded her of music, play and inviting
encounters with parents, partner and children. It was not that Maude dwelled on time, or felt
she was missing out on time, but rather that she appreciated the interview time in order to
introduce me to her figures and trinkets. Time seemed important to Maude because it allowed
her to breathe further life into this mingling of past and present from which she could draw
strength. Time was generous, opening up the space for sharing and the possibility of
constructing a joint experience; a bit like her little boxes, treasures could be found there.

I had observed Maude singing ‘Amazing Grace’ at the end of one of the bingo games with
Gemma. It had been a very evocative moment where spontaneous self-expression had been
tolerated. At Winston Grove, she felt able to be herself. She had not been bothered about the
lack of prizes for bingo; the prize for Maude was being given time to sing a song that brought
her back to herself. Here we see Maude, at ease in her surroundings, afforded the time by
Gemma to express something of herself which belongs to now and a past time.

Maude, the woman to the right of the activities co-ordinator cries ‘bingo.’ There is a round of
applause by all the other residents apart from the one person who has fallen asleep in her
chair. The residents have not spoken to each other during the game. The woman who wins
says that she is happy to have won. Gemma explains that unfortunately she has no prizes this
week. The winning resident says that she will sing a song instead. With an Irish accent, she
starts to sing ‘Amazing Grace.’ Her voice is still powerful. It is very beautiful. ‘How wonderful,’
says Daphne.

Gemma asks for more and Maude sings ‘Amazing Grace’ again. She thanks everyone for
listening, and explains she used to sing the song as a girl in Ireland, and how those were
good, good times.

(Observation, 16 December 2014, Winston Grove)

An oscillation between past and present selves seems to be a feature of dementia, very much related to temporality. As we will see from Sue’s account, a new resident at Winston Grove, there was a need for her to make connections with the past, as if this would provide her with some safety as she faced the uncertainty, unfamiliarity of a new life at Winston Grove. Here Sue was in new surroundings, following a lengthy hospital admission. We see her grappling with the anxiety of where she is and how she has come to be so far from home (her childhood home).

Sue

Sue, a woman in her seventies, originally from Wales, had only been living in the home for a fortnight when I met her. She has long loose hair and glasses. Her face is gentle and she speaks very softly. She has no relatives close by, having been discharged from hospital following a fall. The interview takes place in her room, which is sparse at present.

Sue seems very happy to talk to me. She has been sitting in a lounge, quietly with other residents, when I first approach her. We speak for half an hour. She spends much time looking out of the window. Sue has just been telling me how she needs to get back to the small village in Wales where she grew up. She has talked about her school and church, and about returning to Mum on the bus.

S: It’s very interesting… I’ve never had such a type of a reception from anyone. What do you think we could do?

E: Well I’m trying to think about it with you, I think. What would mum say?

S: Oh cariad (‘love’ in Welsh).

E: Would she?

S: U… This uh got a ball. Old. By the beach.

E: Your home was by the beach?

S: Yes, and we would go for walks. With the dog.

E: You have got a dog, have you, with mum.

S: Yes. Then we get there. I wouldn’t know how to get there, no. Very sad (she is crying)
when people disappear. She takes deep breaths. She clasps her hands tightly together and starts to look out of the window again. Bangor is the university. The time that used to go.

*(Interview, 7 April 2015, Winston Grove)*

Sue was in contact with her emotional world and the profound experience of loss she was undergoing. She had travelled back to a period in her life when she needed school, chapel and her mum. During the interview it became clear how unfamiliar the residential home was, as she yearned to get back to a place among people to whom she belonged. It was the longest interview with any resident that I conducted. Sue was tearful and in mourning.

Sue’s relationship to time held within it a paradox: she knew that school and friends from Bangor were a ‘long time ago’, yet she felt driven to find a real bus outside that would bridge a gap between her memories and her current position. We discussed bus routes and what she would say to people she missed. This allowed her to return to a past-time and act it out in the present. Though it was painful for Sue to summon up figures from her past, especially her mother, I could not help thinking that she needed someone to be present to the changes she was facing internally and in her immediate environment. Sue was able to express gratitude to my being with her, and this in turn made me want to spend time with her. This kind of co-affecting seemed to take place among residents and care staff throughout the home (see Chapters 4 and 5).

It struck me that Sue may not have had a great deal of ‘one-to-one’ time and so this interview was out of the ordinary. Sue noted that she was ‘very very surprised’ by my being with her and for ‘helping her’ as she attempted to understand that times and people past were ‘disappearing’.

Residents at Whittinghall did not mention time, or past lives directly. As a result I will rely on observational data to convey something about the way time was experienced by the residents there. Though time was not mentioned in interviews, time and the impact of loss were more pronounced in observations. This seemed to fit with my view of Whittinghall as a place where residents often withdrew into themselves towards death.

Time was so heavy in Whittinghall, partially because Dorothy was always positioned in the corridor opposite a large clock, as if time had been suspended and nothing seemed to change. She frequently cried out ‘Tuesday, Tuesday, Tuesday’, or ‘Thursday, Thursday, Thursday’ reading out the sign on the wall that told her what day it was. It was as if she was holding on tightly to some kind of temporal reality, yet it seemed simultaneously to be a cause of anxiety rather than
comfort, as if nothing felt real. Similarly when Dorothy read the clock, this made her feel alone and confused, perhaps a sense that time was moving on as she stayed still, all by herself. The following two vignettes evoke the sense of the panic that time seemed to generate in Dorothy.

Dorothy starts to close her eyes and bends her head down into her chest. Nancy says that Dorothy won’t take her medication at 7am and is taking it later now. Dorothy is presenting the team with challenges. This is making her more tired. Yesterday she put Dorothy to bed at 4pm and only woke her up for her tea at night, then she went back to sleep. She said she thought that if she put her to bed now she would just keep sleeping. Dorothy’s eyes open up again, a contradiction. It wasn’t clear whether Dorothy’s medication related to some of her more ‘disruptive’ behaviours, her agitation, demanding calls. Whatever it was Nancy seemed to think that it was knocking Dorothy out at times.

From the lounge a man emerges. Nancy jumps up and asks the man where his frame is, protectively. She asks him to stand still for a moment and she runs into the lounge, retrieving his frame. Dorothy watches this with wide open eyes, then turns her head back to the nurses’ station. ‘That time,’ she says looking at the clock.

Seated each week opposite the clock on the wall above the nurses’ station meant that time was ever present here. It seemed to slow down. The longer hand on the clock would tick on, moments ebbing away, time stretching out in the corridor. This made it seem as though Dorothy was always waiting for the clock to stop, for something to happen, for nighttime to come and take her. The clock, coupled with Dorothy’s rare movement, stirred up thoughts of Godot, of the relentless futility of existence. This was hard to sit with.

(Observation, 9 June 2015, Whittinghall)

In the above vignette, there is a sense that Dorothy wants to cut off. She herself, understood by the staff team as an effect of the medication, is sleeping more. It was as if the sheer boredom of being in the same place everyday, with minimal human contact, was forcing her into retreat. I had the sense sometimes of Dorothy being in solitary confinement. Here she is again, now left with just echoes of her own sound.

Dorothy is sitting in her usual position opposite the nurses’ station, between two red velvet armchairs. She is wearing a beige gilet and a brown polo neck jumper, with brown trousers. She looks smart, very smart. There are no members of staff around. She raises up her right hand as if to wave, but instead makes her hand into the bird’s head, moving it up and down. A fledgling in need of feeding; a silhouette, shadowy figure, in a puppet show, outlines to be
filled in. How do we get to know Dorothy?

‘Hello, hello, hello,’ she says.

Another resident with very big glasses is moving in front of Dorothy, on her zimmer frame.

It is noisy in the corridor, as one of the care assistants is hoovering. ‘What’s he doing, he doing, he doing?’ says Dorothy. ‘Noisy, very noisy, noisy,’ says Dorothy. She looks at the table to the left of her. There is a beaker and a glass of orange juice there. She looks away, moving her feet a little on the wheelchair footrests. ‘Tuesday, Tuesday, Tuesday,’ she says repeatedly, as if this one thing that at least feels concrete. We have been here before and we wonder if this is one way that helps Dorothy to feel less at sea. There is something Sisyphean in this existence, and the rock... it feels as though it is getting heavier as time passes on.

She notices a clock and tries to tell the time. ‘I have no idea, no idea, no idea.’ Perhaps time is standing still.

‘Sally, Sally, Sally,’ she shouts louder, raising up her hand in the bird-like shape to be noticed.

A nurse and the care assistant have a conversation in the corridor about slings and hoists; Dorothy gives up, shaking her head and then placing it in her hands. The nurse disappears. The care assistant puts the hoover back on. ‘I can't hear a thing,’ says Dorothy.

*(Observation, 30 June 2015, Whittinghall)*

An experience of lost objects was palpable in observations with Dorothy. This was also true of Evie, who was sometimes seated next to her in the corridor:

Dorothy starts to try to pull her purple jumper further down over her trousers, as if she is rearranging herself, then stops. She looks into the distance, then turns, ‘Where are the others?’. She cuts a lone figure out here in the corridor. ‘I’m not sure where the others are.’ Someone is lost; Nancy has just gone. Dorothy bends her head slightly and then puts her head in her hands, staying there some time.

‘Sally,’ she calls out, hauntingly.

‘Sally won’t be long,’ says the nurse behind the station, popping her head around to try to make contact with Dorothy. Dorothy nods.

‘Where are the others?’ she asks into the distance, seeming to have heard the nurse.

‘They’ll all be back for lunchtime.’
‘Sally,’ says Dorothy. The nurse’s response hasn’t quelled the panic.

‘She won’t be long,’ says the nurse, this time a disembodied voice.

Dorothy swallows, tears form a little in her eyes.

The manager, Amy, is in the distance showing someone around the rooms in the home. ‘Hello,’ she says to me, ‘Hope it’s okay that I have left you with Nancy.’ And now I have been left with Dorothy. A handing over here and there.

(Observation, 12 May 2015, Whittinghall)

As time moves on, into older age, it brings with it losses. In some cases, like Dorothy’s, there seemed little or no opportunity to think about them, and what they meant to her. As the following field note indicates, Evie, also resident in Huntside unit, was also left with the gap that ‘Paddy’ had left. It felt unbearable to witness these two women cry out for the disappeared, as if they were forced into re-experiencing an absence over and over again.

Dorothy is sitting in her usual position besides the coffee table to her left and a red velvet armchair to her right. Another woman, small, thin and frail-looking, is in the chair to the left of her. She is slouched down in the armchair to Dorothy’s right. One of the male carers is sitting next to her, drinking from his bottle of juice. ‘I can see you, I can see you,’ smiles Dorothy.

The woman next to her has her eyes closed and starts to call out, ‘Paddy, Paddy, Paddy.’

The male carer starts to push himself up out of the chair. A call for me to take up his place? He walks away into the lounge area.

Dorothy is watching the nurses’ station. A male nurse in navy blue is filling out files. ‘They’re not doing anything, nothing at all,’ Dorothy says critically.

(Observation, 7 July 2015, Whittinghall)

This vignette was one of many where Dorothy was observed calling out for someone from a time gone by, and no answer came. It was common for several members of staff to be present and to have time available to respond. Nonetheless Evie and Dorothy were denied their time, minutes which could have been used to more adequately reassure them or to find something out about these lost figures that haunted their everyday lives.
Concluding time

The theme of time was very revealing in terms of the organisational cultures of both sites. At Winston Grove the way that time was treated was contradictory and multi-layered. Time was hankered after by many carers, as if it might be a magic wand, a way into better care and relating. For the staff at Winston Grove, greater access to time signified the possibility of making contact with the residents, and was also related to carving out a position of greater authority (though not formally in terms of role) within the organisation. The time pre- and post-austerity was also thought about. Carers like April and Diane presented a real split between care practices now and then, so much so that the level of reward in the care work felt increasingly out of reach to them. Arguably this felt like an occupational death.

In Whittinghall there was a quiet closing down among the staff team, possibly a defence against being infected by dementia. Perhaps this represented a split between the time of youth and the time of old age. Time at Whittinghall belonged to the workers, as they ordered it into easy-to-manage routines. There was little place in this orderliness to recognise the confused temporal spaces of the residents with dementia, which was very real.

Although Nancy made a lot of effort with Dorothy and showed signs of real fondness for her, she was able to break off quite cruelly, as other members of the team did. Time seemed to belong to the staff, who found ways to keep living by being together and retreating to spaces, psychic and physical, unavailable to the residents, like the nurses’ station.

Among the residents the sense of loss (lost objects, lost sense of self, the need to mourn) was palpable in both homes, though Daphne and Maude seemed to represent the possibility of sharing time with others that facilitated an integration of past and present times; and of inner and outer realities. No doubt the older people I interviewed also enjoyed time with carers to share experience. This replicated my experience during observations where encounters were often slow-moving and involved real tenderness. The one-to-one encounter seemed to be given more status, as if this was where high quality connections could take place.

The dyadic relationship between mother and infant springs to mind here (see Chapter 3b): the desire to feel contained and held is vital in dementia care. Considering, too, that many people with dementia return to earlier periods in their lives yet unconsciously might be in touch with the fact that they are faced with greater losses, or un-developments, rather than gains, the need for carers who have time, or who feel able to share their time, seems to be a pressing issue.
Chapter 3b: Findings

Andre: Andre? Nice name, Andre... Don’t you think?

Woman: It’s a very nice name.

Andre: My mother gave it to me. I imagine. Did you know her?

Woman: Who?

Andre: My mother.

Woman: No

Andre: She was so... She had very big eyes. It was... I can see her face now. I hope she’ll come and see me sometimes. Mummy. Do you think? You were saying she might come occasionally for the weekend...

Woman: Your daughter?

He’s crushed by sudden grief.

Andre: I want my mummy. I want her to come and fetch me. I want to go back home. .. I feel as if I’m losing all my leaves, one after another.

The Father, Florian Zeller (2015)

This second findings chapter focuses on mother figures and how the maternal seemed to have relevance for care homes, for care work. Mother/s, although now dead, were brought to life seemingly for a variety of reasons. In a context where people were becoming increasingly dependent and were faced with death, we might imagine that some aspect of maternal love is yearned for, resonant of Kristeva’s thinking (see p. 24).

In this chapter, I will also explore the theme of death, which was particularly interesting because the care homes managed their anxieties around death very differently. Though I see (as above) a link with dependency and death, and the need for ‘mothering’, I will treat the themes separately as residents and staff did not make this association themselves. Mother/s

Mothers were often called for by residents, particularly at Winston Grove. Care staff there made reference to their own mothers. Mothers figured in interviews with residents and staff at Winston Grove, and ideas about mother/s seemed to shape the way in which some residents sought to orientate themselves to their surroundings and to each other. Similarly, mothering seemed to inform how carers related to those they cared for.
At Whittinghall, mother was notable by her very absence. I did not see any residents call out for mother/s, although in one interview a resident identified herself as a mother, albeit of a lost baby. The care staff talked about grandparents rather than mother/s, which seemed to relate to their youth and to the gap between the care staff’s generation and the residents’.

In his poem, ‘The Old Fools’, Philip Larkin (2003) imagined the minds of older people housing memories of those from lives gone by:

   Perhaps, being old is having lighted rooms
   Inside your head, and people in them acting
   That is where they live
   Not here and now but when all happened once. (p131)

Since people with dementia become increasingly dependent, I want to demonstrate that the maternal figure, a symbol of caring for dependent others, takes on a powerful presence in the erratically lighted rooms of fragmenting minds. However, when carers feel overburdened by the emotional labour of the work, when there is no organisational mother to support them, they may avoid responding to the repetitive calls of the older people who cry out for their mothers.

**Winston Grove: Maternal care**

Like the theme of time, the figure of the maternal was particularly alive at Winston Grove. Mothers with different qualities haunted both the culture, and the residents’ minds. During observations residents sometimes called out for a mother who was physically absent. In reality, these mothers were dead and their own children were soon to die.

This muddled, and muddling, merger of past and present lives and of being mothered, of having had mothers and, for some, of having been a mother to a child was a striking reminder of who, and how, we are at our most fundamental. Always babies to mother/s, always at some level having been connected to an-o ther; one that has given us a dwelling place within her body.

**Out of touch mothers**

Care staff or other residents sometimes came to represent the particularity of mothers once known. During observations, mothers were brought alive and feelings were sometimes projected into them – anxious mothers worried about disappearing children (the residents); containing mothers would soothe; lost mothers were searched for.

Mother was resurrected when Daphne was unwell, as we shall see, shivering in the activities room, upset that she wasn’t being looked after – ‘I don’t know where my mother is. I don’t know
where she is at all’—or when she had returned to Winston Grove after a trip with her long-term partner, Benjamin. The following vignettes reveal how important the internalised maternal figure was for Daphne during anxious times, or when she felt ill-cared for.

Daphne picks up her paintbrush and looks at it. She shivers all over again and puts it down on top of the palette of colours. ‘Blue,’ she says to herself.

Gaynor keeps painting all the tips of her fingers.

‘We are not being looked after,’ says Daphne, visibly upset. ‘They are all happy there.’ She looks towards the end of the table towards Gemma. Daphne pulls her cardigan tight around her body and shivers again. She presses her hands together tightly and holds them together, her two thumbs interlocking.

Gaynor has stopped painting the tops of her fingertips. She begins to tell Daphne that Jackie is dead. The vibrant colours of the butterflies, the push towards life and the living cannot cancel out the memory of death at Winston Grove. She says that Jackie kept talking in a funny way. ‘Woobly woobly woobly.’ She and Daphne laugh for a moment. Daphne retreats into herself, a faraway look over her face.

Daphne is still looking at the other members of the group. ‘At least they like it,’ she says, bursting into tears. ‘I don’t know where my mother is. I don’t know where she is at all.’ She coughs and then takes her left hand up to her throat.

(Observation, 23 December 2014, Winston Grove)

Daphne clearly indicates that her mother, if available, would have provided care. Implied in Daphne’s call for mother is the perceived absence in that moment of good, attuned care. The activity continues and Daphne struggles on. Here Winston Grove is experienced as an out of touch mother, leaving Daphne alone, abandoned in the room.

Anxious mothers

In the following vignette Daphne had come back from a morning out with Benjamin. They had been to the cinema. On return, Daphne was confused: why was Benjamin no longer with her. She started to summon up her absent mother, imagining her worrying that Daphne was lost. What follows is directly observed material.

Daphne is standing in the main lounge, wearing a white blouse with grey flowers on. It has an open round neck. On top she wears a grey woollen cardigan. She is also wearing a mint-green
pleated skirt and slippers. She has on her grey-rimmed glasses. ‘I am worried that my mother’ll be worrying about me, not being home,’ says Daphne. She says nothing more. She starts walking out of the main lounge. As she walks down the short corridor, Daphne sees another resident – head down and making jerking movements with her hands that flop down to her side. This woman is leaving another lounge. Daphne stands aside. ‘Well, when you see that she’s here,’ says Daphne, critically, implying this is not the right place for her.

(Observation, 16 December 2014, Winston Grove)

Daphne seems to experience herself as a lost girl, confused and concerned that no one – not even herself – knows where she is. Daphne communicates her lack of belonging and disconnection from the familiar, from home where mother might be. Each week at Winston Grove brought new challenges for Daphne. By Christmas 2014, it seemed that Daphne was becoming less familiar with herself, and her context. She was moving away from herself as a woman in her eighties and remembering a younger self. As a result, whatever familiarity Winston Grove offered, it would never be as comforting as home, as mother, as a childhood space and time. Through the imagined figure of mother, Daphne seemed able to express her own anxious feelings about not being home. She retreats into being a child, expressing her feelings of dependence on another, who might help her achieve a more comfortable psychic state. At the end of this scene, sensing in Daphne a perturbing loneliness, I found myself sidling up to her. My body’s movement itself saying, ‘I am here with you.’

Comforting mothers

In the following interview with Sue, whom we met in Chapter 3a, asking questions about her life allowed her to open up enough to ‘get back’ in her mind to home with her mother and father. To remind the reader, Sue had recently moved into Winston Grove, having been at hospital two weeks prior. There was a possibility that internally Sue was moving towards ‘becoming-child’ (Crociani-Windland, 2013, p. 347) – an ontological repetition that may facilitate, when noticed by others, comfort during periods of change and the working through of life’s experiences. As Crociani-Windland (2013) notes so poignantly, ‘We go back and we repeat, in order to go forward’ (p. 348).

S: When I was young going to school. So (deep breath and another one, pause). Terrible ill (sounds like illness) such nice people. And um I never forget it the goodness that you’ve done... have to get home to Bangor.

E: Oh. So Bangor is home, is it?
S: Well, school. And I’m in (Welsh village). Still the place I live in.

E: Ok so you live there, and does anyone else?

S: Uh, everybody else lives there. Yes, but don’t know how to get there anymore. (She is tearful and goes very quiet). I’d like to go back. (Quiet again). Listen to the wind. (She hears this sound through the small opening in the window.)

(She is tearful, taking long breaths as she stares out of the window.)

S: It’s very very ill... (Pauses) I’m very very surprised and thank you very much for helping me. (Laughs). I wouldn’t know how to get back again.

......

S: Yes, yes. It’ll do cookery classes... and er... walking and things. And then we go tuh tuh tuh tuh (she does a walking impression). That was a long time ago... Oh. It’s very easy to find how to walk there now. Do you think so?

.........

E: You look as though you have good memories about it.

S: Yes it is. Been nice gone, wa, wa, walk and all sorts of things like that.

E: Um

S: It’s terribly bad to forget things, isn’t it.

E: It must be hard to forget things.

S: Yes and this is not ev, anything very different

.........

S: That’s a long time ago now.

E: But it sounds... do you feel a bit stuck do you?

S: I just need to go home.

E: What was home like? Can you describe it for me.

S: It was where my mother and father... and go to chapel for things occasionally.
E: Did you?
S: Yes. I wonder where... how... could go to Bangor.
E: Um.
S: But there should be a bus ride.
E: Um.
S: I have to think how to get it over with. And then my mother is still alive so we can always have a chat.
E: Um.
S: And then I can go back home.
E: So when you say you want to go home, you want to try to see mother to have a chat.
S: Yes.
E: What would you say to her?
S: Oh hello cariad. (She smiles, letting out an ‘ah’.)
E: Hello cariad?
S: Yes. It’s very very bad, isn’t it when people go away. (She is silently tearful, letting out another ‘ah’). Is there a bus ride... that is there a bus... that there’s a bus that we could get in and go half the way there or something like that.
E: You’d really like to get back wouldn’t you?
S: Yes, Yes. Speak to mother and father, and go to chapel again. Yes

(Interview, 7 April 2015, Winston Grove)

At a moment of great uncertainty, Sue summons up her parents and is compelled to return to them. I imagined that for Sue her parents represented a site of safety, familiarity. They would bring her back to a time when she was carefree, able to move without curtailment. The pain of loss for Sue is unbearable. She has lost her home and her freedoms. A lost girl, unsure of how to get home. I feel impotent to help her in this quest. Yet my bearing witness to the sadness she is experiencing, arguably a function of the maternal or parental, is something Sue has been able
to conjure up in me. I try to listen, to understand what she is saying, allowing her to cry. I had witnessed a capacity at Winston Grove, among the staff team to offer something akin to maternal containment (which Diane describes in this section). However, I am sure that Sue evoked this responsiveness in me because she hadn’t yet found it in her new surroundings. The reawakening of good memories, of vital attachments, held within them the painful experience of loss.

Present mothers

As I have shown, Daphne summoned up her mother, recognising her, present, alive in other people, as a source of comfort as she walked around Winston Grove. Finding her mother within the care home seemed to suggest that sometimes she felt at ease there.

Daphne follows the laminated corridor into a bright white kitchen area. The lights above dazzle, as if Daphne has emerged from the darkness of a tunnel. She looks out of the windows that give a full view onto another courtyard. Two chickens roam around on the paved area near their large coop. Both have the most ornate plumage. No ordinary chickens. A pigeon is looking back at Daphne through the window. Mutual curiosities, two-way mirrors, insides and outsides. ‘He’s taken a liking to you, you know,’ Daphne turns to me and laughs.

Leaving the pigeon, she walks into the central lounge area. In the corner of the room, behind a dining table, a carer is taking out files from a cupboard. She places them on the table, opens one out and begins writing while another resident sleeps to the left of her. Spaces here are all-purpose: working, sleeping, eating.

‘I will have to speak to him,’ says Daphne, pointing at another female resident who is standing up, folding a napkin. This woman is hovering next to another lady, who is trying to talk to her. Daphne gets closer, seeking proximity. She says hello but there is no reply. Daphne walks away to the back of the room and sits down. She does not seem offended. Daphne watches the resident with the napkin in her hand. ‘My mum,’ says Daphne. You can’t help but notice the gentle expression on Daphne’s face as she recognises her mum in this resident. Her lips turn ever so slightly into a smile, eyes softening. ‘It’s good, I suppose, really, at least she gets to know lots of new people now. It can’t be bad.’

(Observation, 29 October 2014, Winston Grove)

Here Daphne revived a mother who was relaxed, settling in. The function of Daphne’s shadowy mother was often to be a mirror to her own experience. Daphne was so comfortable in this
scene that she was able to take notice of her environment and the people in it, in much the same way that I spent my time noticing her, taking her in. There was, it seemed, a ripple effect of noticing which was mirrorlike in itself.

For the staff team, too, the maternal figure was sometimes able to provide comfort.

**Mother at work**

I will now introduce Chaya, a carer at Winston Grove, who immediately summoned up the maternal in her work.

**Reparation**

*Chaya is a woman in her fifties, who has worked at Winston Grove for over eight years. She wears glasses, her hair tied back. She is presentable, smiling a great deal, with her eyes. Her voice is gentle, she is keen to talk. We have our interview in the activities room. A circle of chairs is in the middle of the room, following an exercise session. Overhead are photocopied fish, painted by the residents.*

C: (Short pause) I enjoy myself because being with the people living with experience of dementia, uh, talking to them and, you know, getting to know them and looking after them after, you know them, I feel it’s very... I am very happy about it, I am interested and I’m mostly happy because my mum she lived with the experience of dementia and at that time I did not know what was dementia, I was not trained and or anything like that and my mum passed away and I came here and after I, you know (pause) after I was trained and got so much of knowledge about it I really, really enjoyed working with them and I feel sorry that I didn’t have that experience when Mum was alive, um, yeah...

E: Um.

C: ...because, you know, I feel in these people, I see my mum.

E: Do you?

C: Yeah, yeah, so (short pause) I mean, I know from up above she must be thinking okay, you know like I really enjoy what I’m doing.

E: Yeah. So you think of your mum when you’re working?

C: Every time, every time, yeah, especially when like you know my mum died of urinary infection, like now I know like when they have any kind of, that kind of moments like, you
know like they’re not themselves like it’s a UTI. My mum had a lot of moments like that and I
not know, nobody told me. Was kind of overlooked and she had very very bad urinary
infection and that’s how she passed away.

E: oh. So you wish you’d have known more...

C: Oh, definitely, ja. I think if I had have known this I think she would be still alive.

...

E: What kind of things do you get from the people?

C: Um, like, well the happiness and they know they are understood, you know, and they are
happy like (a resident walks in quietly then leaves). Like him (she says talking about the man
who has just come and gone), I think two years back he was sitting in the lounge and that day
it was a very hectic day and I was doing medication and the people were running around and
some was moving around the table and some was crying. In the middle of medication all
these things happening so it was very very challenging that particular evening and he was
sitting in own corner of the lounge and I was running about giving medication and coming
back. I came into the lounge and he says, ‘Here she comes the light of my life.’ (She smiles,
laughs). It was so, so nice. You know, you know all that tension it just went away.

E: Yes.

C: It was so nice...So many people, so many of them... there’s examples from so many
residents. it gives you so much of happiness. Another... Jane was like sitting at the table and
the night staff were telling her it was time to go to bed, the night staff were telling her ...and
as soon as she saw me she was just holding her hands like that (opened out, palms
upwards)... ‘If there was an angel on this earth that’s you.’ (She laughs and takes a deep
breath.)

E: Well it sounds as if you give them a lot of pleasure too?

C: Yeah, yep.

E: Do you think looking after your mum during that difficult time has helped you in some
ways to be...

C: Yeah in a way like, um... (the dog is squealing). I am sad that I didn’t have that knowledge
when I was looking after my mum, I’m very sad about that but I feel her presence always
there and you know each stage of her life I can see in these residents, each stage of their life.

E: Yeah.

C: It’s nice, I love working with them, it’s... but if you don’t understand them, if I didn’t have the training it’d be difficult... like with Mum, like when she had those anxious moments and she was walking around and I used to get, get actually, sometimes I’d get a little bit angry, I’d say, ‘Mum I just told you... now please sit down.’ I did not know, I did not know that they had anxious moments and I did not know how to approach (dog squealing) and Mum was... when I was looking after Mum but now I’ve got knowledge.

E: It’s made it all the easier to work... Did you come into care after your mum passed away?

C: Yeh. She was actually kind of, she’s (a carer walks into get a hoist, Chaya stops for a moment). She gave me that kind of strength (dog squealing loudly, banging with hoist) although she was not there. You know that strength... as soon as I entered a home for work I could feel my mum’s presence and that’s how I got stuck into it.

E: Okay. In a way working here makes you feel closer to your mum, does it?

C: Yeah, it does... it does... (silence)... it does (more silence)... What else? (laughs).

(Interview, 24 April 2015, Winston Grove)

We see an organisation-in-the-mind, through Chaya, that is unequivocally related to maternal function and practice. It is as if Chaya mobilises not just memories of her mother but an internal mother with whom she is in identification.

For Chaya, being at Winston Grove is an act of reparation expressed through her choice of work (Klein, 1952). She is doing for the residents what she felt unable to do for her mum. Daily life at Winston Grove allows her to reconnect with her absent yet ever-present mother. Chaya explains that she recognises the stages of her mother’s life in the residents. Resonant of Ettinger’s (2006) work on the matrixial field, we see how Chaya interacts with the residents as individuals partially through the lens of this internalised mother with dementia. Chaya casts herself both in the position of a good-enough carer to the residents yet one who came up short in relation to her own mother. Guilt seems to be one of the motivating factors in Chaya’s decision to become a carer.

Maternal failings
Different qualities of the maternal – angry, thoughtful, failing, anxious mothers\textsuperscript{22} – also emerged in the work. Here Elaine, the manager of Winston Grove, reflects upon a situation in which she feels responsible for failing her team.

\textit{Elaine was a diminutive woman, well dressed and efficient. She laughs a lot and often gets her hands dirty. She was quick and to the point. We spoke in the activities room. She was cautious about what she said.}

El: In fairness no. They don’t [the staff]... they don’t complain. Um and sometimes I think they should have done especially I know when Roger (former assistant manager) left and things were quite heavy but because I was short-staffed office-wise they didn’t want to be coming to me saying look we need... cos they told the Inspector because it was her that told me and I said well look that’s not fair if they do have a genuine issue then they should bring it to my attention so I can do something about it. It was only when I was... I put the float back in that... because staff hadn’t been coming to me saying look we need extra help at this time of the morning or that time of the evening... they hadn’t been coming and saying it whereas if I had I could have done something about it sooner.

E: Yep

El: When I was made aware of it I put the float back in... it was needed.

E: So they spoke to the Inspector but they didn’t...

El: Yeah

E: Speak to you but they could have come to you directly?

El: But they thought ... they were trying to be nice in a way but they weren’t helping themselves.

E: So it was as if they were thinking she’s short-staffed in the office... we won’t bother you?

El: Yes, she’s got enough stress going on without adding to it... they... would have been better if they’d just come along and said look we’re really struggling here now we need to do something about it and it would have been done. Ok?

E: Yes (knowingly). OK?

\textsuperscript{22} I have written about missing mothers – ‘Is Mother all right?’ – in dementia care in Greenslade, F. ed. (2017) \textit{Absent Mothers}. Ontario: Demeter Press.
El: You can turn the recorder off now.

*(Interview, 3 March 2015, Winston Grove)*

Elaine described a situation in which the Care Quality Commission Inspector had made an unannounced visit, at a time when there were many staff shortages and the team felt under pressure. Instead of asking for the reintroduction of a helping floating carer, who would move between groups, filling in gaps, some members of staff spoke to the inspector. Common to leader/follower relations, Elaine imagines that the staff team were protecting her, unwilling to make further demands on her directly. Relations to authority figures are often tinged with feelings, partly conscious, that come from earlier child-parent relations. Although Elaine does not refer to these relations directly, I imagined that they might have been present in some degree to the way the staff saw her and how she saw them. Elaine considered herself a robust enough figure to have heard their concerns, but at that time the staff team felt otherwise. In this instance, Elaine was unable to contain the anxieties and respond to the needs of the team yet she does not want to dwell on this situation – possibly because there are further interpretations less benign that she does not want to entertain? Elaine felt unable to consider the full meaning of this experience, perhaps because it was too dislocating for her to think about.

*Maternal meaning-maker*

In contrast, Diane, the carer who talked about racism in the UK (page 96), provides an eloquent account of meaning-making involved day-to-day care work, demonstrating how important the consciously reflective mind of a carer can be in supporting feelings of integration in residents with dementia. Here she is able to show a very different side to Winston Grove to the one she described earlier. The representation of the organisation in her mind is now imbued with a capacity for careful attunement.

Diane spoke this way.

D: I always think like that. This could be mum or dad at 94. It’s silly and it’s soppy and it’s uneconomical but I always think like that. It doesn’t tick any of the right boxes but if I didn’t do it that way I couldn’t come to work. I’d have no motivation to even come in the door, there’d be nothing in it for me. It’s okay earning a wage packet but if your heart is not in it you don’t want it. Don’t want it. (She is tearful).

E: So you really feel as if your heart is in it?

D: (Tearful again.) Um. When my heart’s no longer in it I can’t do it.
E: So there’s something emotional about doing the work, it’s not just...?

D: You have to like people and you have to understand people and they’re here because they need care. They need support, they’re pretty vulnerable. Sometimes they can’t express themselves, sometimes they forget, they might start a sentence and then forget it. You have got to fill in the blank spaces and do what you have to do.

(Interview, 17 March 2015, Winston Grove)

The spectre of the maternal (or paternal) figure is both unsettling in the work, but also helpful. Conjuring up her parents moves Diane, it is arguably at the heart of the work for her, and brings certain emotional realities into the frame. All sorts of questions might arise: how will I bear the undeveloping of my parents, how did I treat them, was I a good or bad child? What is interesting in this construction is that carers might position themselves as children in relation to imagined parents, who are nonetheless dependent. It is a reversal of the original parent-infant dynamic.

Yet Diane also sees herself as a mothering figure, suggesting that she is sometimes able to provide a containing function, in a Bionian sense, when she takes in some of the confused parts of the residents and attempts to re-present them in meaningful ways. When we think of the organisation-in-the-mind, it seems that the brutal organisation Diane had described earlier sometimes had a capacity for empathy. Diane understands that dementia involves the experiencing of holes, spaces, gaps that unsettle being. Part of her role is to make sense of the holes, to fill them with meaning. Implicitly she has to keep the thread-like moments of being alive in her mind so that a social-emotional death does not ensue. Diane conceives of a carer’s role, as one that also sustains psychic continuity. The carer, like the mother, is involved in an interactive collaboration which, through being present to associations and omissions, helps someone to be known. Maternal functions, such as this one, act in counterpoint to efficiency and proceduralism. Indeed, as we shall see from April’s discussion of being interrupted, sometimes delaying the task in hand (inefficiency) allowed care workers to bridge the gap between them and the residents, to make meaning as part of a co-constructive process.

Maternal interruptions

April from Winston Grove, whom we met in Chapter 3a, had some interesting and paradoxical thoughts on interruptions in her care practice.

A: …dementia care should be personal centred... It should be about continuity but I find that we don’t have that at the minute because we don’t have the sort of staffing, um, you can find
yourself working with new people on a regular basis. Take this past couple of days, Saturday, Sunday, Monday three different people, today and yesterday I’im working with this guy I worked with yesterday and today where is the continuity there. You know, it throws a lot back on you as permanent staff because you have to stop to give an induction to this person, telling them about the residents and some residents don’t like new unfamiliar faces and voices so it means more is put back on you, the permanent care staff, cos you now have to go to do ML (you know who I mean).

E: Uh uh.

A: Because if he doesn’t know you and you don’t know how to deal with him because he doesn’t express ‘oh I’m hungry’. It’s like we determine whether he’s had something so before we even go to do personal care... you offer him a drink or a banana or something then he’s much calmer for you to deal with him. People who don’t know him say ‘oh he’s lashing out, he’s this, he’s that’ so for me that’s where the continuity is important. You need to have the staff that know the sort of user... you have different individuals to care for and everybody living with dementia is an individual and presents different challenges and if they don’t know them then that’s where we stuck...The, the continuity of staff and yes they say personal-centred care but for me it’s not happening.

(Interview given on 24 March 2015, Winston Grove)

For April, the staff team were experiencing permanent and negative interruptions in the form of regular temporary workers coming in to fill spaces. This related to austerity measures within social care. These fill-in roles were experienced as a ‘seemingly endless series of micro-blows’ (Baraitser, 2006, p 68) to good, coherent care. Care staff felt more under pressure, taking on the dual role of caring and training on the job.

However, there was a paradox at the heart of April’s discussion on interruption. In relation to the temporary worker, interruption severs understanding. When April allows herself to be interrupted personally by a resident, then something more positive is brought to light, as follows.

A: It can be, it can be. It can be very frustrating but as for me you have to find the time to do the one to one and you can’t rush these people because like D [a male resident] he has his good days and his bad days. One day he’ll try to explain carefully what he wants to say and one day he was walking in the garden, I’ll give you an example... He wanted me to go in the garden and he said, ‘Come, come,’ and I said, ‘D I can’t I have got to give out medication’ and
he said, ‘Come come.’ So I ended up having to put away the medication and I had to say to Alan, ‘Do not ignore them.’ We cannot, and he took me outside and where was he carrying me, taking me to the outhouse where the pads were stored. Alan went there early and he was putting the pads in and, knowing he was going to come back, he left the door open so that’s what he was calling to show me that the door was open, that the breeze had opened the door.

E: So in a way he was helping you?

A: He was, so you can’t... so then I had to say to Alan you have to say, ‘Thanks’ to D. The pad door was open and I had a list with all of these pads so I was putting it away and I pushed in the door but no I didn’t lock it. Well he saw it wide open so he came to get me you know so. But it’s like cannot express himself so you have to stop, listen, engage and just go with them and he’s only one of many. Oh he can’t get it out and when he can’t get it out he will let out one or two swear words because he cannot verbally express what he wants to tell you. This needs time. You cannot rush care you cannot compromise care. You have to find out what they are trying to show you....

E: ...in that moment you have one job to do, which is the medication, but that job has to be put on hold?

A: Oh yes ... you just have to put it back, make it safe and go with him to see what it is he’s drawing your attention to...

(Interview, 24 March 2015, Winston Grove)

Resonant of Baraitser’s (2009) work on mothering and interruption, April notes a moment when she is called upon to confront an ethical dilemma and perhaps a series of powerful feelings in herself –frustration, hopelessness – in doing so. Does she continue to give medication or to follow D? Speaking of the way such breaches characterise mother-child relating, Baraitser (2009) writes of the ‘...tears, puncturings to the mother’s durational experiences’ (p. 68) which bring her time after time ‘into the realm of the immediate... the here and now of the child or infant’s demand’ (p. 68). As we have seen in some of the observations (e.g., Suki’s calls for the toilet, Dorothy’s ‘Sally, Sally, Sally’) when residents cry out and interrupt the continuity of one task or another, that cry serves the purpose of eliciting care from the care worker. Here, D demands a caring, concerned response yet he also offers care simultaneously.

April allows herself to be interrupted on this occasion, her activity punctured. Paradoxically this
rupture leads to a deeper connection with D, both now effectively working together, recognising (Benjamin, 2006) one another. The interruption itself acts as a catalyst for reflection, perhaps giving April greater access to her own complex subjectivity and to D’s. This process was possible when the grip of linear clock time was loosened, where one person’s time frame, sense of personal continuity, could make room for another’s.

April’s thinking about interruption showed it wasn’t just ‘depleting but generative’ (Baraitser, 2009, p. 69). There was some sense here that organisationally Winston Grove could hold together, and think about, paradoxical experiences and modes of being that were both dislocating and constructive.

**Whittinghall: Maternal care**

The kind of meaning-making Diane describes, and April’s learning from interruption, seemed unavailable at Whittinghall. Dorothy’s repetitions were understood only as a symptom of her dementia, the underlying significance never investigated. The same was true of Evie who called out ‘Paddy’ in a haunting voice. To become involved in a process of meaning-making with another person, some curiosity (Klein, 1930) is vital. Whittinghall often seemed uninterested in and impermeable to the affective experience of its residents and thus the organisation was not always able to produce a sense of going-on-being in the older people. Investigating Dorothy’s and Evie’s repetitions may have offered up more generative possibilities, allowing them to find the lost object/s they called for before finally letting go. Given that the maternal seems to have been central to learning and meaning-making at Winston Grove, it is probably unsurprising that their relative absence from Whittinghall was accompanied by an absence of mothers.

**Absent mothers**

In Whittinghall, the maternal figure barely featured in the minds of residents. Dorothy never cried out for her mother, and talked about her own daughter only once. The daughter, in turn, was said to visit rarely. It was during my penultimate observation that Dorothy seemed to create a link between her daughter and home, as if her mothering experience reminded her of a time which provided comfort. As Matthew Desmond (2016) tells us in his painfully human depiction of eviction in Milwaukee ‘Home is the centre of life... We say that at home we can “be ourselves.” Everywhere else, we are someone else. At home, we remove our masks... The home is the well-spring of personhood. In languages spoken all over the world, the word for “home” encompasses not just shelter but warmth, safety, family – the womb. The ancient hieroglyph for “home” was often used in place of “mother”.’ (p. 293)
In the following vignette, time at Whittinghall was beginning to come to an end.

Evie is missing still. But so is Dorothy. Her absence is striking, dislocating.

It is good to see Dorothy sitting with a group of residents and an activities co-ordinator, in her burgundy tunic. Many residents are sitting in wheelchairs. She is seated next to a woman with glasses on. Dorothy’s chin is resting on her hands, forehead and face down. Her eyes are slightly closed. Dorothy asks if it’s time to go home. She asks Nancy about ‘Fiona’ and where she is. Fiona is Dorothy’s adopted daughter but she is not coming today. Dorothy puts her head down again, saddened. She wants to go home.

Nancy asks Dorothy if she has enjoyed herself; she says she doesn’t know. Nancy brings the rose that Dorothy has placed in a vase, closer to her, and says that it’s a beautiful colour – it is yellow.

The activities co-ordinator jokingly says that Nancy is disturbing her. ‘I’d like to know how to get back home,’ Dorothy looks towards the window. ‘I don’t know what I am supposed to be doing here. I don’t know,’ she says. She looks out of the window and notices it is raining again. ‘I don’t know what to do, I think it is time for home.’

... 

Dorothy seems to fall asleep, her breathing heavier. Perhaps, asleep, she’ll somehow find home.

(Observation, 8 September 2015, Whittinghall)

Memories of the baby

Another of the infrequent references to mothers at Whittinghall occurred in my interview with Ellen, a gentle but worried resident. In the course of the interview Ellen presented herself as a mother but, by the end, my sense was of her being representative of a baby in the grip of a dreadful fragmentation, dependent and scared. It was as if she were the baby without a responsive mother, an image that married up with many of my observations in the home.

Ellen spoke to me in her bedroom. In her room were several plants and photos on a windowsill. Dressed in dark browns, with wispy hair falling in front of her face, Ellen struggled throughout the interview to get her bearings. This played out in her trying to decide which shoes to wear. Ellen’s dementia may have impaired her sense of body schema. At one point Ellen takes
my foot as though it is hers, a phantom body-part, perhaps symbolic of her disconnection with the immediate environment. So hard to witness, had Ellen become a series of part-objects to herself?

EL: And the fellow that’s the (mumbles) house was housing up here, was very airy. It was awful. A little girl got there. Think it was the daughter’s child. They were well I think, but I was quite glad to be able to try with mine. But... I don’t... it’s a crazy world. I don’t know where I am, how I am... I feel quite deaf today. Usually I can hear okay but this...

E: Are you feeling pretty confused today?

EL: There are times when I do, yes. I don’t know what I was doing today and when and why. The look in his eyes and we are going to do this this and this. I didn’t take anything home. It was very strange. All the way to go. Thought where is my baby...? Have I left her behind?

E: Your baby? What’s her name?

EL: He’s not very old

E: He’s a he?

EL: I can’t remember. Things aren’t working well with me. I can’t seem to keep top of... I don’t know what mistakes pop and... those aren’t mine.

E: They aren’t your slippers?

EL: That’s a good ‘un. (Laughs)

(She picks up her shoe, taking one of her slippers off and trying on another shoe.)

EL: You won’t believe it, there’s two. What’s that one doing there? Doesn’t quite like but it’s not bed. Bright like. (Laughs). I don’t know that I like the bright red ones really. Bother... Oh it goes with those. Yes it does. That’s that. Oh it changes it’s... Oh what’s this one doing. Oh. I’m going crackers.

(Interview, 18 August 2015, Whittinghall)

At one point, Ellen herself becomes the mother who has lost her own baby. Here, baby becomes a representative of Ellen. She is both mother and baby, someone losing and someone lost. Our interview lasted thirty-three minutes. It seemed important that I stayed with her in what was a very difficult experience of confusion. She was continually flicking the hair out of her
eyes, changing one shoe for the other. I wondered if her laughter was the only way of making it bearable; or whether she feared I might be laughing silently and so pre-empted any mockery. Her shoes, like the sparse room and her slippery words, felt as though they didn’t belong to her. Ellen’s experience of fragmenting was powerful, and it didn’t feel coincidental that she was the only resident who referred to a baby per se. She reminded me of Winnicott’s (1960) infant gripped with the fear of disintegration.

The absent organisational mother

My sense of Ellen as a baby fragmenting in the absence of a responsive mother echoed a wider sense I had of the home, namely as somewhere in which an overarching organisational mother was absent. This absence was particularly felt in relation to the psychic confusions and disintegration of the residents and was manifest in the staff’s care practice.

The following examples show just how impenetrable the staff team could be, which I felt sure left residents feeling all the more disjointed, panicked, in their experience of dementia.

‘Sally, Sally, Sally,’ shouts Dorothy. Louder, louder, louder. She raises her hand into the air and makes that bird-like beak shape with her hand. ‘What am I doing, doing, doing?’ she says. Nancy doesn’t answer nor does the other carer. Dorothy shakes her head and puts her face in her hands. ‘Don’t know what I’m doing, doing, doing.’ Nancy is busy filling in forms, not noticing what Dorothy is saying.

(Observation, 9 June 2015, Whittinghall)

In this next example, a male carer allows himself to be interrupted by one resident, abandoning another in the process. You wonder, given the lack of eye contact, if both residents are seen as tasks to be completed. Certainly, there is no sense here of responsive maternal care.

The male carer doesn’t make eye contact with the man but starts following him to where he needs to go, leaving Evie in the chair in the middle of the corridor. Abandoned. She says nothing, her feet dangling from the chair.

‘Don’t like the look of that,’ says Dorothy, noticing Evie’s predicament. She shakes her head. The phone starts going again but no one answers.

(Observation, 14 July 2015, Whittinghall)

The maternal seems similarly absent from the following vignette or, if it is present, it is mothering of a noticeably distant, uninterested kind.
He (the waiting staff) hands the woman next to Dorothy a Hobnob. He gives the lady next to her another biscuit. The man opposite Dorothy is sitting in a wheelchair, his body looks stiff and his arms are bent in front of him. A debilitating long-term condition perhaps. The man in the waiter’s costume walks past him, doesn’t hand him a biscuit. The man uncomfortably twists his body round looking at the biscuit tray. He looks confused but says nothing. The waiter puts the tray in front of a man next to the man in the wheelchair, and holds the tray still for some minutes. The activities co-ordinator reaches over the man and takes a piece of cake for herself. Begins eating it.

The man in the wheelchair with the contorted body is looking ahead now, silent but sad. After some minutes, the activities co-ordinator walks around to him with a piece of soft cake in a napkin. She takes a tiny amount of cake between her finger and thumb. ‘You are my darling,’ she says. She holds the morsel towards his mouth. He looks at it with his eyes narrowing, and then he takes it with his mouth. She continues to feed him like this, without speaking, chewing her own piece of cake and looking ahead at the rain out of the window as she does so. It is a picture you see in cafes when mums give bottles to their babies while staring at their phones, an image of disengaged giving.

*(Observation, 8 September 2015, Whittinghall)*

This was a particularly difficult observation. I remember watching the man in the wheelchair as he was forgotten about. He said nothing but his eyes looked pained. What made the disconnected mode of relating so hard to bear was the fact that this man was so physically incapable of helping himself. Even the feeding of the cake, usually a good point of contact when Nancy fed Dorothy, seemed absent of feeling and generosity.

**Family constellations: the staff team**

If staff care practices frequently suggested the absence of an overarching organizational mother, it is probably unsurprising that, in contrast to Winston Grove, mothers were almost never mentioned in staff interviews. Grandparents were more commonly discussed, however, possibly because the care team was made up of younger workers. Generationally this kind of conceptualisation made sense. Nancy spoke of being treated as a grandchild and even – and this felt uncomfortable to hear – admitted that sometimes the staff called certain residents granddad or grandma. Although these comments were presented as cheerful and fond, I couldn’t shake the feeling that this was a little too casual, blithe. This got tangled up in my head as having something to do with identity. Real identities overshadowed with distanced make-believe ones.
Prashid, a male carer, speaks to me for 8 minutes. We talk together in the lounge, empty. There is loud classical music playing in the background. All the tables are dressed for lunch with wine glasses and napkins. Prashid seems reluctant to talk, unsure of what I am asking of him. He seems tentative about revealing too much.

P: Well I like working here because it’s a bit different job than I did before. Personally I have changed so many things in my life and this job it has impacted. Working with elderly people it’s like ... you know my culture... the culture I come from we care more about elderly people so normally we don’t have care homes... back home... we look after our grandparents and our relatives. So when I first started this job I felt like I’m back into my culture and working like. I felt it like that. I built up my patience and communicating so lots of things have improved... we don’t have care homes there... facilities wise we are very much backwards but here we have loads of facilities but I’m not very familiar with the culture... Looking at the facilities here it’s very good.

E: And do you enjoy it? How do you find working with older people then?

P: I used to look after my grandparents but not really in a working environment. Here it’s like a job but it’s like a home as well.

(Interview, 11 August 2015, Whittinghall)

Prashid speaks indirectly about his grandparents. This link to people in his life reminds him of his home country. He resignifies Huntside unit from work to home. In fact, this tendency to talk about work in terms of ‘family’ or ‘home’ was one of the most striking things about Whittinghall. However, the family was one in which the mother and, for that matter, the father, were not present. The greatest connections that I observed were among members of the staff team themselves. There were photographs by the nurses’ station of staff Christmas parties; I witnessed quite surprising moments of intimate touch between individual staff members; and staff were often to be seen going off on breaks in groups. If the organisation-in-the-mind for members of the staff team took on a family-like quality, it was as a constellation of siblings where grandparents featured in the distance and parents were wholly absent.

Concluding mother/s

The absence of the maternal figure in Whittinghall was pronounced. Residents did not cry out for mothers of any type and staff did not reference their own parents. To return to the organisational picture, we might imagine that mother here had delegated her role. The children
are doing the care while she remains aloof and out of reach.

Mothers imbued with different qualities were present in Winston Grove. They were often summoned up by residents, as if feelings belonging to them could usefully be projected onto phantazised figures from the past. This mechanism seemed to make way for the expression of a vast array of feelings that belonged to the residents, but which ended up being located in ‘mother’. This might have meant that different aspects of maternal care (good, bad and in-between) were in fact present at Winston Grove.

Death

The final organising theme that emerged from the data was death. Although death is a very final interruption, there are of course many forms of dying in institutional care that precede the death of the body. We might see this particularly perhaps in terms of ‘being dead to’ the full experience of others and indeed self. And of ‘being deadened’ by organisational protocol and procedure. In short a deadening towards relating – personally or institutionally. Additionally, as I have already said in Chapter 3a, there seemed to be a real need to find time to do the work of mourning in both organisations. Some staff expressed regret about changes to care practice and to the care environment, and the associated occupational losses; and residents indirectly communicated untold losses of loved ones, home and cognition.

The organisational culture of both homes had an impact on how people connected and, hence, on how emotionally alive the homes felt. Quite possibly, the number of different types of mother/s that were brought to life, particularly at Winston Grove, spoke of this emotional aliveness. Winston Grove seemed to be the more playful environment and ways into intimacy often consciously involved singing, games, laughing, activity. In my mind, Winston Grove represented a lively home, although at times this felt like a manic defence against the dying. The number of interruptions I witnessed at Winston Grove seemed to be reflective of this manic functioning. Although the activities room had a privacy sign on the door, every interview there was punctured by sounds or by people. Residents often entered, hovering behind their favourite carers, or Gemma’s puppy would let out a loud squeal for attention. Senior carers wandered in, as if making a point to return to work, or workmen entered to pick up equipment. It seemed as if there wasn’t – organisationally speaking – a respect for the privacy of bounded beings, who could withdraw into themselves if they needed to do so. It reminded me of the anxious mother constantly checking to see if the newborn was still breathing in his sleep.

At Whittinghall, waiters also entered rooms offering ‘biccy biccies’ or cups of tea, but
interruptions were much fewer. I will first consider the theme of death in relation to Whittinghall because the environment was palpably deadening at times. I often sat with a sense of the heavy futility of human life, as if I were trapped inside a bin with Beckett’s Nagg and Nell, watching the world around me spin, helpless like Dorothy, in the corridor.

Whittinghall tended to represent dying, a waiting space, while Winston Grove tended to represent active aging. Although this split is too reductive, many factors fed into this general assessment. Winston Grove was an open-planned dementia care site. Residents walked around a lot, and were free to do so. The only areas which were out of bounds were the kitchen, the staff room and the laundry. Whittinghall was compartmentalised, in a physical and structural sense with different units offering different types of care. Though the units weren’t key-padded, only one male resident, relatively young, crossed the boundary between ‘dementia unit’ and ‘elderly frail’.

At Whittinghall intimate moments of connection were few and far between. When tender encounters did happen they often hinged on the sharing of food, as we see here. Encounters such as this one were also very short-lived.

Nancy walks past pushing another resident into the hairdresser’s office. She walks back to the nurses’ station and pulls out a cupcake from somewhere. She walks over to Dorothy and offers her the cake, taking the paper from around it. ‘What do I want that for, that for, that for? I don’t want that, that, that.’ Food: an oral sensation of existing? Dorothy flicks a lot of chocolate topping at Nancy, but then takes the cake, takes a bite of it. Nancy walks back to the nurses’ station and sips a drink from a bottle, re-energising? All the while Dorothy has her eyes on her.

The nurse is jotting things down in a file, and the young female carer has her left hand touching the nurse’s neck. This is an unexpected moment of intimacy. Between staff.

‘Sally, Sally, Sally,’ shouts Dorothy, holding the cake in the air for Nancy.

Nancy walks over, takes a bite and hands it back to Dorothy. Dorothy smiles, taking another bite. Once she has eaten that one she calls out again, ‘Sally, Sally, Sally,’ holding up the cake again. Eating, drinking, usually connects them.
Nancy pretends to take a bite then hands the cake back. ‘No, no, no more,’ says Dorothy. Nancy takes the cake and throws it in the bin behind the station. Enough play for today.

*(Observation, 24 June 2015, Whittinghall)*

Connection, intimacy, and disconnection relate, I think, either to the capacity to be alive to other people or to the need to close off to them (to be dead to...). What I began to formulate was that the more regulated a care site, the less scope there was for taking risks in the relating and getting it wrong. Care became more professionalised, which led to a more distanced, deadening sense of relating.

The sense of disconnection present in Whittinghall could be seen and felt in a range of factors: uniforms created clear demarcations between residents and staff, not so at Winston Grove; Dorothy was not free to move and often care staff would put the brakes on her wheelchair (p. 103), whereas Daphne walked everywhere; and the nurses’ station at Whittinghall was a designated space for staff to do their work in, whereas at Winston Grove staff members sat side by side with residents filling in care plans. Huntside was also designated ‘elderly frail’, which seemed to enhance its overall sense of paralysis. Given that Winston Grove was a home specifically for people with dementia, it is unsurprising that I noticed more people with advanced cases of dementia there. Interestingly, Whittinghall felt more deadening even though some people in Dorothy’s unit were mentally alert. This lifelessness was seemingly captured in the image of Dorothy stuck in the corridor, the residents in bed behind closed doors.

That is not to say, Whittinghall was wholly without life. As I go on to discuss in Chapter 5, one resident noted a protest at the end of a corridor; another made a demand for more wine at lunch. These two residents suggested that life, and agency, were represented in the home, though not as well tolerated as it was at Winston Grove. Nevertheless, its deadened atmosphere was palpable. I concluded that Whittinghall felt this way because the organisational response to failing health was to erect fairly rigid procedures, to compartmentalise roles. At one point an iPod care-planning device was introduced, seemingly another example of tidying the place up, managing efficiently but rather inhumanely. A sense of stasis and unimaginative interaction between residents and staff often ensued. Here we note Dorothy trying to get attention, again to no avail. As a result, she withdraws into herself, a symbol of social death.

‘Can you hear me, can you hear me?’ Dorothy says. She drops her head down and rests her chin on her right hand. Heavy again. She stays in that position, looking down at her stomach, her breath up and down. She half-closes her eyes.
The phone is going. No one is answering it.

Nancy walks into the corridor. She looks tired. She talks about time passing, summer ending, autumn beginning soon. The new system. All members of staff are carrying devices, iPods. Each person can note down episodes of residents’ care as they go, on the job, tapping on icons to record information about different types of care – food, hair, teeth. At the moment staff seem unsettled by the development, but soon they might come to like their phone devices.

*(Observation, 18 August 2015, Whittinghall)*

The other feature of Whittinghall was the apparent cut-offness of the residents. It was very rare to see residents walking around the home, particularly upstairs in Dorothy’s unit. The same was true of lunchtimes in which the large dining room was barely used. Tables were left empty with only a few residents ever making use of the social space.

I will now introduce you to Peter, one resident who spent each and every day in his room, as many others did.

*Peter*

*Peter was a man who kept himself to himself. His room was very comfortable, with photos of his daughter on a mantelpiece, an image of him, younger, by a yacht. The television was on in Peter’s room, very loud, with something like Antiques in the Attic on. Peter was lying in bed, a cotton sheet pulled up to his chest. He had a white shirt on underneath. He was chatty and welcoming. He laughed a lot. Despite the seeming liveliness of the laughter, Peter seemed stuck in his room, in his bed.*

P: I could do it on my own. I will do it. I’ll just buzz off somewhere… Cornwall or somewhere.

E: Oh, would you?

P: Since the time I’ve lived here, not seeing anybody. But uh. (Phone is buzzing). Unless I meet a young lady and she has plenty of money… I’d say that’d be nice. I’ll have your money and we can buzz off. (He starts laughing).

E: That would be nice, to meet someone and buzz off to Cornwall.

P: Yeah… (he is laughing). We all want to do it. (Silence) I don’t think that would ever happen though… (Silence). I don’t think that’ll ever happen… go face there (something inaudible)…
that’s it. (Silence). Don’t know. Apart from that, you know… that’s it, isn’t it really. Well when you live here like I do you think well, what shall I do today? Well… that’s no good to me… that’s it. Well. Like to go to Cornwall or somewhere, travel around a bit. But uh… I wouldn’t sort of sit here and think of (inaudible)... I’d just do something or whatever...That’s it... but um.

... 

P: You know, that’s it. You know. I don’t want to meet some old girl just for her money. She can keep her ruddy money. I’m looking at it so (inaudible). Crikey. (Laughs). Think hello hello, she’s after my loot. Which has all gone... But uh there we are. Well uh it’s all right sitting here like this innit, sitting here, watching your toes go up and down (he looks at his feet underneath the cover and moves his toes up and down). Yeah, watch your toes thing. (Laughs).

(Interview, 4 August 2015, Whittinghall)

The pain of Peter’s isolation was intense at times. He seemed preoccupied by money, mentioning it twenty-two times during the interview, and by finding a companion (whom he feared would take his money). Money would allow him to find the companion, and also help him to escape to Cornwall. Yet, on some level, Peter recognised these were pipedreams, which made his predicament all the more depressing. ‘That’s it,’ he uttered several times as if it were ‘game over.’ I noticed myself feeling marginally uncomfortable, sensing a low-level erotic transference. But watching Peter, under cover, television booming, heightened the pain of loneliness and the inevitable slowing-down of life, of desire. At Whittinghall, there seemed to be an absence of the possibility for play and, though death was discussed in interviews with staff, the home did not offer the residents the possibility of mourning their losses. The environment tended to be sterile, and this had seeped into the resident experience. Dorothy was for ever wiping crumbs from her top as if nothing could be out of place.

Peter’s stuckness in the room was hard to be around, despite his performance of jollity. I wondered whether his laughter expressed a self-criticism, as if to say ‘silly old fool’. Finally when he talks about lying in his bed watching his toes go up and down, I felt the full weight of this deadening paralysis. Peter seemed to represent something about the risks involved in being alive to an-other. He imagines being together with a woman, but that togetherness is tinged with a fear that connection leads to loss (in his case ‘loot’). This seemed to mirror the sense I had of Whittinghall, where carers remained at a distance, perhaps partially conscious that deep
attachments were too emotionally costly, in the face of death. Or perhaps, being a privately run home, the staff imagined they had to be more businesslike, professional; that the concept of care was intertwined more closely with notions of service provision, of having customers.

I had observed something of the unbearable nature of this heavy isolation each week. The haunting voices of Dorothy or Evie calling out for ‘Sally’ or ‘Paddy’ repetitively were very hard to sit with. What made it harder was noticing these cries going unheard, ignored. This meant that Dorothy and Evie were almost always alone with the experience of a lost object, who could not be brought to life creatively either through memory or simple conversation with a member of staff. One particular observation was striking. Not only was Evie left to look after herself, but she was given a cup that read ‘Funeral Directors’. I couldn’t help but remark on the link between the absence of caring relationships and an acute sense of death in the residents’ social world.

Evie is calling out, ‘Paddy, Paddy.’ Every now and then she pushes herself forward slightly and grabs a piece of toast with marmalade on it, taking a bite. ‘Ooh, ooh, ooh,’ she calls out after finishing her bite. She is slumped down low in her chair; it is as if the armchair is swallowing her up. Her loose skin falls around her neck, which seems almost weighted down by it. ‘Paddy, Paddy,’ she says. Her cup of tea reads, ‘Funeral Directors.’ Sometimes you might think there are subliminal messages everywhere.

‘Sit upright, sit upright,’ Evie tells herself. Evie is parenting herself, it’s painful to witness.

*(Observation, 14 July 2015, Whittinghall)*

Interestingly Nancy and Sonia, the senior nurse, explained to me how residents sometimes decided they were ready to die in Whittinghall. I am not sure that this is what I was observing with Evie or Dorothy, who still raged against the inattention. However, this did make sense of Peter’s self-exclusion there, and there was doubtless much truth in both Sonia’s and Nancy’s assertions that many residents had chosen to stay in their bedrooms. I acknowledged this, but also thought about the way Dorothy shut herself in whenever she felt rejected.

Having said that, Sonia, in particular, was very thoughtful about what she had experienced with dying residents. She spoke to me for over twenty minutes – the longest interview with staff at Whittinghall. Her willingness to try to engage with the emotional component of her work, trying to understand what this did to her, surprised me. This seemed to be in contrast with the professionalised distance of many Whittinghall staff that I’d observed. She gave a thoughtful account of the home and the residents, and it dawned on me that perhaps part of the distance I
experienced, in Sonia’s unit (Huntside), at least, had to do with the fact that the team at times handled palliative cases. In fact, they were conscious of palliative work in a way that Winston Grove didn’t seem to be. The preparation for death that Sonia notes might well have involved a necessary cutting off.

S: Yes and some people they think oh that resident is in their room... and don’t want to do anything. It’s not like that. Some residents are very very old and just want to rest. We have Evie and she was here in the morning and we try to make her walk and we take her, because it is better for her, out of her room. But what she really likes, if you’d let her, she would stay in her bed all day. But her family don’t want her to do that. So sometimes she will sit in a chair for a long while and then she’ll ask to go to bed and if it’s what she really wants and she is more comfortable there then... She feels tired.

E: And I suppose you have to respect that, don’t you?

S: No we can’t just take her to do things if she doesn’t want to...

......

E: I understand. It sounds sensible to respect that some people get exhausted and can’t keep being encouraged...

S: You can’t just come here and expect to see everybody doing something. Some of them just don’t want to do anything else. And it’s hard as well to see, when we... we know a resident for a while and we have someone that used to be active and do things and were interested. And suddenly they just give up. It happened before. It’s hard for us to see that....

E: Really

S: ...And with dementia you just won’t ever get better you tend to get worse, and it’s really difficult for them to accept that. Sometimes you have to deal with the resident and with the family as well.

E: I imagine it can be quite difficult talking to families about the changes taking place.

....

S: And it’s very difficult when we have a resident who gives up and they say ‘I think it’s my time’; ‘I’m not doing anything else, I just want to go, I am tired of living.’ This is hard for us to hear as well because when we know them and we saw how they were before ... so I can
understand for the family it is even worse. But we have to respect that and we can’t force
them.

E: To keep on living?

S: This happened before. We had a resident and he said that he wanted to live just to
celebrate his 90th birthday. He came here, he was fine. He had a big party. And after a couple
of months, maybe 2 months, he began to deteriorate... He stopped eating, and um he
seemed more depressed and he said that he wanted to go. And yeah he did. And it
happened. He just said that he didn’t want to live anymore, he'd had enough...

When we are expecting a death we kind of prepare ourselves...Sometimes we think oh it’s
just work but it’s not a work where we deal with machines, we deal with emotions. And
when we deal with the emotions of someone else we need to deal with the emotions of
ourselves and it’s not easy. And sometimes we need a break, a holiday just to focus on
something else to recover and come back but if we like what we do we manage to do it.

(Interview, 11 August 2015, Whittinghall)

Speaking to Sonia helped me to understand that Whittinghall’s pervasive sense of deadness did
not simply stem from a proceduralised and inflexible culture, one in which capacities for
connection and thinking were minimised. Nancy had also explained that she tried not to get
too attached to residents, for fear of them dying. It hurt. Things that hurt are often avoided.
Perhaps the cost of engaging with residents who were increasingly withdrawing from life was
too great. I began to wonder how the young staff team were supported organisationally to
process the deaths they encountered. Apart from informal chats, hugs and holidays, which
Sonia spoke of, there didn’t seem to be anything in place to process loss.

Winston Grove was, at least on the surface, quite different. During my observations there, I was
frequently struck by my countertransference – a feeling of being on edge in the face of loud
music, whooping sounds to the hoopla. The lively atmosphere also jarred with the slouched
bodies of residents trying to sleep through the noise and laughter. I came to think this was an
organisational denial of, a manic flight away from, the nameless and inevitable pull of death,
which was in the home yet spoken nowhere.

An empty room is a telling sign. People don’t talk about death at Winston Grove, though
people here die. Disappearances are marked by empty chairs and RIP signs scrawled on the
staff whiteboard, but spending any time thinking about the losses of people you might
actually like is perhaps too much - especially in a home that likes to keep active.

It is now up to Erica to organise the trinkets and clothes for the grieving family to pick up. With a file in her arm, and the supervision of the assistant manager, she will cross-reference what is left behind against the inventory noted on the residents’ arrival at Winston Grove.

Beyond memories, just a handful of remaining items symbolise a life that ends in the small space of room two.

*(Observation, 28 October 2014, Winston Grove)*

Although taking a different form from Whittinghall, anxiety around both physical and social death was also defended against at Winston Grove. In the final observation I conducted, Diane talked about funeral of Daphne’s long-term partner, Benjamin, who had died the week before as if this were just another of Daphne’s trips out. Though Daphne’s anxiety was at a very heightened level that day, the home keeps going – active, alive – and the response to her psychic pain was to take her out to the local coffee shop. The quiet solitude Daphne might have needed was well out of reach.

Today she is sitting at a dining table. Diane is explaining to Daphne that she is giving her her medication. ‘I don’t know what to do,’ says Daphne. ‘Open your mouth, Daphne, and I will pop this in your mouth,’ she says pointing to a tablet. Daphne opens her mouth and the carer gently places the spoon and tablets inside. She screws her face up. Diane hands Daphne a glass of water and asks her to drink it all down. She looks up at the carer, and smiles at her.

This is care; the everyday realities of making sure people keep on going; the everyday realities of watching people become more dependent. Newborns, fledgling birds, old, old people opening their mouths and waiting for some kind of care. Life’s circle closing, closing in.

Elaine’s dog, Screech, walks in to the dining area and stands at the doors that face out onto the garden. ‘Oh, hello there,’ says Daphne. ‘You want to go out Screech,’ says Diane to the dog. Daphne pushes herself up from her chair and walks towards the door and stands close behind the carer. ‘Bye bye,’ she says to the dog, endings in her mind. ‘Bye bye.’

Daphne is wearing a grey floral blouse, a grey cardigan, black skirt, black socks, black shoes. She has on her purple tinted glasses. She stands by the door for some time and watches the carer go into the kitchen. Daphne looks at me, sadly. ‘I don’t even know who I am,’ she says, and it’s hard to think about what Daphne says without thinking of Benjamin and the meaning that his existence had given her. ‘I don’t know what to do.’ The dog reappears at the door,
and Diane notices. She stops by the door and opens it up. ‘Back already,’ she says.

Daphne makes a noise as if she is in pain. It is a quivering sound. ‘I don’t know what to do, where I am. I want my parents,’ she says, looking around the room. Lost children, in lost continents.

Daphne walks into the room where Gemma and another carer, April, are getting residents ready to go out.

‘Their worlds don’t understand my world; my world doesn’t understand theirs,’ says Daphne. ‘They are too busy. They can’t pay attention to you.’ She begins to make this quivering, anxious noise again, holding her hands together tightly around her. You imagine Daphne is falling apart inside. She begins to stare at an empty chair, loss, while April is getting one woman ready. This woman doesn’t have a coat in her bedroom and so April sacrifices hers for now. ‘Is that okay?’ The woman puts on the carer’s coat and seems delighted. ‘Oh well very well then,’ she says. ‘How wonderful this is.’

‘I think all I can do is sit down,’ says Daphne. She goes to a chair, stands over it but doesn’t sit down. She walks back towards the carer, Diane, who is now speaking with Suki who seems to have changed her mind about going out. Daphne is watching. ‘Help me, help me,’ she says in a quiet voice.

‘What will I do then?’ she asks. ‘Well you are going out on Thursday,’ says Diane to Daphne, but going out we know is for Benjamin’s funeral. This is not for leisure. ‘I want to come with you,’ says Daphne to Diane.

‘Well I am staying here with you, Daphne, and we can make some tea together and eat some custard creams.’

‘Oh good,’ says Daphne. ‘I don’t really know what to do. Can we help each other?’ Daphne is clutching at people and you wonder if this is because she knows, deep down, that she has just lost Benjamin.

(Observation, Winston Grove, 15 February 2015)

It is as if Daphne is dying inside here. It was impossible for the carers to attend to Daphne in the way she needed. The carers were busy, carrying out the physical tasks involved in a trip out on a cold day. The emotional and psychic turmoil that Daphne was experiencing had little place, in that moment. She needed someone present to her ‘world’, one that was increasingly incomplete.
Daphne had an ability to communicate exactly what was going on for her, and when she looks at the empty chair, it is as if she knows that there has been a death, one that makes her feel as if she too is unravelling, empty.

This observation was a very difficult one because I also knew that I would be leaving Winston Grove, as the observational study had come to an end. Daphne had already lost a major attachment in Benjamin, not only an attachment to love and connection, but also to the outside world and her past. The loss was tremendous and leaving her worried me, imagining that each empty space and chair at Winston Grove would represent yet another death for Daphne.

Gemma, the activities co-ordinator, arguably represented a denial of death for the organisation. After all, being so close to grief, the impact of a death, could be very disturbing. The activities Gemma led were boisterous and had an air of celebration. What follows is Daphne’s struggle to join in, in need of something calmer, some peace.

A pile of books has been pulled out of the bookshelf, discarded on the floor. Daphne is in the toilet, the door is wide open. This was the all-hanging-outness of Winston Grove. A member of staff appears, closing the door gently, seeing that Daphne’s privacy is at stake.

Daphne emerges from the toilet. She is fiddling with her fingers, worried. ‘It is a concern that the children are here without their parents.’ Thinking about how they will be looked after is making her nervous. She is concerned about her mother, too. ‘Although,’ she says, ‘I suppose I could stop myself just there and look at her.’ She stares outside at the fountain for some time then turns to me. ‘Perhaps if you think it would be okay, I could come and help you do what you do.’ She hasn’t seen that she is helping me now.

Bitterly cold outside, despite the sun’s rays, Daphne is dressed in a warm cardigan and a blue floral blouse which ties – a loose ribbon – around her neck. She begins walking. There is no one in reception today. Daphne stops, looks around and keeps going past the unit where she has her breakfast, towards loud music dating back to the 40s. She stands at the edge of the double doors to another lounge, watching, cautious.

A man is throwing hoops at the target in front of him. There are about fifteen residents there, most in chairs. Some are clapping in time with the music and others mouthing the words, ‘Goodbye Piccadilly, farewell Leicester Square.’.

Daphne is observing. ‘I don’t want to look silly today,’ she says, explaining that she tries her best not to be a stupid old woman. It hurts to hear this. She wants something ‘quiet’ today,
as if she is conscious that her social world is shrinking further out of reach; as if conscious that she is losing the Daphne able to filter the appropriate from the inappropriate. The fear of doing something shameful leads to her self-exclusion. She goes back to her regular lounge. She sits, squeezing her hands together, as if holding on to some semblance of Daphne, to self.

*(Observation, 18 November 2014, Winston Grove)*

During Gemma’s interview, it became clear that she felt the experience of being dependent in a care home could lead to a meaningless existence. She seemed preoccupied with ‘doing’ as a way of remedying this futility. She wanted residents to retain their capacity for activity. Doing was a marker of life.

G: As I’m the activities co-ordinator. So I kind of deal with the social life of residents with dementia… trying to keep them motivated …

E: Aha.

G: Have a purpose in life... keep them busy really... trying to keep them going (large sigh), I suppose. Cos if it was me and I’d been put in a home... well not everybody wants to go in a care home, it might be better for some of them because they were... social isolation.

(Two work men walk in and start moving a chair in the background then walk out).

G: Well for me if I’d been put in a care home... and they’re just... I don’t know... you have your lunch... you get up... you have your lunch at this time... It’s something to keep you... You’d be like ‘why am I living? What’s my point?’ So it’s something to keep you going... Do what you used to do. Going out for walks, as we have done today.

E: Yep.

G: Um... and not just being sat in a chair to fall asleep in front of the TV all day and cabbage out. Life doesn’t end just because you’ve come in a care home, I don’t think.

*(Interview 3 March 2015, Winston Grove)*

Gemma’s attachment to residents’ past abilities is an interesting phenomenon – perhaps symbolic of the organisation’s struggle with allowing mourning. This is one possible set of meanings. Another might be that by holding so tightly on to former identities, the changing self can neither be fully borne or accommodated by the organisation, although my observations
generally suggested that care staff tried to adapt to the residents’ changes. Nonetheless the avoidance of mourning, dependency, loss and death was striking; so much so that death – the word – was not mentioned by any single interviewee at Winston Grove.

Relatedly, death in dementia care is often overlooked, minimally explored in policy. It was striking that Sonia and Nancy had broached dying as sensitively as they had done. It left me with questions: what does death stir up in workers; how difficult is it to accept the failure involved in letting someone go; what about compassion fatigue and how does an organisation support being over doing?

Concluding death

The theme of death allowed me to expand my sense of the organisations, whereas initially I had found myself prone to splitting them into good and bad care sites. Around the theme of death I could see that both were imperfect and both had qualities. There was in Winston Grove the possibility for spontaneity and aliveness, where identities could show themselves easily and make stands, yet the home didn’t always offer the privacy and solitude needed by those who were increasingly dependent or dying (socially or physically). Whittinghall’s professionalised manner created a compliant culture in which complaints were swallowed down with biccies, as if the biscuits could medicate away ill-feeling. Possibly, though, the quiet distancing in Whittinghall afforded some residents a calm in which the long rest could finally take place.

The distanced mode of relating found in Whittinghall made room for some capacity to look death in the eye, which the manic activity in Winston Grove did not permit. Winston Grove took risks in human relating, which allowed people to be heard a little louder and seen with greater complexity.

Conclusion

Through speaking with staff and residents, and comparing these interviews with the observations I conducted, glimmers of the organisations which existed in people’s minds began to appear and a more general picture of the homes to emerge. As will be apparent they were very different sites, one plush and well ordered, the other rough around the edges, even if routines were often timetabled, a necessary factor in institutional life. Both homes displayed a paranoid-schizoid mode of functioning, where splits and rifts were noticeable. In Winston Grove this splitting was present between permanent and temporary workers, old and new forms of care practice; between stealth and efficiency and slow and humane treatment; at Whittinghall, most pronounced between the young staff and the residents. But it was not all black and white.
Both care homes often seemed to exist temporally in the present moment – ‘Tuesday, Tuesday, Tuesday’, as Dorothy would say – often seemingly cut off from the wider socio-historical context. Apart from the reference to austerity measures by some staff at Winston Grove, and Diane’s eloquent account of racism in the UK (Chapter 3a), it was as if everyone who lived and worked in the home existed very much in the spatio-temporal context of the home itself. It was hard to think about all the possible strands of existence which fed into the relational and experiential field of both care homes. At times, I got the impression that staff and residents were seen as subjects of the homes’ routines and tasks, and as a result I wondered how everyone had come to be there. In some ways, this seemed symbolic of a different type of death: the death of a rich and complex identity of both the residents and the workers.

With both sites, what became clear, especially through the interview material, was that the experiences of the staff and residents were not processed organisationally in a formal third space (Britton, 1989, 1998, 2004). In other words, the capacity for meaning-making, arguably a feature of the maternal, as noted in Diane’s material, was barely available at an organisational level. This absence was noticeable at both sites, neither providing staff with reflective opportunities to share their experiences of the work and to promote the development of the relatedness of the workers to their internal worlds, to one another, and to the residents.

In the following chapter, I will attempt to flesh out the themes of time, mother/s and death by underscoring them with insights gleaned from the relevant psychoanalytic literature I set out in Chapter 1. I also wish to demonstrate how the original framework of the mother-infant dyad began to expand, as I became more and more familiar with the care home sites. Additionally, I will touch on issues of class and racial difference, which certainly demanded thinking about in the work with two members of staff particularly.
Chapter 4: Analysis

It was one thing to know in private that my brain had become unfaithful, but it was frightening to learn that my brain’s private betrayal had become publicly observable.

(Anna Dartington, 2010, in Dartington, T., p. 155)

The aim of this chapter is to revisit the major themes that emerged from the corpus of the fieldwork – namely time, mother/s and death– and relate them more closely to psychoanalytical theory outlined in Chapter 1. I will endeavour to demonstrate how psychoanalytical theory shapes my understanding of the themes, while making a case for using what appear to be disparate and contradictory theoretical frames. I will also flesh out my understanding of the maternal to include the potentially more expansive formulation of Ettinger’s (2006) matrixial. Finally, I will explore the significance of class and race in the care home environment, which I began to discern most clearly through countertransference responses to the interview material/to interviewees in the room.

Issues of race and class take us into the wider socio-historical context. Relatedly, then, I will briefly summarise some of the ways in which the values found in national policy, tied into our contemporary political situation, sometimes had an impact on the relational styles of caring in both care home sites. This will effectively be a brief introduction to the comprehensive account of policy found in Chapter 5.

This chapter focuses mainly on the organisational dynamics and styles of relating found in the care homes, explored through the three major themes that emerged from the data and understood from a psychanalytical perspective. In order to do this I wish to keep in view the notion of the organisation-in-the-mind (Armstrong, 2005). The organisation(s)-in-the-mind(s) that was evoked in interviews, as well what I had gleaned from the micro-interactions between people during observations, together told a story about the way that organisational cultures influenced intimate relationships and practices of care, and vice versa.

To reiterate, Armstrong’s (2005) organisation-in-the-mind is arguably an analytic object, one used in his day-to-day consultation work with organisations and clients therein. The organisation-in-the-mind is a term used to describe the relatedness of a person-in-role to a particular system. In terms of consultation with a client, all the content brought to a meeting is understood as some aspect of the experiential reality of an individual’s organisation-in-the-mind. Although the experiences expressed by a client are assumed to say something about the client’s relatedness to the organisation, Armstrong takes this one step further. He assumes that this experience, or the quality of this relatedness to the organisation, also contains clues about facets of the psychic life,
and materiality of interpersonal space, of the organisation itself.

Armstrong is clear that his thinking developed out of different strands of object relations theory (Klein, 1946; and Bion, 1961) and systems organisational schools of thought (Turquet, 1979; Menzie’s Lyth, 1989; and the Tavistock tradition). The way he draws, and combines understanding, from individual and group approaches to psychic experience mirrors the way that the organisation-in-the-mind, as a theoretical tool, is one that encourages the making of links, on a systemic basis, not only within the reported content but also in conjunction with the consultant’s experience; links which may not at first sight appear obvious or relevant. Hutton, Bazalgette and Reed (1997) describe the concept not simply as an analytical object but also a transitional object (Winnicott, 1953), which helps to contain irrational thoughts and ideas, as well as rational ones. To them, this is a mode of thinking that is both created and discovered in the space between the consultant and client. I flag this up because, as discussed in the literature review, I too borrow from theoretical models that appear at first glance to be disparate and attempt to make some links between them.

What I hope to show here is that, on closer inspection, the range of theories I employ allows me to broaden my thinking about the relational field in dementia care. Each theory I have selected offers insights into different mechanisms involved in relating, and often focus on different developmental stages. Given that old age is a point on our developmental path, this seems apt. To me Armstrong’s (2005) organisation-in-the-mind provides rich insights into the relational context, partially because it seems born out of a sort of theoretical pluralism.

Beyond this, Armstrong (2005) points out that both psychoanalytical theory and organisational approaches foster a particular ‘mental disposition’ (p. 53) towards the subject of study. This is:

...the disposition of attention to and formulation of emotional experience and the strategies of evasion deployed to ward off the burden of anxiety such experience may provoke. (p. 53)

He goes on to explain that, in his line of organisational work, the instrument used in the practice of attending to experience representative of the emotional reality of the organisation, albeit registered in the client, is something akin to countertransference.

But countertransference, like transference itself, has a distinct flavour in organisational work in that what is evoked in the consultant is some element of his or her own ‘organisation-in-the-mind’ (p. 53).

In other words, the countertransference here is not telling a story about the individual psychic space of the client but expresses something about the organisation as a whole, which is brought to
life via the consultant’s organisation-in-the-mind. However,

To say that the only real difference between psychoanalytic work with individuals and in organisations is the boundary within which one is making observations tends to foster the idea that this shift of boundary is not finally of much significance... on the contrary... this shift is qualitative: that we cannot fully understand the place of emotions in organisations without reference to the boundary conditions that define an organisation as a human construct. Making this shift... significantly affects not so much how we understand the conscious and unconscious processes underlying emotional life in organisations, as their meaning. .. emotion in organisations – including all the strategies of defence, denial, projection and withdrawal – yield intelligence. And it is because they yield intelligence in this way that they may be worth our and our clients’ close attention. (p. 93)

Of course, this research was not a study in organisational consultancy, but the way in which I began to understand the punctuation of interpersonal space through the boundary conditions of task, role, time, and historical context (eg, p. 76, 95), and the emotional reality of each care home was indebted to Armstrong’s notion of ‘organisation-in-the-mind.’

As we can see from the quote above, Armstrong demonstrates how he has drawn on a wide range of theory and work to refine his own understandings of organisations. He talks about defence, denial, projections, resonant of Menzies-Lyth (1989).

Although I am not attempting to identify social systems of defence in the manner of Menzies-Lyth’s study, her work was nevertheless important in alerting me to the way in which aspects of organisational practice, culture and structure were employed defensively in the service of multiple anxieties. In both homes, a particular anxiety seemed to be related to the fear of death and madness (dementia), although the way that the flights from these understandable fears manifested themselves organisationally took on a markedly different quality in each site. At Winston Grove, attachments to residents were often formed easily and spontaneously, but this seemed to happen against the backdrop of an organisational fantasy that perhaps no one would ever die if they were kept active, well cared for. The care practices in Whittinghall, on the other hand, were more distant, disconnected possibly because the pain of a given death was on some level anticipated. At Whittinghall, on some level it was understood that close relating could lead to the possibility of hurt and vulnerability when someone died.

However, although this seemed to be one of the major anxieties that the staff teams faced, there were others. In interviews, particularly at Winston Grove, some staff members were very anxious about the impact of austerity and the state of care work today. These anxieties were pronounced, leading to organisational splitting between times past (seen as halcyon) and the contemporary milieu of under-resourced social care; and between temporary and permanent workers; workers and management. I will now consider these anxieties through the lens of time, beginning with
Winston Grove.

Time

In Winston Grove, one particular feature of the thinking around time was a pervasive splitting. Bridget, the housekeeper, April, the longest-serving carer, Diane, the carer, and Gemma, the activities co-ordinator, differentiated good caregivers from bad according to the way that they treated time. Among all of them there was a sense that those carers who stretched, slowed down time were doing care ‘right’ by the residents. These four members of staff claimed that they adapted their pace to the residents’. Bridget and Gemma saw this as a privilege of their roles, while April and Diane felt they were making a conscious protest against organisational time pressures in order to offer the best care they could give. All distinguished themselves from ‘bad’ carers on the grounds that they ‘made time’ for residents as human beings. In Armstrong’s terms, they resisted the punctuation of interpersonal space that time-as-task-management represented.

For Bridget, carers were at a disadvantage because of the routinised task-focused structure of the home. This meant that the speed at which carers worked precluded them from getting to know the residents. Gemma spoke of the carers with a mix of frustration and empathy. Gemma understood that carers hurried time along so that physical jobs could be done. However she was also critical that they were, as she saw it, both unable and unwilling to slow down to enjoy and benefit from the social, emotional component of the work, which she felt she represented for the organisation as the activities co-ordinator. Gemma’s ambivalent account demonstrated that there was some capacity organisationally to hold in place contradictory understandings and feelings, that the defence employed was not always an obvious splitting.

Interestingly, April and Diane, both carers, did not feel at a loss in the way Gemma described. They railed against perceived time constraints and avoided succumbing to a ‘hotel model’, ‘conveyor belt’ style of relating. Their protests, they suggested, meant that they understood the complexities and needs of the residents, allowing them to do a better job. For April and Diane, the divide was not between overly busy, hands-on care staff and those with time to relate to residents, but between those staff holding fast to ‘person centred’ approaches to care and, as they saw it, those assimilated to the new ‘hotel’ model promoted by a management needing to do more with less. As a denigrated mode of caring, the ‘hotel model’ practices were located in other members of the team. For April, temporary workers offered care in this way and, for Diane, these practices belonged to those who considered themselves efficient workers (the ‘super, super’ people).
For both women, the treatment of time seemed to be a vehicle through which certain organisational power dynamics played out, of the type that Benjamin (2006) describes as doer-done-to relating. In interviews with Diane and April, an unspoken power dynamic during the course of our conversations was palpable. In my countertransference with April, I felt small, inexperienced, unknowing about frontline care. I sat on the edge of a bed listening to her intently, as if she knew things that I knew nothing about. I felt strangely infantile in relation to her dominant voice. With Diane, the power dynamic may have played out around which one of us understood what was really happening in the care context. You may remember Diane pointing out that she might not be the right person with whom to speak. There was also a power dynamic, I thought, around our racial differences, which I will discuss at the end of this chapter (and which I barely addressed during the course of the interview in the same way that the home avoided thinking about people’s experiences of race and racism). I wondered how much a sense of guilt about my own privileged white, educated researcher status had fed into me, unconsciously inverting the power dynamics that are often present in society at large.

With both April and Diane, and to a certain extent Bridget, I had a sense of being inadequate as a researcher, and I wondered whether this was how they felt in relation to the way that care work\(^{23}\) is generally undervalued. Relatedly, in the countertransference with all three, I had a strong sense that I needed to give them time to express their thoughts and experience, affording them an authority and agency that perhaps felt out of reach societally and within the organisation. In Gemma, too, the question of knowing and authority materialised in her interview, when she asked me if she was on the right track. Returning to the organisation-in-the-mind, it is quite possible that these interviews provided me with varying pieces of intelligence about the emotional reality of the Winston Grove, particularly around a sense of helplessness associated with not being heard. An experience that may also have resonated with the residents.

My feelings of not-knowing vis-à-vis April, Diane and Bridget, and a feeling of knowing in relation to Gemma possibly suggested that there was something known in the emotional and imaginal life of the organisation, but which had eluded formulation (Armstrong, 2005, p. 51). In relation to all four participants, this thing which was known yet couldn’t be thought about was the precariousness of occupational authority in times of austerity, also perhaps the divisions of power associated with class and race. It was telling that with all four women, I felt that I really needed to give them time, listen to their stories. Although the domineering voices of Bridget and April were possible reactions to my presence as a bearer of academic privilege and knowledge, to a former

\(^{23}\) Considered low-skilled, often carried out by women considered working class (Gallagher, *Guardian* 2017, n.p.)
colleague who had left the real work behind, I suspect they were also striking back at the loss of being valued in their role/s.

This all begged a further question, which was not necessarily just bound up with the insecurities brought about by austerity. I wondered to myself ‘Why was it important for workers to feel a degree of precariousness in their roles?’, and through a sort of institutional projective identification ‘Why should I feel so unknowing as a researcher?’. It seemed to me that it was highly likely that these vulnerable experiences mirrored the experience of increasingly dependent people with dementia, reliant as they were on a system that was, despite the optimism of the National Dementia Strategy (2009), itself more unstable and uncertain than before.

Diane and April had framed their interview around the wider care crisis, brought about by austerity politics. I had a sense that Bridget also feared an occupational death, a real sense of being undervalued in the work she did. It seemed, then, that the splitting that all women engendered was brought about by a harsh, austere reality that fostered this kind of psychic response among members of society, particularly among those most likely to be penalised in relation to class, gender and race. By undermining certain segments of the population (the elderly population and those who care for them being one branch), a need to reassert, to find power and voice seemed to be imperative – in the face of possible social and occupational annihilation.

Splitting: time to care

It is worth reiterating that, in the minds of staff at Winston Grove, speed was equated to routinization, inhumanity. A slower pace was seen as supporting human agency. Despite the fact that there was some evidence of an unrealistically demanding organisation-at-work at Winston Grove, there was room for carer discernment in the use of time. Even though there was not a rigidly strict protocol around time, time was at a premium. Indeed, stretching time for residents even came at a personal cost to staff members (leaving later; a build-up of care planning work and so forth).

In terms of the organisational culture of Winston Grove, the neat black-and-white split of good and bad care could be understood from a Kleinian perspective. Diane and April used ‘making time’ to communicate a psychic split related to a resistance to organisational change; Bridget’s splitting seemed to be around the care home hierarchies, which distinguished between roles, and may have related both to class and race; and finally Gemma in terms of status distinctions between peers. One of the reasons why Klein (1946) is so helpful is because she explains the psychic mechanisms involved in split states of mind. It is possible to recognise patterns of relating, and
thinking, between individuals which create organisational cultures where a paranoid-schizoid functioning exists.

I have shown that some of the splitting among the staff team was a response to the wider austerity agenda, and arguably to the position one found oneself in within the organisation. It is also possible that the staff were reacting to, and were receptacles for, the splitting pervasive in the client group in a care home. Klein recognised that there is an ongoing potential across the life course for the emergence of destructive states of mind in the face of persecutory anxiety. Indeed, people with dementia often feel persecuted by the condition itself.

As Froggett (2002) notes, in a human care context, ‘welfare agencies, hospitals and schools are very familiar with splitting in clients who rage against a particular worker while idealising another’ (p. 37). As I have said, this kind of splitting was noticed in both homes.

*Time to integrate life and death*

Chaya, Gemma and Bridget, at Winston Grove, were often idealised by residents. Similarly Nancy was by Dorothy, at Whittinghall. Other carers, though, such as Diane, were denigrated and disliked. This allowed residents to protect certain carers from their more destructive feelings, seeing in the good objects of care (Gemma, Chaya, Nancy, etc) the possibility for rescue. Some members of staff arguably became the receptacles of aggressive projections and others housed all the good feeling. This made the organisation appear to be a split unintegrated place. Often those staff who were idealised were those able to push aside the task and give their time over to the residents. Diane, who claimed she valued residents’ time over her own, was sometimes painfully slow to serve up lunch. This enforced sense of waiting may have made her a target for bad-object attacks. We may remember how attached Dorothy was to Nancy until Nancy began to take an increasing number of breaks, then a holiday. It was after this point, when Nancy had less time, that she was no longer such a good object. A weaning of sorts, in dementia care, is unlikely to generate the kind of recognition Benjamin (2009) might describe.

The same was true of the way staff members appreciated some residents over others. At times, it was as if a sort of love-hate feedback loop was in play. However, I also observed movements out of paranoid-schizoid states into states of a more ambivalent depressive nature (Klein, 1937). The latter was particularly evident when carers reflected on the fear of damaging those they looked after. I remember being struck by Nancy’s moving reflections on Dorothy’s potential death, explaining to me that she would have to leave Huntside, the unit for elderly frail residents, once Dorothy died. Bridget also talked about losing her patience with a resident, and feeling guilty for
months after. In both homes, though, there was a sense that time for this kind of reflection was needed.

Influenced by Freud, Klein’s (1946) work is primarily in the realm of primitive instinctual drives. Her ideas are helpful for dementia care because when people are post-verbal, there is arguably a movement back towards more unfiltered experience, drives – particularly the death drive, we may surmise – regaining power and hold over individuals. In a care context, as noted on page 35, anxieties about existence easily leak into psychic and organisational space. The death drive is a hugely powerful internal primitive tendency, arguably on the borderline with the psyche and the soma, always in conflict with life drives and the need for connection, love. The split between notions of good and bad care are quite possibly responses to the anxieties aroused by such conflicts, likely to be heightened in an end-of-life context. There might have been a fantasy at Winston Grove about which members of staff were able to keep people psychically, socially, physically alive. The way that stretched time was valued over momentary encounters may have been viewed symbolically as a way to stave off death, although my observations in both sites led me to believe that joining residents at their own pace was vital for connection.

The idea of death/life drives can be linked to the very real need for time to care. When staff take time to care, the effect for the residents might amount to a certain re-fusing of the death and life drives, enabling them to be. For the staff there may also be a kind of re-fusing of the drives in the face of the time-driven pressures of the organisation, under austerity conditions, which generate feelings of ‘dying’ occupationally. Unrealistic time pressures on the staff disrupt the capacity to care, one consequence of which is that the drives for both residents and staff become prone to defusion and the subsequent organisational splitting that follows.

At large the organisational splitting at Winston Grove was undoubtedly in the service of a paranoid-schizoid organisational functioning – the desire to retreat into bad and good part-objects (Klein, 1946; 1952), creating entrenched positions to avoid thinking about the pain of being personally close to the dementing and the dying. Thinking about the residents’ precariousness and fragility proved to be intensely difficult because a sense of occupational precariousness was also around. It had been reported that in former times, the training budget allowed for Alzheimer’s Society training and dementia care diplomas. There had also once been a visiting psychologist who discussed residents on a case-by-case basis with members of staff. None of this was currently available.

The split between notions of good and bad care was a multi-layered response to neoliberalism, to austerity agendas and also towards the hierarchies within the organisation. This split also related
to an existential fear aroused by working around death and dying. Certainly for Gemma, less inclined to protest against austerity (although she did mention corners being cut), she saw herself as central to maintaining the life of the home. However, in terms of day-to-day care practice her role was peripheral, and perhaps she felt guilty that she could claim time to play. Bridget also carved out an important position, which related to her taking time to get to know people, all in contrast to her lowly position within the hierarchy.

**Time to mourn**

We might also speculate that the loss of past approaches to care, which April talked about at length, where greater solidarity within the team was remembered, might cause anger that, undigested, got located in different places and people within the organisation. This is interesting because my hunch was that there was not really space for any form of mourning to be done. Relatedly Froggett (2002) makes the point that,

> The paranoid-schizoid position is essentially a timeless one in which the present is split off from the past and future alike and only the feelings that belong to the here-and-now can be entertained... They deny past experience and rewrite history in terms of the present (p. 39).

At Winston Grove, there was a capacity to remember the past, to remember care practice as it had once been, but being able to make the link between the current sadness, anger and this loss proved difficult. By keeping the two apart: *this is now; that was then*, there was a sense that, organisationally, a limit had been set to further thinking, enquiry. Mourning and reflecting on mourning may well have created a bridge between these two historical points in time that may have provided insights into the experiential reality of workers, and relatedly allowed for greater empathy with the temporal, cognitive, physical and material losses that the residents were undergoing. It is not to say that the organisation-in-the-mind at Winston Grove was entirely split, but rather that paranoid-schizoid functioning was a large feature of it.

The dementia care field is often in the grip of moment-by-moment affective states. The past is not often thought about, reflectively, but nonetheless it comes to inhabit the present, an unprocessed spectral influence. The dementia care context is in some ways a timeless context, partially because people with dementia live through the immediacy of their emotions, cognitive function often inadequate to the task of thinking about feelings. It is quite possible that, without thinking spaces written into organisational practice, staff members also become drawn into this non-reflective present moment. When I was observing, it often seemed hard to get the historical thinking distance (a space within my own mind) from my immediate responses, compulsion to act pressing in both homes.
The ultimate consequence of the splitting meant that the more enriching, generative possibilities of coming together and re-imagining the primary task of the organisation stayed out of reach. It meant that the primary task was constantly being interpreted, understood and misunderstood at the level of the individual worker, in part because the leadership was also operating in a split way. This confusion was both personally burdensome and ethically challenging. On many levels, this allowed for the level of anarchy in Winston Grove that made the organisation both exhilarating and muddled. The immediate management, as represented by Elaine, was also anxious about the economic climate, and about having to care for an increasingly dependent client group despite the mounting cuts to resources. Rather than think this through, Elaine subversively joked about sneaking a pig into the garden without the knowledge of her senior management team.

It is possible that, having felt under attack, by local and national government, Winston Grove had no inclination to enter discussions with their senior management team (possibly regarded as the mouthpiece for austerity) and to negotiate. Perhaps the organisational splitting was employed in the service of a rebellious protest, seen as necessary. Elaine’s interview with me was very short, stopping abruptly when some real thinking was demanded (see p. 125-6). It is possible that she believed no amount of thinking/talking time would remedy the reality of slashed budgets and more intense time pressures, that only actions that would have an immediate impact on the lives of people at Winston Grove mattered. I had a powerful sense that thinking for Elaine was seen as a barrier to action.

Having said that, there was capacity for thinking at Winston Grove, as represented in the part-time care worker, Ursula, who deployed a depressive level of functioning (Klein, 1949) in her interview. She was able to manage something of the uncertainty of working with people with dementia neither prone to idealising Winston Grove nor denigrating it. This could be seen in her understanding of both the values of temporal routines and simultaneously the need to bend them. Ursula had not been in the home as long as carers such as Diane and April, and I wondered if this gave her less of an impetus to split between the good past and bad present. Instead, since she had little to compare it to, she was able to see both the bad and good aspects of the present. Although Ursula’s was a reasonably isolated voice, there was some room organisationally to consider the imperfect reality of the contemporary care field. With a structured thinking space, I wondered if this would allow greater engagement with the senior management team, the opportunity to express a range of views.

Whittinghall seemed to have a long way to go in terms of ‘making time’ to reflect upon the paradoxical aspects of the work, and the sheer volume of feeling associated with those losing their
minds. Representative of this difficulty with thinking was the fact that the longest interview with a care worker was only thirteen minutes. Time to process the worker experience was not valued. Around the theme of time, there did seem to be a process of splitting at work. However, this played out in a very different way at Whittinghall.

Indeed, my own countertransference towards staff at Whittinghall was one of irritation, an irritation based on the reality that I would not be able to gather a great deal of interview material at Whittinghall. I also wondered if this was related to a broader organisational irritation about staff time being interrupted by demands, of the residents. I realised I could not express my irritation, and started to imagine that this may have expressed a passive-aggressive stance towards dependent others. It was telling that Amy, the manager, did not enquire at the end of my study about Dorothy, about the findings. I had felt cut off by this, and by the short interviews. Equally staff were anxious that time for themselves was not interrupted, cut short by the demands of the residents, whose lives were nonetheless at risk of being cut off via death. The organisation-in-the-mind that I registered, through my countertransference response, was one that cut itself off to the feelings of, and talking with, those facing one final temporal cutting-off. The lack of interview material represented on some levels the reality that there was little time to converse and to think.

Nancy’s interview demonstrated that time belonged to the workers. It was ordered, controlled by them. As she said, ‘...there is a set routine but if the routine changes, the staff, we are happy to do whatever... We all know who to help and who to go to at that certain time.’ Nancy spent some time in the interview listing the staff on shift and going through the rota. The clarity of the routine, we might surmise, ensured that the muddle and confusion of dementia would not get into the staff team, protecting them from coming into contact with their messy feelings. There was something deadening about the neat, routinized nature of Whittinghall, which seemed to prevent the freedom of human interaction. By compartmentalising time, there was less chance of an encounter with the frightening experiences of dementia. Generally, at Whittinghall, there was a chasm of a split between the workers and the people with dementia, and it seemed that time, which belonged to the former group, held more value organisationally than the latter’s. This possibly communicated something about the developmental position of the young staff team, where time to live took precedence over time to disintegrate and die. If we are to think of the organisation-in-the-mind, then, we might begin to conceive of one where the life and death drives had not been integrated. This reflects perhaps a wider societal split, at least in Western cultures, between youth and age, the turning a blind eye to an experience of ageing which is debilitating and difficult.
Potential space; time to play

Klein has been particularly useful in determining some of the psychic mechanisms which commence in internal spaces, and which get projected outwards into the organisation. Winnicott, however, emphasises moments where there is a simultaneous inter-subjective creation and discovery of psychic states. This takes place in a space, neither wholly inner or outer.

Play seemed to offer the possibility of a meeting point between worker and resident experience, of the type that was often absent at Whittinghall. As Nancy had pointed out, in Chapter 3a, with reference to Christmas Day, pleasure and fun were scheduled there. Arguably a different use of time at Whittinghall that might have enabled moments of off-rota connection is worth considering via the Winnicottian concept of play, a notion through which interesting insights into the organisational cultures of each home emerge.

In Winnicottian terms the capacity to play leads to creative experiences that preserve the sense that ‘life is worth living’ (Winnicott, 1971, cited in Borden, p. 31). Creative living is about interacting with the world and the environment, with others in and through the fullness of one’s paradoxes. For Winnicott, this is in counterpoint to engaging with others inauthentically through a false-self carapace. Play is a spontaneous, creative act that allows each of us to make contact with ourselves and with others in an unashamedly truthful way. Playing paves the way for an exploration of experience in which inner psychic reality meets with the realities of others, through a potential space free of judgement. Following play, it is possible that we are able to rediscover a true self, into which we can relax. Winnicott believed (Borden, 1998) that this true self exists before the onset of object relating. Maternal care either hindered or supported its (true self) evolution. Play seems vital in dementia care, since it helps people to return to a place in which they can recreate and rediscover something of their very being.

A lack of play involves a relationship with external reality based on compliance. The following quote resonates with my experience of being at Whittinghall, where I often felt as if the observations had taken on a Beckettian quality.

… the world and its details being recognised but only as something to be fitted in with or demanding adaptation. Compliance carries with it a sense of futility for the individual and is associated with the idea that nothing matters and that life is not worth living. (Winnicott, 1971, p 65, cited in Borden, 1998, p. 31).

In his book on Winnicott’s life, Adam Phillips (2007) highlights the consequences of a lack of play in an analytic session, suggesting that without time to play a meeting becomes dogmatic and compliant. In terms of Whittinghall, an organisation absent of play may be held to account for the
same thing. Indeed residents were far less likely to become troublesome or to be expressive at Whittinghall: those who were (Dorothy) would be restrained (the brakes on her wheelchair were clamped tight, as per page 103,) or medicated (her sleepiness). Winston Grove, on the other hand, found time to offer moments of spontaneous play as well as the structured play that Gemma represented, which sometimes led to free-flowing play too. It stands to reason that, if we follow Winnicott’s line of argument, the residents there were able to move in and out of different versions of themselves, even rebelling against the time demands of the staff team. It is entirely possible that one of the reasons that the staff team were so much more conscious of the value of the residents’ time was because, through play, some residents’ still communicated a joy in living.

Although Winnicott received supervision from Klein, his ideas departed from hers. His theories focused on the space between the inner and outer world of the infant, and the projection outwards of this experience. Klein’s focus tended to be on internal primordial instinctual experience. Winnicott moved outward, concentrating more on the micro-interactions between mother and child. Of course, Klein noted that the mother, with her offering up of the breast, went some way to detoxify major internal anxieties, but unlike Winnicott, and also Bion, her theories do not flesh out how the mother, as mediating object, facilitates the development either of ego strength or of identity (Winnicott) or the thinking mind (Bion). Although of course an infant is object-relating in Klein, there is less of a sense of how the external shapes the internal, as noted in Chapter 1. For dementia care, Klein’s work on the noisier drives and states of mind is invaluable, but I also need Winnicott, particularly his detailed exploration of environmental provisions. A mother making time for play is a mother that supports the development of the capacity to be authentically in the world; in dementia care terms, one wonders if an organisation willing to make time to play is able to support older people to be themselves without recourse to feelings of shame, or under pressure to conform to the demands of the organisation.

As discussed in Chapter 1, Winnicott’s ideas take us on the developmental trajectory of the child from dependence to relative dependence through to independence, and the move from unintegrated states to integrated and sometimes disintegrated ones, from which, all being well in early development, we can recover. Dementia takes a person to an increasingly disintegrated state, so part of the work involved in dementia care relates to facilitating moments of reintegration. It is in play, linked to the notion of a transitional space, that people might be able, in relation to others, to experience their authentic selves — even in a state of dementia. I wish to suggest that in a transitional space, where there is an opportunity to experience connection and separateness with others (often through transitional objects, both me and not-me), a person with dementia might be embarking on an inverse developmental trajectory to the infant. Soft toys,
musical toys, dolls, were used by many residents in Winston Grove, a place where mother was often mentioned. Daphne herself spent one observation, moving a doll into a more comfortable sitting position (page 165). As Winnicott notes,

The [transitional] object represents the infant’s transition with being merged with the mother to a state of being in relation to the mother as something outside and separate. (Winnicott, 2005, p. 19)

Playing, particularly through the use of transitional objects, might at times serve to indicate that a person with dementia is un-forming gradually, making the journey back eventually to a mother (and to the womb). I will provide more details about this inverse developmental journey under the theme of mother/s, to come. What is important is that, for Winnicott, play provided a space for growth more than knowing; in dementia care, a transitional space is possibly one in which adaptation to, and moments of reintegration on, a precarious journey can take place.

Winston Grove was a place where play opened up a potential space (Winnicott, 1971, p. 72) where staff and residents were able in the moment to be themselves. There were many examples of formal purposeful play at Winston Grove, led by Gemma, but this kind of play did not offer up quite as much potential for free association among participants. Nonetheless, the informal moments found at Winston Grove – strikingly absent at Whittinghall – where care staff danced with residents, or joined in Daphne’s wordplay gave space to ‘communicate a succession of ideas, thoughts, impulses, sensation’ (p. 74) that were not necessarily linked but which helped to achieve a ‘relaxation that belongs to trust and to acceptance... the resting state out of which a creative reaching-out can take place’ (p. 74-75). Under the right circumstances, play became a space of possibility for the residents.

As Winnicott (1971) points out:

It is in playing and only in playing that the individual child or adult is able to be creative and to use the whole personality, and it is only in being creative that the individual discovers the self. (p. 73)

When thinking of Daphne and Dorothy, we are not talking about the discovery of the self, but perhaps of recovering aspects of that self. It was clear that Daphne benefitted a great deal from moments of play. Many staff joined in with her ‘Hey Ho the Barley Mos’. When she picked objects up in group activities, resignifying them, like a tambourine-turned-halo, staff were not critical but seemed to engage with her capacity for creating new symbols and meanings out of them. This was important to her, for her residual anxiety was of being seen as a ‘silly sausage.’ It was as if this release into play gave permission for people to encounter themselves in different states of mind,
also for the staff to step out of their professional roles and engage on a different human level.

This seemed harder to achieve at Whittinghall, which appeared to package play up in clearly delineated timetabled spaces. I saw very little evidence of the type of spontaneous play Winnicott describes. As we saw, in Chapter 3b (page 131), from the session where I observed Dorothy’s attendance at a flower-arranging activity the engagement with the co-ordinator was minimal. It felt staged, full of discomfort, as opposed to a potential space in which it were possible to re-experience the self, able to meet with whatever capacity for cognition. An organised activity such as this one—and others found in both homes like bingo, quizzes – may have been able to produce a form of play, in a Winnicottian sense, but, unlike Winston Grove where play often transpired in Gemma’s groups, this was not what I witnessed for Dorothy. Following Winnicott’s thinking (Winnicott, 2005, p. 75), even a lack of play in the clinical setting leads to sense of hopelessness in the client, for she is unable to communicate nonsense. Whittinghall’s approach to a time of play was to organise and timetable it, thereby denying the nonsense that, quite possibly, the residents needed to express.

It seems perhaps paradoxical that in a context where people are confused, and some are dying, that play is a vital source of expression. However, moments of play undoubtedly led to helpful communication and psychological sustenance. It is clear from what Bridget had said in her interview that time and its availability supported playfulness:

I have the nice bit. I’m going to give you something to eat and we’re going to have a laugh and a joke, and a song whereas a carer doesn’t have that time cos they’ve got 8 to 10 residents on their unit that they need to be giving personal care to.

(Interview, 3 March 2015, Winston Grove)

Confusingly, time for play was available at Whittinghall but was not taken up because time was more commonly used for bureaucratic tasks and play (or rather break-time) for staff. To think of Armstrong (2005), play at Whittinghall punctuated interpersonal space by establishing conformity and routine as opposed to the creation of an interpersonal space in which mutual nonsense may have fostered connection, becoming. This communicated something about the implicit values woven into the fabric of organisational culture (managerialism foregrounded over relationships), and how policy is perhaps interpreted at the level of the individual site, as I go on to explore further in Chapter 5.

By tapping into the way that Daphne played, much could be gleaned about her internal states. On
one occasion Daphne played with a doll, inviting it to sit and look out on the lounge, as follows:

She takes the doll in her hands and looks in to its eyes. ‘Aren’t you a special little one? Isn’t he?’ She looks quite the mother now. Daphne puts the doll back gently in a new position, with its back resting on the back of the chair now. ‘You can see the room better now,’ she says. It’s important to see things.

*(Observation, 16 December 2014, Winston Grove)*

With the use of this transitional object (Winnicott, 1953), Daphne seemed able to express her impulse for attachment and tenderness while also showing me that she too was still capable of observing the world around her, like her doll. She was, in other words, connected and detached. As an object that was both me and not-me, I wondered if her use of the doll was symbolic of a slow return to a mother, reconnecting with this earliest relationship while also sustaining a separate self. Daphne shifted into a maternal position and then back into herself. So here making time for play may help residents with dementia adapt to their shifting identities, in and out of dependence, and moments of continued relative independence.

Maude, introduced in Chapter 3a, also interacted with the soft toys in her bedroom as if they were transitional objects, all her teddies and soft toys. It was as if Maude drew on them to be in the world. During the interview with her, the soft toys like Quack Quack and Rupert, whom she and I talked to, were used by both of us to create a potential space (Winnicott, 1960), a combination of inner and outer realities. Maude brought them to life, imbuing them with history and making them chat to one another as she and I were.

I got the impression that, together, the potential space that we had created and discovered was one which allowed Maude to be comfortable in herself. She had the freedom to explore identities belonging to different periods of her life, through these soft toys and with me.

As Winnicott (1971) points out: ‘The infant can employ a transitional object when the internal object is alive and real and good enough...’ (p. 13). It seemed Maude may have had good enough beginnings, as a young child. It was as if Maude’s internal landscape allowed her to feel good about Winston Grove. She was not in a deeply melancholic state about being there, and seemed able to take in what she needed from the experience in order to sustain her in her dementia. Generally her view of Winston Grove was a benign one, resonant of a safe holding environment (Winnicott, 1960; 1962).

Maude’s interview was important because it demonstrated that making time for play was valued...
at an organisational level. This mirrored my observations, where playful encounters took place between staff and residents, and between residents, each day. It was also in contrast to the interviews with residents at Whittinghall. Maude's bedroom itself was full up, suggestive of a life still worth living. Peter and Ellen's bedrooms, in Huntside unit, were sparse, absent of any notable transitional objects. Ellen had her shoes, and Peter his television. In the interviews with residents at Whittinghall, I felt my function was to bear witness, to hold (to be discussed in the section on the maternal) something of the distress the residents encountered. Playful engagement was not on the agenda in the same way.

Container-Contained: time to think

The importance of finding time to think in both organisations was vital, as I have already touched upon in reference to splitting. What I wish to consider here is how Bion's work on containment provides a framework for the quality of thinking that is needed in dementia care.

As we have seen, Winnicott departed from Klein by placing more emphasis on the external world of the infant (i.e. mother). Play is, often, an inter-subjective experience; Bion's (1962a) container-contained process is also embedded in a relational encounter.

However, whilst Winnicott's focus was on a process that supported the development of an authentic sense of self; this was not Bion's focus. Bion highlights the importance of the mother-child relation in the formation of a thinking mind. Arguably, a mind able to think is also implicitly a mind of one's own, able to understand different feeling states and responses to situation. This leads to a form of getting to know, one surmises, oneself, and loosely relates to authenticity but the emphasis, as I have already said, is qualitatively different. Play doesn't necessarily lead to thinking, but being; containment leads to thought, thinking and communication.

Play takes place externally, leading to creativity, to formations of culture, between people. Container-contained processes happen between people, and this process leads to the formation of mind, something structural, deeply internal. That said, this is too straightforward a reading, because both processes involve processes of projection, introjection, re-projection and re-introjection. They are also processes or experiences we draw upon through the life course.

Klein's concept of projective identification was a germinating force behind Bion's container-contained. Bion (1962a) highlights intra-psychic processes more than the mother's physical and emotional responsiveness to the baby's signals, as Winnicott did.

The very mechanism of projective identification, though, at the basis of the container-contained
process implies that there is an unconscious awareness in the infant of the mother being outside him in order to project something into her. This is another area where Winnicott and Bion differ. Furthermore, the container-contained process can be a destructive one and, though, in good circumstances it can lead to meaning-making and the development of a reflective mind, the projections from the baby are seen as an expulsion of intolerable fragments of experience, which are, in phantasy, sometimes violently pushed outwards.

Bion’s (1962a) container-contained provides a detailed account of the way in which intra- and inter-psychic processes affect each party in the mother-infant dyad. This is particularly important for dementia care, as I often witnessed moments which could be described as co-affecting ones between a professional carer and a person with dementia. Beyond this, Bion’s explanation of containment and its relationship to a sense of continued existence also resonates:

Normal development follows if the relationship between infant and breast permits the infant to project a feeling, say, that it is dying, into the mother and to reintroject it after its sojourn in the breast has made it tolerable to the infant psyche. If the projection is not accepted by the mother the infant feels that its feeling that it is dying is stripped of such meaning. It therefore reintrojects, not a fear of dying made tolerable, but a nameless dread.(Bion, 1962, p45)

We might remember Ellen, at Whittinghall, whose anxieties were pronounced during the interview. I not only felt helpless being with her, but also very confused by what she was saying. Carers might often receive such projections, and if they are unable to mobilise their alpha functioning (what Bion, 1962, might determine as thinking apparatus) in order to digest, to make sense of such projections, the projections are returned to the person with dementia in an unmanageable way. The mind is likely to continue being in turmoil.

In a care home, feelings are often projected into the staff team. Similarly feelings from the staff (i.e., feelings of vulnerability, hatred, love and anxiety) are often projected into the residents. Although carers were able to contain the raw emotions of the residents at times, in both sites, the organisations themselves did not offer up spaces deliberately set up for thinking. Staff couldn’t formally reflect upon what they might have become receptacles for, or about using the residents as projective objects for their own unwanted emotions. Thinking, in a Bionian, sense, involves the ability to distinguish between conscious and unconscious thoughts and leads arguably to a capacity to be able to recognise one’s motivations and one’s role among others, to see oneself. Relatedly Bion’s approach to containment, and the development of alpha-function, has been well used in the psychodynamics of organisational theory as evidence of the need for structured thinking spaces, as per the work of Armstrong (2005) and Lowe (2014).
If the opportunity for thinking is not part of care home culture, there seems to be three possible consequences. The first would be that communication might stay at an unconscious level, in a perpetual loop of forceful projections between staff and residents, which in turn would affect the capacity for either thinking or the holding on (for people with dementia) of mind. Secondly, as Bion points out, although projections might be more forceful, without a reflective alpha-function stance, the projections would be ‘denuded of the penumbra of meanings’ (1962, p. 45); hence misunderstanding and misinterpretation would be common. Finally, thinking, in Bion’s formulation, is closely linked with the capacity for communication and the articulation of truth-statements, which he argued was essential for harmonious group functioning. In Winston Grove, it was particularly evident that the need for the team to think together was vital.

In the following extract, Diane relates makes a link between the perception management have of her as doing harm, and her own vulnerability in the face of being thought of this way. Though we were unable to explore this link further, or to make it more conscious, I did see that the interview offered the beginnings of a glimmer of containment. Indeed, it pointed to a lack of time, at an organisational level, for staff to process sometimes unbearable feelings.

D: Because if anybody comes in they might think you’re abusing her, doing something you shouldn’t be doing, so there might be a problem with safeguarding. I don’t expect the manager to understand or even give me any support. So I have to cover my own arse and protect myself.

E: So sometimes you do feel pretty alone.

D: Yes sometimes you do feel very vulnerable.

(Interview, 17 March 2015, Winston Grove)

The conversation enabled Diane to express the vulnerability that she registered in relation to the organisation and to her life. When Diane depicted Winston Grove as an inhumane place, likening it to 1970s London, in which she was excluded as a young black woman, the full force of her feeling of aloneness, rejection, came into view. We were able to touch upon this and do a little thinking about her vulnerability as a worker there. However, I had not fully registered what she may have been projecting into me (to be discussed later in the chapter). Nonetheless, this interview, spoken about at length in Chapter 3a, implicitly addressed the way that projections moved around the organisation, from resident to staff member and back again, often unprocessed, left uncontained. A resident accuses Diane of abuse, and she in turn feels abused by
management, the thinking about feelings of injury and of helplessness remains un-thought. People stay in pain, knowing at a deep level, but unable to formulate it clearly so others also know. This interview, because of its length and content, provided evidence for the need of staff teams to be given access to a third, reflective space (Britton, 1989) to process the emotional labour involved.

In terms of residents, the interview with Sue, the older woman from Wales who had recently moved into Winston Grove, had qualities of a therapeutic encounter, in which a client’s feelings might be projected into the therapist and thought about (Bion, 1962). Sue was able to process some of the raw feeling of loss she was experiencing when we talked about her experience. She says:

S: Yes. Then we get there. I wouldn’t know how to get there, no. Very sad (she is crying) when people disappear. She takes deep breaths. She clasps her hands tightly together and starts to look out of the window again. Bangor is the university.) The time that used to go.

(Interview, 7 April 2015, Winston Grove)

Such a containing moment (also on pages 109-10) was unlikely to work for people with dementia if it were time-tabled or installed into a slot in the day. The containing moment needed to be in the here-and-now otherwise it would be lost. It started to make sense that, when containing encounters in the here-and-now were lacking, residents would return to past relationships, through which containing structures had been implanted. I wondered whether it was at these moments of non-containment and heightened anxiety, a mother (or occasionally a father) would be brought to life in residents’ minds. The interviews, which seemed to offer something in the way of containment, were also relatively long, which, I would argue, shows that time to think and to meet in the care home is something which ought to be seen as an imperative part of the work.

Concluding time

Time was a very interesting emergent category, particularly because it opened up avenues into thinking about the relational dynamics in both organisations; and what kinds of practices hindered or supported relationships. It highlighted omissions in policy (see Chapter 5); the reality of stretched workers endeavouring to relate to increasingly dependent others with minimal resources; and the strain of expectations of managerial efficiency.

Removing a coat from a resident who is anxious, and resettling them into a care home after a trip out demands the slowing down of time; walking with someone to a table when they are sturdy on their legs but wobbly of mind cannot be rushed. However, there were occasions, when
momentary encounters also had meaning, perhaps a short spurt of time to play, to sing, to stroke a hand.

Equally, time for the ‘super super people’, in Diane’s words, is to be fought with and speeded up: a race against time, a competition between one’s own efficiencies and the clock. Elaine, the manager of Winston Grove, enacted this wider organisational relationship with time in her interview with me. She gave one of the shortest interviews there, cutting off abruptly towards the end because the interview touched on a situation that might have been hard to speak about freely. Certainly, she was at pains not to reflect on it at any depth. Organisationally, time for reflection in both homes was hard to come by, and simultaneously hard to accept. Indeed, Amy, manager of Whittinghall, couldn’t make time for an interview at all.

Elaine, though, acknowledged the hardships that carers faced: ‘...staff do not have the time to spend with residents now... A lot of the time it is: get the tasks done and that’s not the staff's fault.’ Elaine seemed to understand how unrewarding this might be, identifying with the carers’ position. She distanced herself with this kind of practice, implying that this development belonged to ‘now’, to the wider political environment, her bosses’ bosses in local and national arenas. Elaine imagined the punishing voice of senior management – ‘get the tasks done’– to which she felt accountable, as did some members of staff. We have seen that without the time to think, to develop a containing organisational structure; without the time to work through anxieties through play, there is a tendency to become entrenched in widespread splitting as a defence against the emotional labour of the work and of the experience of having that work undervalued. I would argue that time be made available for different kinds of spaces, which allow for the sustaining of mind in both the workers and in people with dementia, too.

Mother/s

As we have seen from Chapter 3b, mother/s often appeared at Winston Grove. During observations, Daphne made sightings of her mother, embodied in different residents. It was noticeable that the figure of the mother she evoked took on certain affective qualities. It was as if these maternal figures became containers for Daphne’s own unwanted anxieties. When Daphne felt lost or alone, she would imagine her mother worrying about her well-being or safety. Daphne perhaps found this projection into an imagined or symbolic realm a helpful way of communicating her own uncertain state. There were also times, though, when Daphne projected into a surrogate mother figure (usually a resident) a feeling of greater ease, communicating something about her own immediate experience of comfort.
The way that Daphne mobilised an internal mother was something repeated by many residents, often when they felt homeless and worried. These maternal figures (internal hauntings and memories) were brought back to life possibly in order to anchor the residents. Sometimes mothers were located in care workers; sometimes in residents. In interviews, staff also imagined in the residents their own mothers. It was clear that at Winston Grove, there was a role for the maternal.

In contrast, at Whittinghall, as noted in Chapter 3b, Dorothy did not call upon her mother, at least when I observed her. Similarly at Whittinghall, staff members did not refer to mother/s. A possible conclusion was that the organisational function of mothering was thin on the ground. It could be argued that the metaphorical caring mother had delegated her role, leaving it in the hands of paid staff.

At Winston Grove, where mother/s were mentioned, there was seemingly a distinct difference in the way that staff and residents made use of the mother figure. The residents seemed to mobilise an internal mother, as a source of holding, as per Winnicott, and of containment in a Bionian sense. For the staff – particularly in Chaya – there were identifications with an internal mother who was possibly part deprived of her care, which was offered to the residents in an act of reparation.

I will say more about Chaya’s account, as it was a powerful evocation of mother/s in the work, and the act of reparation that might have motivated, in part, many to become carers.

Mothers: guilt and reparation
Chaya’s interview was striking because her reasons for working at Winston Grove were closely tied to memories of her mother, of looking after her. Chaya had been her mother’s primary carer when she succumbed to dementia, though Chaya had at the time been unaware of the diagnosis and of what this meant. Chaya acknowledged feeling out of her depth and frustrated with her mother, unclear why her behaviour might have been changing. Chaya had been ashamed of this, but once trained she recognised behaviours in the residents she had seen in her own mother. For her, getting a job at Winston Grove had, in a sense, allowed her to go home to mother. The interview itself reads like an ode to the human capacity, and need, for reparation. Chaya’s interview was gentle. She made references to angels. I imagined Winston Grove as a site of perfect care, of the Virgin Mary, as I listened to her. At times, it felt unthinkingly idealised, and among more critical accounts (Diane’s, for example) Chaya’s account was strikingly optimistic. Chaya had felt guilt, we might surmise, for having damaged the maternal object. Working as a carer helped to make the damage better through her continual exemplary care towards others.
In order to understand the reparative compunction that might be a guiding principle of care and welfare work, it might be useful to turn to those working in the Kleinian tradition. As Froggett (2010) notes:

At first sight, then, Klein’s work seems unpromising as a basis for models of welfare which seem to require a degree of optimism regarding our ability to care for one another... it is difficult to find its justification in a view of the mind that identifies a persistent potential for destruction: in which split ‘paranoid-schizoid’ states are part of normal functioning; in which the propensity for gratitude and love is described in terms of the achievement of a ‘depressive position’... Yet despite, or perhaps because of, the fact that we are condemned to an ongoing struggle between our love and our hate, there is in Klein an account of love in which it is possible to discover not only our capacity for destruction but also our ability to make good the damage that we do. It is the reparative impulse born of guilt and gratitude that forms the basis of ethical life. This lends itself to an understanding of compassion – love directed to recognition of and care for the other. (p. 36)

As we know, it is within the infant-mother relationship that these first acts of psychic reparation take place. Let us go directly to Klein:

The anxiety relating to the internalised mother who is felt to be injured, suffering, in danger of being annihilated or already annihilated and lost for ever, leads to a stronger identification with the injured object. This identification reinforces both the drive to make reparation and the ego’s attempts to inhibit aggressive impulses... This tendency, as we have seen earlier, is inextricably linked with feelings of guilt. When the infant feels that his destructive impulses and phantasies are directed against the complete person of his loved object, guilt arises in full strength and, together with it, the over-riding urge to repair, preserve or revive the loved injured object. These emotions in my view amount to states of mourning, and the defences operating to attempts on the part of the ego to overcome mourning.... The reparative tendency too, first employed in an omnipotent way, becomes an important defence. The infant’s feelings might be described as follows: ‘My mother is disappearing, she may never return, she is suffering, she is dead. No, this can’t be, for I can revive her.’ (pp. 74-5)

Chaya’s interview showed that there was a capacity, from an organisational perspective, of facing loss from a depressive position. Despite the overall idealisation of the work, Chaya is able to recognise both the love for her mother and the frustrations, anger, she experienced towards her. In facing this ambivalence, she restores her mother as a whole object, and her own ego, able in the course of the interview to experience and re-experience her feelings of loss.

For others at Winston Grove, the reviving of mothers was perhaps representative of a strand of institutional defence, which guarded against mourning all those loved objects who perhaps no longer visited or were no longer alive. Though the residents and staff were not infants it is possible that working in a place where losses were so pervasive meant that the resurrection of mothers also related to ongoing omnipotent phantasies of keeping people alive – this does seem to fit with Winston Grove’s overall tendency to deny the fear of death.

_Holding_
A further function of the mother figure was – particularly for some of the residents – the provision of some kind of holding, particularly in times of difficulty and distress. This enabled residents to go on being both in a temporal and spatial sense, as Winnicott (1960) notes:

The term 'holding' is used here to denote not only the actual physical holding of the infant, but also the total environmental provision prior to the concept of living with. In other words, it refers to a three-dimensional or space relationship with time gradually added. This overlaps with, but is initiated prior to, instinctual experiences that in time would determine object relationships. It includes the management of experiences that are inherent in existence, such as the completion (and therefore the non-completion) of processes, processes which from the outside may seem to be purely physiological but which belong to infant psychology and take place in a complex psychological field, determined by the awareness and the empathy of the mother. (p. 589)

As we saw from Ellen’s interview on page 132, which I consider again below, holding might have offered her a sense of temporal continuity in counterpoint to the experience of psychic and physical fragmentation.

Ogden (1986), referring to Winnicott’s work, states:

If we view holding as dominant among the functions of the mother in the earliest stage of development, and weaning as the dominant function in the period of the transitional phenomenon, in the depressive position the critical task of the mother can be conceived of as surviving over time. (p. 191)

Holding, offered to the pre-verbal infant by its mother, supports the continued development of a child’s emotional and psychic reality. The baby’s survival over time is in a sense related to the mother’s survival over time. I want to focus on holding because, although containing mothers were also, and importantly, brought to life, containment, in a Bionian sense, does not operate in this distinctly temporal mode. In Ellen’s interview, it is her un-development that is striking. Her words seem out of reach, and I wondered if she was returning to a set of experiences which were less about sustaining the structure of a thinking mind (Bion, 1962), but more about finding a way to support a sense of ongoing-ness.

Holding is, in Winnicott’s view, a function of the mother or primary carer. It includes both bodily – via handling – and emotional care to support ego integration. Although ‘holding’ can be done by anyone (indeed it can be done through institutional arrangements), in a culture where mothers do most of the close caring for and nurturing of infants, holding is inevitably imbued with maternal associations.

I will say a little about my interview with Ellen, as seen in Chapter 3b, because the interview seemed to offer something of the quality of a brief holding experience. Here Ellen talked
poignantly about her lost baby.

El: There are times when I do, yes. I don’t know what I was doing today and when and why. The look in his eyes and we are going to do this this and this. I didn’t take anything home. It was very strange. All the way to go. Thought where is my baby...? Have I left her behind?

(Interview, Whittinghall, 18 August 2015)

We might imagine that the baby (see Millet, Chapter 1) is the prototypical subject of care, dependency and responsibility. In Whittinghall, I felt that the holding environment was shaky. Rather than carers making careful attempts to reflect the residents’ emotional states or to adapt to their needs, the staff seemed to erect a boundary between them and the residents that foreclosed empathic response. This was seen in the staff congregating around the nurses’ station, impervious to Dorothy’s cries; the need for staff to use their water bottles (not the home’s glasses), the talk of holidays, breaks; and the photos of staff nights’ out dotted around the station.

This was very much in contrast to the purpose of holding that Winnicott envisages where an infant’s being is sustained, owing to the thoughtful responsiveness of the mother, the bedrock of ‘human reliability’ (Winnicott, 1987). Of course, residents in a care home are not infants, but I did wonder whether the intense levels of dependency experienced by some people with dementia, like Ellen, made one-to-one highly responsive care essential. It made me think that a holding response, of the sort Winnicott describes, was an appropriate one. It is interesting that Ellen even misrecognised my foot for her own, symbolising perhaps a powerful need for connection and imagined unity. Very early on, I understood intuitively that questioning Ellen, as I had done in most interviews, was unlikely to be helpful to her. Instead, I made myself available to her need to go over and repeat a part of herself, the internal child, which seemed to help her to manage the intensity of her distress. This intense distress is apparent, for instance, in the moment when she said ‘I go total blank... most of the pieces aren’t here...’

At Whittinghall holding was very rarely seen. If we think of Evie, who occasionally sat in the corridor next to Dorothy, there was an instance where Amy, the home manager, insisted that she keep trying to stand up with her walker. There was not much sympathy shown for the frail body that might have wanted to be held in place. In the absence of instances of maternal holding at Whittinghall, it was tempting to consider the organisation as one that either proactively valued standing on one’s own feet – independence – over a supportive holding (interdependence); or one that denied the existence of need. Arguably the two were related but not entirely the same. That said, there were also equivalent instances at Winston Grove – take the lady with impaired
sight who was marched, precariously, dancing to a lunch table; and Suki’s desperate cries to be toileted, which went ignored.

A holding environment, then, is about the mother’s early good enough adaptability to the infant’s needs, both the way the baby is ‘held in the mother’s mind as well as in her arms’ (Phillips, 2007, p. 30) This process can only be done well on the basis of the mother’s imaginative elaboration of the infant’s states; feeding into the structure of the infant’s psychological matrix. In other words, through her capacity to translate the cries, a communication, mother becomes mirror-like in her responsiveness, thus creating within the infant the sense of reliability and security which set the foundations for ongoing ego strength.

For Winnicott (1960), a good holding environment for the infant is tied up with the move from dependence to relative dependence and on to further independence, which he argues can only be successfully achieved should the child be able to draw on memories of dependable maternal care and thus offers a sense of confidence in the environment. Winnicott’s notion of holding is, from a maternal-infant care perspective, a generally positive experience, an almost sensuous experience for the infant, a building block towards a sense of internal safety.

It is quite possible, in dementia care, that the person with dementia feels more at ease and less fragmented should the holding environment – in this instance, made up of the network of carers around him or her – be carefully attuned to his or her needs. During the journey of dementia a sense of disintegration might be occurring as a result of the illness. In this stage of unravelling, a good enough holding environment might allow for moments of re-integration, or at least going-on-being - continuity, that would provide respite from feelings of existential precariousness. This of course is an aim, since the reality of perfectly adaptable one-to-one care is, as we have seen, short on the ground. Arguably, as perhaps the carers and staff at Winston Grove were advocating, a good holding environment can only be offered when time and resources are available.

In dementia care, we might wonder if an individual’s experience of dementia interacts with the level of their pre-existing ego strength. In the communal context of a care home, is it possible that those more able to bear frustrations have had a more fulfilling earlier experience as we might have seen in Maude’s interview? Possibly Maude’s internalised holding mother paved the way for her capacity to make use of play and potential space as well.

*The Matrixial*

Though the maternal was clearly a theme to emerge from both the observational and interview data, I did begin to see that other figures from people’s past lives were also important. Daphne
herself imagined at times that her sister, May, was in the building; she saw her former partner Benjamin asleep in a chair (when he was no longer visiting); another resident waited patiently at the door for her brother; Sue remembered her father as well as mother; Maude talked about her husband; Gemma thought about her grandparents as did Nancy and Prashid too. There was Dorothy’s Sally, and Evie’s Paddy, objects for whom no history was known. In other words, there were other figures imagined and reimagined who populated the corridors of both care home sites. From this perspective, Ettinger’s (2003) matrixial web provides a rich and helpful theoretical frame to understand what might have been happening both internally and externally at both sites and at different times. The notion of the matrixial might also demonstrate why the care home site is such a complex social world to navigate both as a worker and as someone with dementia, whose temporal horizons keep on shifting.

I borrow from Ettinger for two reasons: a) because distinct from the theoretical models I have drawn from up till now, hers focuses on the pre-verbal experience in utero. This is a point in development which is much earlier on than the focus of those following Klein or Winnicott; b) secondly, Ettinger both acknowledges the figure of the maternal as a founding source of the human capacity to share and co-affect while simultaneously recognising the impact of significant internalised others, also summoned up, in moments of inter-subjective encounter. For her, there are multiple transferences going on between people at any one time, all of which are embedded in an originary experience of co-affecting (which first took place between mother and foetus).

Her work has particular resonance with the dementia care field because, as both the observations and interviews bore out, it was not just the maternal figure that was in view in both care homes but many others. Though I might argue that mother had the greatest absent-presence, other figures and traces of figures existed in the psychic fields that existed between people. This meant that I had to expand my formulation. I have already mentioned brothers, sisters, fathers and grandparents emerging in speech and seen in others. I will briefly say something about how all these important influences interrelated, creating something of a family, or organisational, resonance field.

In Winston Grove, particularly, absent fathers, grandparents and siblings were located in those living and working in the home. This reminded me of a matrixial field (Ettinger, 2006), a psychic landscape made up of deeply embedded memories from divergent family albums.

For Ettinger (2006) whenever ‘I’ meets with a ‘non-I’ there is an encounter, which comes to form a particular psychic resonance field. Each resonance field is located with and alongside other fields of resonance. An intricate web of meetings of one with-in the other, with each meeting belonging
to several clusters of fields. The matrixial web is conceptualised as a body-psyche-time-space of the intimate, which is made up of the traces of personal histories that are inhabited by several others. It is from the onset transgressive in so far as human experiences, inner worlds and body worlds, come into contact, overlap. Despite their different theoretical approaches and scholarly preoccupations, there are perhaps echoes with the way that Armstrong’s (2005) organisation-in-the-mind ignites the organisation-in-the-mind of others, also considered something of a psychic resonance field.

I take this to mean that, although each subject is distinct from one another, bounded, what takes place in specific encounters between two people, or more, is the evocation of some aspect of the self with all its constitutive objects, memory traces, pre- and unconscious resonances. In dementia care, this sense of many others relating through different spaces and temporal zones seemed tangible. Witnessing this process of losing and finding, transferring and displacing, made transparent the way in which our internal territories can interact with the outside and make new realities. Similarly it made transparent how each individual’s internal landscape is mapped out by encounters with significant others who affect and shape our lives, that our ancestral objects interact with the traces of objects which belong to the well-trodden terrain of others even in an organisational context where interpersonal space is punctuated by role, task, status and projective and defensive processes. Let us return to Prashid reflecting on his grandparents back home.

E: And do you enjoy it? How do you find working with older people then?

P: I used to look after my grandparents but not really in a working environment. Here it’s like a job but it’s like a home as well.

(Interview, 11 August 2015, Whittinghall)

What I wish to alert the reader to was that absent, masculine and feminine identities, family and friends, were enlivened in both care homes sites. This is important because I am not suggesting that the care field is only the domain of women or the feminine. On the contrary, I wish to suggest that the dementia care context is one where myriad phantasmagoric identities exist, are talked about, often (particularly for people with dementia) in an unguarded, non-defensive way – and this allows those in the field to see just how helpful it is to employ both male and female care workers, from a range of ages and indeed backgrounds.

Nonetheless, I do not wish to lose sight of the maternal. This was, after all, a powerful theme that emerged in both data sets. I wish to conclude this section with Ettinger (2006) in mind, though,
because for her the feminine in utero experience (mother’s womb) leaves an originary psychic trace of interdependency, impossible to obliterate. It is possible that in our ending days we might at a deeply unconscious level yearn for a return to a space in which an-other encounters us; that in finitude one final holding experience (Winnicott, 1960; 1962) akin to the womb allows us to un-become; that there is some felt presence of a m-other-like-encompassing in the moment of our very absence. I am not likening un-becoming to a process similar to Winnicott’s notion of disintegration, although dying fills some people with intolerable levels of fear and panic. Rather I also envisage a possibility of un-becoming, in a womblike direction, perhaps to my mind, on a par with letting go, or alternatively akin to Barbara Low’s Nirvana Principle, which Freud approved of and considered tantamount to the removal of tensions between the life and death drive (Freud, 1949).

Death

The final theme of note, emerging from the fieldwork data, was death, considered in Chapter 3b. Given the differences between each site around the theme of death, it would be tempting to suggest that one site foregrounded the drive for life, the other for death.

As I have pointed out elsewhere, Winston Grove generally felt like an alive home, although this aliveness was tinged with mania, quite possibly a systemic defence against the fear of death. Being forced into life (through singing, bingo, dancing, painting, joking) and into living was not always appropriate, and seemed to prevent staff at Winston Grove from thinking about the unbearableness of loss. It was possible that denying death served a purpose: in maintaining a fantasy that the residents could be kept alive through the provision of good care, this might have meant that carers put considered effort into relating intimately with those in their care, ensuring they knew all the small details that made things better for individuals. The other side of this denial, though, was that staff at Winston Grove did not seem able to reflect upon experiences of separation, endings and loss as some did at Whittinghall.

Represented in Gemma, the activities co-ordinator, there were moments of a manic triumphalism, and denial, over death, as seen in her comment during an exercise session. She moves very fast, but jokingly criticises the residents for going slowly, like ‘wet lettuces’. Finally, when Benjamin had died, no one was able to broach his death with Daphne. The whole issue was swept under the carpet, Daphne was taken on a trip to a busy local café, with other residents, in response to her mounting levels of anxiety.

The environment at Whittinghall, on the contrary, felt deadening. Peter’s toes going up and down
in his bed, alone in his room, bored, paralysed, watching *Antiques in the Attic*, symbolised an organisational lack of liveliness, as follows.

But uh there we are. Well uh it’s all right sitting here like this innit, sitting here, watching your toes go up and down (he looks at his feet underneath the cover and moves his toes up and down). Yeah, watch your toes thing. (Laughs).

*(Interview, 4 August 2015, Whittinghall)*

The sterile, still environment at Whittinghall was, I think, partly due to the absence each day of residents wandering freely around, the absence of freedom outside the confines of the routine. The neat compartmentalised and compartmentalising culture meant that residents were unable to live spontaneously alongside one another and the staff leading it seemed oblivious to these minute-by-minute social deaths. Nonetheless this socially frozen organisational culture seemed to give people space to withdraw into themselves in order to retreat into death. Alternatively, there were moments when I wondered if organisationally Whittinghall was not capable of generating life, the expectation being that people would die: I remember noticing Evie’s mug, stamped with the words ‘Funeral Director’s’ along the top.

I also wondered if the pervasive presence of death – there were palliative cases at Huntside – meant that staff distanced themselves from getting close, from becoming too vulnerable to loss. This may have been one of the reasons why staff adopted more professionalised modes of operating. Whittinghall’s approach to death was noticeably different to a palliative care model of death, though, which takes on a more existential approach: one in which caring for dying people is seen to provide rich opportunities for connection and the discovery of meanings. In essence, it seemed that death anxieties were inarticulable in different ways within each organisation. In the face of death, there were very different organisational reactions. However, as Klein argued in her (1940/1975) formulation of mourning, building on Freud’s *On Murder, Mourning and Melancholia* (1917/2005), we might begin to see that a far-reaching anxiety about the residents (old age and dementia possibly experienced as persecutory) may have underpinned the defensive responses to the dying context.

In ‘Mourning and its Relation to Manic-Depressive States’, Klein (1940) shows how the work of mourning involves the reactivation of the original depressive position in which the infant, at the point of weaning, feels the loss of the good breast, experienced as damaged by his own greed and aggression (1940, p. 345). This fear of losing loved objects owing to one’s own destructive thoughts and impulses repeats throughout the lifecourse according to Klein, particularly in relation
to parents and to siblings. Her contention was that, in the process of normal mourning, anxieties about having destroyed real loved objects are reignited. In normal mourning, however, the adult would be working from a place of a secure internal world in which ‘good’ objects were brought into the ego and restored during the depressive phase, where one can accept both one’s loving and hating feelings. In other words, the depressive position successfully worked through provides a prototype for normal mourning later on.

At both Whittinghall and Winston Grove, I felt that I was observing a pervasive difficulty with the process of normal mourning. I turn to Klein:

The fundamental difference between normal mourning on the one hand, and abnormal mourning and manic-depressive states on the other, is this: the manic-depressive and the person who fails in the work of mourning, though their defences may differ widely from each other, have this in common, that they have been unable in early childhood to establish their internal good objects and to feel secure in their inner world. They have never really overcome the infantile depressive position... It is by reinstating inside himself the ‘good’ parents as well as the recently lost person, and by rebuilding his world, which was disintegrated and in danger, that he overcomes grief, regains security and achieves true harmony and peace. (p. 369)

At Winston Grove and Whittinghall, I am talking about the psychic life of the organisation as a whole (Obholzer & Zagier Roberts, 1994; Armstrong & Huffington, 2004), and am not suggesting that both care homes were populated by staff who had not worked through the depressive position. Chaya and Ursula, for instance, were both able to mourn and to integrate apparently contradictory ideas. This is not about pathologising care workers in any way. However, if we are to take on board Klein’s idea that the depressive anxieties, of damaging and the associated guilt, reactivated each time there is a significant loss in someone’s life, and we know that this is not an easy position to work through, in the first instance, without a backdrop of ongoing love and support, we might surmise that working closely with people who will die poses workers with the permanent threat of having their internal worlds destabilised.

As I pointed out before, Winston Grove had a particularly manic quality of activity, and sometimes an ‘obsessional nature of the impulses to reparation’ (p. 353) which were ways of mastering the anxiety that the staff had in relation to being close to dying residents. Equally, Whittinghall could have been regarded as obsessional in its control of the residents’ freedoms, as symbolised in the regularity with which Dorothy’s wheelchair brakes were put on. Beyond this, there was a marked example of idealisation in the interview from Chaya, and towards the organisation itself from Nancy, Sonia and Prashid which defended against reflecting on the toll of the work. Klein notes that,
Idealisation is an essential part of part of the manic position and is bound up with another important element of that position, denial. Without partial and temporary denial of psychic reality the ego cannot bear the disaster by which it feels itself threatened when the depressive position is at its height. Omnipotence, denial and idealisation, closely bound up with ambivalence, enable the early ego to assert itself to a certain degree against its internal persecutors and against a slavish and perilous dependence upon its loved objects and thus to make further advances in development. (p. 349)

Although Winston Grove and Whittinghall reacted very differently towards death, it does seem possible that without the opportunity to do some meaningful thinking about loss, it was difficult for individuals to rebuild their inner worlds, or to integrate ambivalences, characteristic of the successful process of mourning. I wish to leave this section on death with the pertinent words of Daphne who said the following:

So that in itself has brought this to life so although it doesn’t seem totally full in the world today there, it clearly is part of it and it does tell part of its part to other people there so they can get used to things for themselves. And start talking about their experience rather than where it is or how old it was and didda dada um bombom...

*Interview, 24 March 2015, Winston Grove*.

Daphne seemed to understand that the experiences of being in a care home were multi-layered and that it was important to speak about being in an intermediate place not ‘full in the world’, one in which moments of joy in living existed side by side the fear of dying. Not full in the world because the residents were also moving out of the world. Trying to understand and to tolerate this (transitional) space of life and death seemed to be important for residents and staff alike, even though for the most part there was a need, it seemed, to keep such thoughts out of conscious awareness.

**Thinking about class and race**

As I have alluded to earlier, race and class were also issues which tended to be pushed out of the organisations’ conscious awareness. Though the section that follows will not provide a comprehensive discussion about class and race in a care home context from a sociological perspective, I hope that it will touch upon further experiences, flagged up in Chapter 3a, that have a real bearing on the relational work of care. I mention this to highlight the fact that there were further complexities involved in an already demanding workplace.

When talking with Bridget, the cleaner, and Diane, the carer, I noticed how (socially constructed) categories of class and race seemed to have got inside both women to shape who they were, their subjectivities. This subjective quality, in turn, was one that, I felt sure, had an impact on our
interviews. During observations I also noticed the diverse backgrounds of both carers and residents, how at times there were very obvious differences between the older people and their carers. In Whittinghall residents were generally very affluent yet workers were not well paid; residents were elderly and staff members were in their twenties; in Winston Grove the people with dementia tended to be white-skinned and many workers were black-skinned. As such, confused power dynamics and competition were often observed. These power dynamics interacted with the punctuation of interpersonal space, through the boundaries of role and task. For Bridget, she inflated her authority within the organisation, quite possibly in protest against the class category she felt she had been assigned to in life, and relatedly against the role she had been employed to do within the organisation; Diane pushed against the task of time-driven personal care, possibly in resistance to the management which she experienced as a brutalising, abusive one. These differences were palpable in both sites, differences saturated with social power.

I remember Dr Jesmond (see Chapter 5) who very much related to the staff team as ‘service providers’, clear that he was a paying guest, entitled to make demands for wine. In the minds of the staff team, though, he was not a consumer but a vulnerable older man. There was also Suki who repeated that her son was a doctor, educated and professional, in contrast to her reluctant carer, Zalee, who nonetheless had the power to get Suki to the toilet on time or not; and there was Diane’s harrowing recollection of enduring racist abuse at work while understanding that she was in charge of her abuser’s care and could therefore be accused of abuse herself. These kinds of issues were often kept out of mind in the daily work of the care home site, and so I feel it is vital to say a little about how ‘deep and injurious the impact’ (Ryan, 2014, p.133) of being defined by categories such as race and class can be and how resentment might leak into the work, disconnection ensuing, if it is not thought about.

I have been inspired by Frank Lowe’s (2014) book, Thinking Space, based on his initiative at the Tavistock Clinic, described as a forum offering a ‘container for thought’ (2014, p. x), one in which race and other differences were to be taken seriously enough to encourage an organisational curiosity about difference, rather than shutting it down and splitting it off.

I will start first by considering the way that class dynamics emerged in my interview with Bridget. Joanna Ryan (2014) writes, in her exploratory study on class in the consulting room, about the way that ‘class and class difference can enter into and contribute to the structuring of the transference-countertransference matrix...’ (p. 127). Two things are of note in her paper. First she discusses class-related transferences and countertransferences that therapists reported, and how hard professionals found it to speak of class openly in their relationships with clients; and
secondly, she understood this repression as being a manifestation of the anxieties around what Layton (2004, cited in Ryan, 2014) describes as the ‘internalisation of class relations.’ (p. 129)

Both are significant. In my interview with Bridget, there were times when I felt intuitively that she may have been attacking my status as an educated researcher while elevating herself as someone who could do things that ‘you can’t.’ Bridget seemed to be both nervous (she laughed a lot) during the interview and also domineering. I surmised that this was because she knew me from years back before I embarked on more academic study, now she was no longer sure where she could place me. It seemed to me that Bridget also wanted to be an authority figure, respected. It was as if she could not bear the possible powerlessness that a housekeeper’s position might have implied in terms of the hierarchical dimensions of Winston Grove. To think of Armstrong (2005), Bridget’s organisation-in-the-mind was populated with categories of hierarchy that were seemingly crafted by local government, and which led to splits and the punctuation of interpersonal space around both role and task, in her case.

Bridget represented, I thought, a sort of inverse snobbery where I became unknowing and useless (‘education gets you nowhere’) while she had all the answers. Bridget was not to be disparaged, yet I felt at times as if inadvertently I was being critiqued. I wondered if her fears about being judged were being projected into me.

Bridget made it clear that her position within the organisational, and social, structure did not preclude her from thinking, and this was certainly the case. She had a lot of wisdom. It was as if there was a reversal of the inequalities that she may have experienced outside of the care home or even within it, even within our interview, in which I certainly began to feel less knowing than she was. A similar feeling was evoked in me with April, which I have touched upon in Chapter 3a. I only wish to say that with both women there were moments where I felt, as a middle-class (defined societally rather than personally) person with a degree, that I was the incompetent one. It was hard to tease apart how much these dynamics related to an anxiety about our different social statuses or whether it was simply the case that, organisationally, in this instance Bridget and April did in reality have the most important knowledge (the histories of residents).

However, I could not help but wonder if perhaps the psychic pain of powerlessness and inequality that these women endured in relation to more affluent residents (the home was in a middle class ward of the London borough) had had an impact on the way that they took up power in the interview. Of course, my study had not been about class-constructed senses of selves and so I did not follow this line, but I wonder now in retrospect how these wide discursive categories, which shape subjectivities and construct subjects, influence the way that people relate to one another in
the care home site. I am sure, at least, that it affected our interview.

What race has in common with class is that it is another ‘term ... used to sort varieties of humankinds. Implicit in this possibility is the apparent truism that there are indeed different kinds of humans to be sorted’ (Dalal, 2002, p. 9). There is little room in this thesis to take up a detailed exploration of race and class in dementia care, although I think it important to acknowledge Rustin’s view (1991, cited in Dalal, 2002, p. 10) that “race” is an empty category filled with different sorts of projection and that notions of race can serve a worrying function: the ‘function is the naturalisation of power relations by retaining the divisions of humankind.’ (p. 13). These socially constructed differences, and divisions, presented by some as the natural order within humankind, are implicitly considered effects of wider power relations, and the discourses they entertain.

Simultaneously, I wish to suggest – in line with Frank Lowe’s work – that for someone like Diane who seemed to feel herself to be positioned as a racialized other, a denial of the way that race (see also Lewis, 2010) had made its mark on her life, and in her work, seemed to make her feel isolated and further brutalised. In the interview with Diane, as she sat opposite me, it was clear that our experiences of working in the same care home had been very different. I had never been attacked on the basis of the colour of my white skin.

As I listened to Diane, and she pointed out that she wasn’t the ‘right person to talk to’, because, ostensibly, her account was not a flattering one, I wondered whether she felt I might also reject her interview material, in the same way her stories of racism had been rejected by the senior team. Was I no good, allied with the white manager of the home, who put a stop to hearing Diane’s experience; or was I allied with the white residents, who attacked her care; or was she no good, as a black woman, whose material didn’t fit an idealising script? I had no answers to this because sadly I did not re-interview Diane. Nor would I have asked these questions since it was not in the remit of the thesis. What became clear, though, as Diane’s powerful interview was disrupted, interrupted by a senior carer, is how easily thinking about race and its effects on the experience of working in the care home was dismissed. Organisationally race was ignored as a factor affecting the caring experience at Winston Grove, (and enacted in the countertransference) and it was not mentioned at all at Whittinghall. Furthermore, as I suggested in Chapter 3a, the historical backdrop, so important in forming Diane’s experience and quite possibly the resident she described, were disregarded, which suggested that at times residents and workers were seen only through the lens of the immediate care task, or the routine, in hand.

Without developing thinking spaces, third spaces (Lowe, 2014) or, in Winnicottian terms, potential
spaces, within care homes, dividing lines exist between staff members and residents, and within each group, based on arbitrary categories (which nonetheless impact the lived experience, entering into individual psychic spaces) that prevent real engagement. Since I was unable to investigate how categories of race, gender and class intersect with the micro-interactions of daily relating in a dementia care context, I now believe it is vital to do so in order to prevent entrenched power dynamics that fundamentally hinder intimacy and the sharing of human vulnerabilities.

Finally I wish to turn momentarily to Jessica Benjamin (2018), the relational psychoanalyst, whose work I have briefly quoted in connection with April earlier in this chapter. Preoccupied by finding a way into relating beyond the power dynamics of doer and done-to, which arguably race and class categories feed into, Benjamin describes a process of mutuality which comes about through the development and subsequent engagement with thirdness. This is an important idea if we are to reflect on what a thinking space might offer an organisation such as Winston Grove or Whittinghall. To quote Benjamin (2018),

> Rhythmic thirdness depends on co-creation, that is continuous mutual adjustment that persists through variation of patterns, which allows for acknowledgement of difference and deviation of both partners. (p. 78-79)

Space to reflect upon the emotional labour — the power dynamics involved in human relating, the fear of causing further damage to objects already considered damaged — is certainly not advocated in *Living Well: A National Dementia Strategy*, as we shall in the following chapter. As a result, many care organisations are ill-equipped to deal with the emotional cost of intimate human relating. Broadly speaking, though, it was clear that some of the values found in contemporary dementia care policy had either found their way into the relating, or there had been a quiet backlash against them. Whittinghall seemed to be more compliant, adopting clear ‘pathways’—structural pathways thought to be able to diminish uncertainty — and efficient management, the use of technology to facilitate care (the iPod system), all advocated in the National Dementia Strategy; Winston Grove took a more rebellious stance against such apparently rational ways of organising daily lives. The resident population too seemed to mirror either the compliant or non-compliant culture of each home; and the relating between carers and residents seemed to be linked to this organisational state of mind. As I have said, there was a cautiousness in the relating at Whittinghall as if there was a right way of doing things (very much evident in policy, as we shall see in Chapter 5); this compliant quality seemed to relate to a lack of playfulness. Caution was thrown to the wind at Winston Grove, which made for a more spontaneous relational experience. Among some members of staff it was as if there was a fight going on against the homogenising (and perhaps occupationally deadening) concept of the ‘workforce’ that remains voiceless.
throughout the Strategy. However, it is in the following chapter that I flesh out in detail the way that notions found in policy seeped into each home and as a result affected the dynamics therein.
Chapter 5: Policy and Practice

Femi turns up and on every new ward he feels the same sneering, hostile glare from the permanent workers. He knows they see him as an agency worker: a threat, undercutting their trade unions, their employment and their pay. He is on a zero-hour contract. But the moment Femi, with his... manly, thoughtful voice and worried, childish smile, has charmed them into sharing their tea – the agency wants him elsewhere.

Ben Judah, *This is London: Life and Death in the World City* (2016, p. 379)

**Introduction**

Underpinning the provision and receipt of care is the involvement of two parties, carer and cared-for. This chapter seeks to understand how *Living Well with Dementia: A National Dementia Strategy* (2009) conceives of the relational field in dementia care. I hope to explore the connections between (i) the ideological frames surrounding the strategy; (ii) the ways the needs of those who receive, and provide, care are viewed in the strategy and; (iii) the tensions between policy and the realities of the embodied and psychic experiences of those involved.

The chapter will focus primarily on the *National Dementia Strategy* (2009) because it has been the major policy framework shaping dementia care in recent years, the main aim of which was to improve the quality of health and social services for people with dementia. The strategy will be analysed in the light of material from my field work. More specifically I will aim to interrogate the notion of ‘living well’ found in the strategy while also speaking to the experiences of the staff team—of Dorothy and Daphne and other residents—in Whittinghall and Winston Grove. This will enable me to point to some aspects of the relational field which I believe need further illumination in the policy domain.

I wish to do this for three reasons. Firstly, I recognise that people with dementia in moderate or advanced stages can experience profound sadness and losses, and that workers are not always prepared for the intensity of emotion they may encounter. This dimension – the emotional cost of the work – is often overlooked in the policy domain. I wish to examine how much space is given to the feeling work of care in the *National Dementia Strategy*.

Secondly, I have sympathy for Hoggett’s (2009) argument that, ‘Western democracies have given rise to narcissistic [achievement-oriented] cultures that are in flight from dependency and the acceptance of human limits’ (p. 164). He points out that policymakers often express an intolerance of dependency, although my observations of daily life in care homes demonstrate...
that sometimes people just want and need to be looked after, that bodies and minds begin to fail. There is, even in a dementia care policy context, an attempt to tidy up human vulnerabilities and suffering (Froggett, 2002; Hoggett, 2009). Service users are conceptualised as rational decision-makers whose needs will be met through the provision of outcome-focused services, responding within reasonable timescales. As a result only a ‘thin’ (Froggett, 2002) conception of human need is acknowledged which turns a blind eye to the importance of being known, recognised. Hoggett (2009) states that:

new technologies of performativity have created a thick skin... that mediates between the state and its managers and policy makers on the one hand and the many victims of social suffering characteristic of increasingly socially polarized democracies under the conditions of neoliberal globalisation on the other. (p. 169)

This thick skin seems impervious to the emotional cost of facing greater dependency, death and decline, and social policy peddles a fantasy that such anxieties can be assuaged by efficiently performing services more so than through compassionate micro-interactions between people. I wish to examine if there is a denial of dependency in the National Dementia Strategy, and, linked to this, an implicit undermining of the importance of relational ties in responding to such dependencies.

Thirdly, Hunter’s (2015) complex, feminist psychosocial reading of the state’s personality provides a useful frame of reference for the study of dementia care policy. Hunter’s work is hopeful in that it proposes ‘...possibilities of renewal and reparation which potentially come from within the state via its relational politics. Not by its institutional structures and processes but from its ongoing everyday ethical life’ (p. 16). I hold on to this notion of relational politics as I read the National Dementia Strategy against my time at Whittinghall and Winston Grove, to demonstrate how the ‘messy, uncontrollable agency constitutive of the everyday state’ continually rubs up against an ‘idealised, coherent singular abstracted state of (neo)liberal fantasies’ (p. 16).

Other dementia care policy

Needless to say, the National Dementia Strategy was not the only dementia-related policy initiative of recent years. Among the more important were the Prime Minister’s Challenge on Dementia (2012, and then 2016), which reinvigorated the debates on the condition. They built on the progress of the National Dementia Strategy and, though both challenges discuss health and social care, this is predominantly in relation to what has been achieved to date. There is no
specific focus on the care home sector, which is the subject of this study.

Noticeably, the Challenge (2016) promotes the notion of dementia-friendly communities (pp. 53-57), ostensibly to counter the stigma people with dementia face. This provides evidence of a break with the strategy, possibly subordinating dementia care to the demands of austerity politics. Dementia-friendly communities are conceptualised as places where individuals, businesses and third sector alliances form to support people with dementia. The community is arguably constructed as the site of action, and is embedded in the ‘politics of collective and individual responsibility’ (Mooney and Neal, 2009, p. 56). In such imagined communities the need for health and social care is side-lined.

The Challenge (2016) also highlights the UK’s achievements (global leadership, pp. 17-21), research investments, pp. 29-31) and the government’s performance. Similarly Jeremy Hunt’s (2013) Dementia: A State of the Nation Report on Dementia Care and Support in England also focuses on achievements. It calls upon individuals to fight back against dementia (p. 2), summoning up the narrative of war to do battle with a persecutory Other. All three pieces of policy, we might surmise, were written for political consumption rather than as a real intervention in the everyday details of the care field. Consequently, although a critique of them would provide interesting insights into the increasingly changing landscape of health and social care provision, I will not be analysing any of them here.

The Strategy

Living Well with Dementia: A National Dementia Strategy (2009) is a 102-page document, authored by Sube Banerjee, Professor of Mental Health and Ageing of the Institute of Psychiatry, and Jenny Owen, Executive Director of Adults, Health and Community Well-Being in Essex Council. It was published under Gordon Brown’s New Labour administration.

To produce the National Dementia Strategy the then Department of Health held ‘over 50 stakeholder events... attended by over 4000 individuals’ (NDS, 2009, p. 11). The strategy, the result of extensive dialogue between health, social care and third sector professionals, informal carers and people with dementia, was seen as a much-needed challenge to the imbalances in dementia care services.

Many of the themes in the strategy pick up on earlier policy published by the Department of Health, research from academia and knowledge from the third sector. Joint health and social care planning and working, personalisation, care in the community and service-user ‘choice and
control’ – many of which are cited in the strategy – feature to different degrees in earlier policy documents. Indeed the document states that it draws on: ‘… policy statements such as Our NHS, Our Future, Putting People First: A shared vision and commitment to the transformation of adult social care… the National Institute for Health and Clinical Excellence (NICE) commissioning guide on memory assessment services, the Carers’ Strategy (Carers at the heart of 21st century families and communities) and the National End of Life Care Strategy’ (NDS, p. 10).

The strategy is an outcomes focused document. The outcomes fall into three major themes:

A) Awareness raising
B) Early diagnosis and support
C) Living well with dementia (NDS, p. 19).

Under each theme there are specific related objectives. In sum there are 17 objectives in the strategy. By raising awareness, it was hoped that the strategy would help to reduce stigma which in turn would result in more help-seeking and help-offering behaviour. This was thought likely to lead to higher early diagnostic rates which would allow people with dementia to ‘make choices themselves’ (NDS, p. 7) and ‘direct their own care’ (NDS, p. 380). Implicitly there is a sense that living well with dementia is inextricably linked with the making of choices and that living well is equated with living in the community independently, also echoed in the Challenge (2016).

The three major themes of the strategy are ordered in the above way because these reflect the general progression of dementia, a ‘life course order’ (NDS, p. 19). They follow a temporal trajectory, apparently not based on policy priorities.

Given that this thesis is concerned with the experience of living and working in a care home, I will look most closely at Chapter 5 of the strategy, headed ‘Living Well with Dementia’. Among the objectives linked to it, number 11 concerns ‘Living well with dementia in care homes (NDS, p. 12) and number 12 ‘Improved end of life care for people with dementia’ (NDS, p. 13). ‘Living well’ is thus linked specifically to moderate and advanced stages of the condition.

I will also consider Objective 13, found in Chapter 6 of the strategy which focuses on its delivery, partially through ‘An informed and effective workforce for people with dementia’ (NDS, p13). This objective is relevant since it provides insights into the assumed needs of care workers. However, before I go on to examine the living well discourse, I will provide some context to the strategy’s emergence. This will include a short discussion of neoliberalism, human rights and also ‘Putting People First’ (2008), the personalisation strategy, published a
year before the *National Dementia Strategy*, and which it references throughout (pp. 10, 19, 46, 55, 64, 68, 72, 73, 78, 95, 96).

*Influences*

The *National Dementia Strategy* emerged in a neoliberal context and there are many traces of this ideological influence in the strategy, something particularly noticeable when the strategy considers the needs of people in the early stages of dementia. In the neoliberal vision, the individual subject is positioned as an empowered consumer, making choices, within a marketplace (Froggett, 2002, p. 70). In the strategy, there are references to choice and control, and the buying in of services through personal budgets (personalisation). More recent dementia care policy, such as the *Prime Minister’s Challenge* (2016), has been further shaped by this context and reiterates the importance of choice and control, personal budgets and independent living.

Dementia care policy has also been influenced by a discourse on human rights (Mental Health Foundation, 2015). Human rights provide a powerful legislative frame for those who may have been silenced historically because of disability, mental incapacity, race or gender. In this discourse, the individual subject can sometimes be positioned as a violated citizen, in need of advocacy. Despite the differences between neoliberal and human rights agendas, the individual subject is nonetheless the main focus of each. This becomes particularly evident in the strategy. Each of the three major themes are introduced with a series of autobiographical quotations (I voices), in which nameless individuals, mostly carers and people with dementia, relate their unique experiences of the condition. As Clarke (2007) notes, this shared focus on the individual means the human rights discourse is all too easily appropriated by neoliberal governments and reframed in a ‘consumer culture narrative’ in which ‘discontents and dissatisfactions’ (p. 38) can be made use of against, perhaps, the overburdened public sector.

There are other influences on UK dementia care policy, for example disability activism, academic research, charity and business agendas. Many views feed into the social policy domain and, as a result, paradoxes and discontinuities between ideas can be observed. The *National Dementia Strategy* is no exception, though in its case the multiplicity of voices often knit together, combining to form a seamless, normativising mode of thinking which tends to emphasise a rational, independent subject with dementia whose difficulties will be best ‘managed’ through efficient performance. Even those reaching the end of life with dementia are positioned as being able to ‘be involved in planning end of life care’ (NDS, p. 61).
Personalisation

I wish to consider the personalisation agenda (‘Putting People First’, 2008) as it is a key example of a contradictory policy site that attempts to bring together the bottom-up contested claims of service users with top-down political agendas and transformations. Personalisation was seen as a way of delivering more person-centred individualised care, responsive to challenges from service user groups, while simultaneously fitting with an overall policy frame bound up with the objectives of neoliberalism, such as value-for-money efficiencies through privatisation and third sector opportunities.

As I have noted, from a neoliberal point of view, the user of services is conceived of as mirroring the consumer in the marketplace. As a result policy such as ‘Putting People First’ (2008) has to demonstrate it is in conversation with the very people it serves, ‘the customer’. Hoggett (2009) might suggest that policymakers and service-users are enmeshed in a form of ‘as if’ relating, in which there is an appearance of responsiveness to human need through the drawing up of outcomes and procedural measures, but where the ethics of care or compassion seem forced into the shadows.

Although the personalisation agenda has its roots in campaigns to bring about constructive change for people with mental health difficulties and learning disabilities as practised by the ‘In Control’ movement (Sowerby, 2010), there have been understandable fears about personalisation among practitioners (Parkinson, 2010). These concerns may also be applicable to the living well discourse: Can the emphasis on the self-reliant individual ‘distract attention from cost cutting in adult social services’ (p. 248) or welfare provision; will this lead to further developments of a ‘new private market in welfare’ (p. 248); and most importantly for this discussion, ‘how is dependency to be understood within this arena promoting “self-directed support”?’ (p. 248)

As Sowerby (2010) highlights, for people with disabilities trying to navigate the complexity of the personalisation agenda, there is a need to be in dialogue with someone you trust to help you. Personalisation, he suggests, ‘...would surely be lit most securely by a development approach that fostered its principle of co-construction’ (Sowerby, 2010, p. 280). As he goes on to argue ‘...if a person has little regular speech, voluntary control over their body or apparent capacity to understand options or express choice, it is important to have someone available who knows them well and cares about them’ (p. 274). In speaking with people, he noted, the ‘...keenness, hunger, for real relationships was the strongest sense I have been left with’ (p. 274).
The personalisation agenda claims to put service users in charge but, in order for them to have control, they need to be in close dialogue with someone knowledgeable they can trust. In other words, choice and control emerges out of a relational sphere, even though the service user is simultaneously conceived of as an independent entity. Indeed, helpful guidance from professionals is advocated in ‘Putting People First’. These are some of the contradictions found in the policy.

No wonder, then, as Sowerby (2010) points out, that there is a lack of synthesis between the ideals of policy statements, what those implementing policy imagine they are doing and what the proposed beneficiaries of policy are experiencing in daily life (p. 273). Sowerby quotes:

Cooper and Lousada reflect on Titmus’ observation that the gap between aspiration and realisation has been a constant feature of social policy and points to the danger that the hope invested in new policies can overwhelm practice experience that has some understanding of what works and what does not (p. 273).

**Living Well**

I wish to turn my attention to the living well discourse since this is an example of where policy aspirations seem to be in denial of the realities of practice experience. The central organising idea of the *National Dementia Strategy*, the notion of living well, is used in the title of the document, also heading up the chapter which deals with the experiences of people in the later stages of dementia. In what follows, I will explore what living well means within the strategy. I will also consider how well, if at all, this notion can be applied to the relational field in an institutional setting.

The strategy, as the title and joint authorship from Health and Social Care implies, is about joining up services to help ‘all people with dementia’ to ‘live well’ (p. 7). One of the roots of the living well discourse is to be found in the campaigning work of the Alzheimer’s Society. This draws on a bio-psycho-social model aimed to destigmatise the experience of dementia and provide a counter-narrative to discourses of failure, alienation and disintegration. Intended to be empowering, the approach is used by many organisations tasked with improving the situation for people with dementia, from consultancies such as Dementia Care Matters to charities such as the Joseph Rowntree Foundation, and research departments in the Universities of Stirling, Worcester and Bradford. The approach assumes that people with dementia are fully agential beings, who still wish to participate in things they find enjoyable, to be part of families and communities.

---

24 See publications on living well with dementia, [https://www.alzheimers.org.uk/](https://www.alzheimers.org.uk/).
The living well discourse also builds on the work of Tom Kitwood, academic and psychogerontologist, whose innovations I touched on in Chapter 1. He established the Bradford Dementia Group, with his work becoming known internationally. Author of *Dementia Reconsidered: The Person Comes First* (1997), he noted systemic failings in institutions, and sought to change harmful care practices, promoting in their place the notion of person-centred care. Through his work, recognising the agency of someone with dementia became associated with combatting objectifying cultures of care.

Implicitly, living well is thought to be made possible by involving people with dementia in their own care, in keeping with the personalisation agenda. This seems to hinge on the ability to make choices. For instance, one of the main focuses of the strategy is to improve rates of early diagnosis, with a view to ‘giving those affected and their families … the ability to make choices themselves’ (NDS, p. 7)\(^{25}\). Similarly, under Objective 6 of the strategy, it is argued that, ‘The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them’ (p. 47). Of all 17 objectives in the *National Dementia Strategy*, Objective 6 (NDS, p. 46) is most obviously tied to the notions of individualised ‘choice and control’. Focused on personal budgets, in this part of the strategy the ‘consumer-patient’ can be seen to enter a care marketplace.

For some people with dementia, particularly those in the early stages of the condition, these ideas will resonate with their experiences. Nevertheless, what the approach risks leaving out are experiences of passivity, dependency and failure that are especially acute in the condition’s later phases. Although the strategy acknowledges that dementia can have a ‘devastating impact’ (NDS, pp. 3, 16, 17), the notion of living well that it promotes is largely silent on these matters. Additionally, as Clarke (2007) points out, choice is a contested issue and, in a neo-liberal context, has to be managed since resources are constrained. Under neo-liberalism, limiting people’s expectations becomes an inevitable part of care work – another matter from which the *National Dementia Strategy* shies away.

Moreover, despite the strategy’s emphasis on choice and control, it is difficult to identify the extent to which people with dementia living in care homes (those whose agency is perhaps on shakier grounds) had a voice in its production. Phil Hope, then Minister of State for Care Services, points out in his Foreword, ‘I have met many people living with dementia …their role in developing the Strategy has been crucial’ (NDS, p. 6). It is evident that, at the heart of the strategy, was a model of co-production and service-user involvement. Nevertheless, it is

---

\(^{25}\) The language of choice and control is also taken up in the Prime Minister’s Challenge (2016).
unclear how many of these service users were care home residents. The strategy notes only
that ‘...the views of diverse populations were taken into account... young people with dementia;
people with learning disabilities; people from minority ethnic groups; people from rural and
island communities; and older people in prisons’ (p. 18). Care homes are notable by their
absence.

In sum, although living well incorporates some of the language of activist claims, owing to the
neoliberal agenda for economic efficiency, there are absolute limits to how well someone can
live if dependent on welfare provision. Equally because dementia can be such a dislocating
experience in and of itself, it is vital to incorporate the idea of what it is to live unwell into
dementia care policy and to recognise that living well, on an ontological level, has clear limits.

I will now focus on the detail found in Objectives 11 (care homes), 12 (end of life), and 13
(workforce training) and relate them to my observations of Daphne and Dorothy.

Living well in care homes: choice and control

When we reach Objective 11 of the National Dementia Strategy, which focuses on care homes,
the use of the word choice disappears entirely. This resonates with the experience of Daphne
and Dorothy for whom making choices, particularly about things which might seem abstract
(e.g., end of life planning), could quickly become frustrating and anxiety-provoking. As semantic
memory becomes impaired, big decisions, and sometimes smaller ones, can feel overwhelming.
For some people with dementia, many decisions may no longer seem important. The strategy,
however, is on tricky ground in relation to such issues. The noticeable absence of ‘choice’ in
this section could possibly undermine the bio-psycho-social model of care, the ever-agential
self, that it is said to advocate. What I am struck by is the difficulty of acknowledging in policy
how complex and nuanced ‘choice’ is in this field of care.

In the context of a care home, choice can be about what can be seen in the present moment – a
glass of blackcurrant juice or orange juice?; the choice to go out for a walk or stay in; who you
like or not. These small choices often take place in connection with a real person, who acts the
possibilities out, shows you things. Choice in a care home is available, but it is more limited than
outside. Moreover, choice is always embedded in the relational: carers may hinder or support
choice. If it goes well, choice is not an isolated or isolating process. It is quite different from the
kind of choosing that a self-directing consumer makes.

Dorothy’s and Daphne’s sphere of influence was limited. Certainly, there was little evidence
that their experience approximated to one of a consumer in a care marketplace (Clarke, 2007).
Even the more limited choices open to people with dementia are sometimes withheld in care homes. Such moments can clearly represent a breakdown in care, but perhaps they also speak to the contradictory demands placed on carers (such as organisational demands that counter residents’ needs), the inevitability of getting things wrong from time to time, and the sheer difficulty of providing choice to people who are highly dependent and sometimes without language. Sometimes choice is not always practical, even with the best of intentions. Perhaps, it is even the case that, occasionally, choice is simply not the right thing for someone with dementia (or with any of us!). We might imagine ourselves faced with the ever-growing range of washing powders, all with apparently unique scents, on a supermarket aisle; a toddler overwhelmed by plastic toys whose differences are almost imperceptible; and a person with dementia, just woken, being offered four cardigans when a choice of two would do. Yet this is seemingly difficult to give thought to.

There were opportunities to express autonomy for both Dorothy and Daphne but, owing to time constraints, and perhaps the ambivalence associated with working with people whose minds are steadily unbecoming, care workers often made decisions on their behalf. Sometimes decisions were supportive of and in recognition of particular identities, and sometimes decisions appeared to override Dorothy and Daphne. At times like these relationships entered into a power dynamic, Benjamin’s (2006) doer-done-to scenarios emerged. The following vignette, from Whittinghall, demonstrates where the locus of control could sometimes be found:

Nancy says that Dotty’s hair is messy and she will get a comb. She walks into the hair salon and comes back with a comb. She shows it briefly to Dotty and goes to the back of her head and starts combing. ‘No, no, no,’ says Dotty, grimacing. ‘That hurts, hurts, hurts.’ ‘But it’s messy,’ says Nancy. ‘It’s nearly done. ‘Don’t do it, don’t, don’t,’ says Dotty. Nancy finishes the combing and then looks at Dorothy and says it’s better now, smiling.

Dorothy shakes her head and quietly bends her head down. It looks as if tears are forming in her eyes.

(Observation, 28 June, 2015, Whittinghall)

Nancy, a reasonably patient carer, infantilises and objectifies Dorothy in the above scene. As a well-regulated home, where human mess was barely visible, I wondered if Nancy felt she too had no choice but to make her charge presentable.

At Whittinghall, there was one resident who was keen to make choices and take control, have some influence over procedures. The following is an introduction to Dr Jesmond.

I interviewed Dr Jesmond in his bedroom for 20 minutes. He explained that his stay in the home was a temporary one, although in actuality it was permanent. He said that his wife visited daily to have lunch with him, although this was questionable. He looked physically very fit, with only one or two grey hairs. He was a domineering presence, a bit of an anomaly in terms of other residents I spoke with. He was very keen to make sure wine was available for lunch, even though alcohol only appeared on special occasions. The appearance of wine might have acted as confirmation that he still retained some agency.

The presence of the care marketplace found its way into the interview with Dr Jesmond, the only resident with whom I spoke who had a sense of himself as a consumer.

E: What’s a good day like?

J: (slight pause) a good day, everything goes smoothly…the food’s all right; the wine’s all right; the service is all right (he has a little chuckle). You know it’s… that’s all it is. Do things go well or not. I suppose it’s just the same as anywhere else in the country. You know, um, I think on the whole the service is very good…

E: um

J: But at the moment I don’t know where my wife is… she’s somewhere around and, uh, I quite like, I like getting in touch with her for the, the meal, or I’m not quite sure, the supper.

(A pause.)

E: She comes in, does she, for lunch?

J: Well, yes, unless there’s a special arrangement been made for her by somebody else in the building, saying well we’ve made an arrangement for you to go to such and such… and on those occasions she quite likes it if they sort of say we’ve got your husband to come along too… so they tell me (he breaks into laughter). It’s just that if I’m out all of the time I don’t see her (a strange noise in the background, like building and I can’t hear Dr J)... we’ll just have to wait and see. But um I think on the whole it all goes reasonably well but speak to somebody who’s not very pleased and see what they say.

E: What’s today like? Is today all right. When I first met you were looking… I think you wanted to make sure some wine was available?
J: That’s all I was doing in actual fact. My main objective because um I knew that the food… They have a kitchen for that...

(Dr J laughs.)

J: So I think that touch wood it’s probably going to go all right today. But you’re never 100 per cent sure until the time comes and I think well why aren’t we having this or that or the other… and then trying to find somebody who I think should be responsible for that particular element of the meal, the drinks or whatever and then I try to tap away and say ‘What’s happening?’ and if I’m lucky they’ll say, ‘It’s all going ahead as planned’ (he laughs) and if it’s not they look at you blankly and say, ‘What are you talking about?’

E: That must be frustrating

(Dr J laughs.)

J: That is very frustrating because I think to myself... I am talking to them about their job and they should come back immediately and say this is what we are doing and this is how it’s going and as far as I’m concerned It’s all going well. But you know life is like that... it’s like that... and in the big outside world too.

I find it very difficult, you see, I can’t predict some of the problems. You conclude usually that some idiot in the team has done something very silly... (sighs) and you wish they hadn’t... Okay well...little time to waste.

(A pause.)

J: So I’m just sort of hanging around, waiting for the next hopeful stage in the procedure... Which I thought ought to be... a little wine... not necessarily handed to people but at least a little bit of wine in the area... so when we need it we know where it is... accessible.

(Interview, 11 August 2015, Whittinghall)

Dr J is holding on to the wine. Getting it would be a victory in this comfortable place which nonetheless confuses him. Having lost his wife, he needs to try to take control of something, something that reminds him of the person he once was, a man who talked about his memberships to some of the elite local clubs.

In both homes there were other more mundane examples of choice being made – teas, coffees, coats on or off, blankets – over which Dorothy and Daphne had some control. However,
fundamentally, the experience of dementia is one that destabilises that part of us which might be independent. At base, someone with dementia is moving in the direction of greater dependence, which implies a gradual relinquishing of both ‘choice and control’. To whom we entrust that ‘control and choice’, as one day Dr J would have to do, is therefore potentially a risky business; but finding someone who can be attuned to us with some constancy may well alleviate the anxiety of becoming more dependent. Someone able to make supportive choices for a person with dementia is someone capable of recognising her. This process in itself takes patience, experience, and reflection, all qualities which can be supported by institutions in which the staff team is also noticing.

The sheer difficulty of this task – staying attuned to someone with dementia and allowing him a degree of choice – was brought home to me in an interview with Dirk.

*Dirk was a resident at Winston Grove, who often participated in Gemma’s activities. He had worked for London transport and knew his way around. I interview him in his bedroom. Banging noises could be heard outside.*

*The interview begins well but soon changes, with Dirk responding to his immediate environment. Thinking about his experience in the home seemed to be too much, too abstract, too testing, too painful a reality? His mind raced away with him, and he seemed uncertain of the starting question. The interview ended up representing the way that people with dementia may feel out of control. There was no way of knowing how the condition may unfold, just like this interview.*

E: My question to you Dirk is can you tell me what it’s like to be here.

D: Depending on the time.

(He looks at my hands and, seeing a pen, he reaches for it.)

D: Next door’s coughing. (Dirk listens to the coughing for a while.)

E: Do you like the people here?

D: Debatable.

E: Debatable.

.............

D: There’s so much, is, there’s no real buzzy buzzy when the people are working over there and consequently they don’t, we don’t work too close enough. You know, somebody that’s
sort of daft really, and you go in there (pointing to the toilet) and underneath. It’s been too far away for me, very poor. Which you don’t want. Eh, don’t know. I’d like to paint that.

(He gets up.)

D: I’ll go and see if anybody is approaching us.

(He walks towards the toilet and checks it, walking back out.)

D: I’ll see if there’s one.

E: Shaving? (I am watching what he is picking up in the toilet).

D: Yeah, shaving. Could you tell me what’s got to get on right now. It doesn’t come on as clear as it should do. So give me a book or you a book so you should be able to. Or so the girl can. Is she selling up?

E: Is this the girl that does the shaving? Or maybe me? Because I don’t think I’ll be selling up.

(We laugh together. Dirk smiles, as if he is pleased. He points to the toilet.)

D: Depends what you think. Go along, see what you think. What’s in there then?

E: The toilet, by the looks of it. So when you want to do your shaving does someone help you with this?

D: Only when it’s boom boom. Toilet crash bang.

E: Has there been a lot of crash banging recently?

D: Yeah, it’s the second lot that I’ve cut out of the house. There’s a better go and have a look and see.

E: You better go and see?

D: Yeah.

E: Is it making you worried?

D: Well, it’s...

(He walks back into the toilet, checking in the cupboards. He comes back into his room, opening the drawers one by one, searching.)
E: Are you looking for something?

D: Um. Yeah, I am. The thingamabob.

(He keeps looking and picks up a brush.)

D: That’s good. Yeah that’s good. Don’t’ know if we found it yet though.

(Drilling starts up again in the background. He walks towards the chair in his room, moving it in front of the television.)

D: I wonder which one.... Actually that might...

(He mumbles to himself and stands up again. He looks in a drawer near the television, picking up the remote control. He smiles.)

D: That’s the one

(Interview, 31 March 2015, Winston Grove)

Dirk demonstrated just how little control he had and how hard it was to be in control in the care institution – during the interview he searched for his remote control, which perhaps symbolised both lost objects and the desire to be in charge of someone or something, at least a television. Dirk also takes the pen from me. Experiencing the increased dispossession of his mind, perhaps the only way to hold on to himself is through the increased possession of things which could provide an external structure when the internal one was so fragile. In the absence of the relational ‘thing’, perhaps the object was a temporary replacement?

Dirk is happy towards the end, forgetting that my purpose is to interview him. He is delighted to find the remote control, soon switching the television on, and invites me to sit with him, demonstrating how he is able to find different channels. He moves from an initial place, I think, of feeling possibly tested and out of control – he can’t retrieve his words – to finding some control through the remote, which perhaps alleviates the anxiety associated with not-knowing where ‘things’ are. Equally he has found in me someone who he can trust to be with him, abandoning the interview and its associated pressures and demands. Needless to say, the difficulty for care staff is that they cannot always abandon the task in hand – personal care or medication, for instance – since caring for the resident depends on its completion.

One of the more noticeable features of the National Dementia Strategy is the way that, in its pages, choice and control sit side by side, the assumption being that choice leads to increased
control over our lives. But choice always involves questions, either posed by others or to ourselves. For people with dementia like Dirk, or even those in the early stages of the condition, too many questions can stir up fear, a sense of being out-of-control. Yet being flustered, ashamed or inadequate are not states associated with choice in the *National Dementia Strategy*. As I have already argued, what supports choice in these circumstances is a trusting relationship. If we are really noticing the complexity of the experience, we ought to notice that choice does not lead to control for everyone, nor is it is something that can always be exercised on one’s own. These concepts so liberally applied in neoliberal policy discourse need to be more meaningfully considered for those with advanced dementia.

One of the focal points of the strategy is the establishment of an efficient care pathway. The pathway is formalised as a joint enterprise between health, social care and the third sector, holding the person with dementia, and his carer, without undue anxiety. Although the care pathway might be able to minimise some uncertainty and produce an illusory feeling of control in terms of systems and structure, Goodman (2015) points out that the notion of a pathway is problematic. A pathway implies a known and clear direction, one that can be predicted, understood. This is not the reality, though, since no one knows the trajectory of any life.

To be in conversation with someone with dementia, particularly in the early stages, about what might be next and where appropriate care is available is obviously important, but to imply that uncertainty can be managed structurally is wishful thinking. It seemed to me that carers often provided pathways in the moment, by responding sensitively to the feelings of lostness that a person might be experiencing. This kind of pathway was not about offering control, but about establishing trust.

A pathway, clear and decisive is helpful, yet this desire for certainty might also relate to the anxiety professionals experience in relation to ‘getting services right for people with dementia’ (NDS, p. 10). Indeed, the idea of a clear pathway of care might easily set expectations too high and carers up to fail. As Froggett (2002) notes, ‘...the infinitely perfectible organisation requires an infinitely perfectible client’ (p. 127). In care work things sometimes go wrong. Thus, while few would deny that planning a care pathway is useful, the inability of the strategy to recognise explicitly the inevitable difficulties involved in dementia care is problematic. The language of planning, pathways, directives and outcomes tends to deny the muddle, tidying it away. These neat simplifications not only feel in disconnect with the experience of dementia, particularly in a care home, but may also lead to an organisational response that is critical of care staff when a shift is not smooth.
The fear of getting things wrong was evident in my interview with Gemma (see Chapter 3a) who asked me to stop the tape recording minutes into our discussion because she was worried that she wasn’t saying ‘the right thing’. Another example of this was when I spoke to Violet, a new resident at Winston Grove. Repeatedly, she pointed out that she didn’t know what was going on, that she was ‘stupid’. In my diary notes, I write:

It reminds me of Oliver Sacks: brains, impairments, wives being mistook for hats. You were mistaken for someone’s sister today, and you yourself mistake the home for a hotel, a school, a church. It is so hard to pinpoint where and who we are at any given time, let alone your time. Now. I know my name but not what I am... As you felt stupid, and asked me to spell it out, to give you the answers, I realised I had the all facts but would they help anyway? I could be the clever one for a couple of minutes, the knowing one who could get it right, but where would that get us in the end? And really, at base, I knew nothing because how could I break it to you that this place – this school, hotel, church – was now your real home, break it to you so it would be all right?

(Diary entry, 31 March 2015, Winston Grove).

Other times, carers knew just what to do. The following observation takes place after Daphne has returned from a trip out with Benjamin, her long-term partner. Here the carer is able to provide Daphne with more certainty, interpreting Daphne’s needs well.

‘Um,’ Daphne says, and smiles slowly again, as if there is pain in the vague memory of pleasure. A slow and pensive smile. ‘Will Benjamin come back here?’

‘Benjamin knows you are here,’ says the carer, ‘and he comes to see you here.’

Daphne looks puzzled. ‘Oh,’ she says. ‘I just don’t know what to do. What am I supposed to do?’ The carer notices Daphne still has her coat on. ‘We are about to have lunch, Daphne. Will you let me take your coat off so that you can sit and have lunch, and it’ll still be kept lovely and clean, a million dollars?’

‘Oh thank you, yes,’ says Daphne. ‘Ok let’s go and find a place for you to have lunch,’ the carer says. Daphne turns to the carer and asks, ‘Can she come too?’ She is referring to me. ‘Of course she can,’ the carer says. The carer slowly and gently unzips Daphne’s coat and at a careful speed and pace, takes the coat from Daphne’s shoulders and brings it from her arms. The carer folds the coat and places it over her arm, and with her other arm, invites Daphne to hold on to her as they walk towards the table at the back.

(Observation, 2 December 2014, Winston Grove)
Daphne is initially bewildered. The scene symbolises the kind of anxieties that are aroused in all of us as we move from one position to another, like a child leaving home to go to nursery: a fear about the change in the continuity of care. It is as if Daphne is re-experiencing the pain of weaning, a fundamental prototype for loss. She has lost her partner and fears that if she forgets him, she too will be forgotten.

However, the carer is able to take charge and guide her (a human pathway). Here lunch, something tangible, helps Daphne to become more oriented. The carer is able to find Daphne a place, aware of her experience of lostness. Despite the gentle treatment of Daphne, there is no time to speak with Daphne about the loss of Benjamin, an external and internal object able to give her some certainty about who she is. The carer can’t make it right for Daphne, or take the pain away, but at least she is able to provide Daphne with a focal point, enough to hold her together in that moment.

The current discourse around dementia tends to highlight potent, active aspects of subjectivity, disavowing that which is frail and struggling. Perhaps the focus on a clear pathway of care, although a vital objective, speaks to the anxieties we all have about dementia? The certainty represented in the pathway is not irrelevant in a care institution but the quality of certainty needed is different. It seems to me that quality involves the kind of sensitivity towards another person that allows them the possibility of going-on, of taking another step forward in that particular instant.

I noticed that living well with dementia – understood in the terms identified in the National Dementia Strategy – was sometimes very hard to attain. Indeed, living well was not always an appropriate frame through which to think about an institutional care experience. However, within daily contextual and temporal confusions, possibilities of brief encounters existed which allowed the residents to ‘go on being’ (Winnicott, 1960). I wondered if this is what living well meant in a care context because, no matter how hard care staff tried to provide a good experience for residents, the latter’s anxieties – brought about by feelings of material and psychic displacement – regularly interrupted any approximation of living well (Ramsay-Jones, 2016).

I want to point out that there were good moments of connection through mirroring and play: for instance, the scene at Winston Grove, in Chapter 3a, between Daphne and the temporary Deputy Manager.

‘Always these smiling faces, how very nice. Good good fun,’ says Daphne.
The temporary deputy manager, Anne, comes out of the room and says good morning to Daphne. ‘Hey ho the Barley Mow,’ Daphne says at the top of her voice. ‘Hey ho the Barley Mow,’ says the deputy manager. ‘Hey ho the Barley Mow,’ she says again. ‘You know, Daphne, I can’t stop saying that,’ she says. ‘It’s really stuck in my head.’

‘I am sorry. I am a silly sausage, I know.’ Lynn must be moved, and so she does move... closer to Daphne, putting an arm gently around her shoulders. Their heads almost meet, touching. ‘No you’re not, Daphne, you are so much fun.’
‘With the bum, bum, bum,’ says Daphne, trying to rhyme.

‘Thank you,’ says Daphne, recognising the kindness. ‘Every loves.’


The concept of living well might in a care home be taken to mean an encounter-event (Ettinger, 2006) with a carer, in which a person with dementia is recognised as they are and where a space opens up for meaningful exchange. What I am advocating is an extension to the concept of living well to include these momentary attuned encounters. However, I am also conscious that there are strong neoliberal currents running through the living well discourse, which play down the vulnerability involved in relating and which blend together to create a barrier to thoughts such as these.

The difficulty of extending the concept of living well to include in-depth thinking about meaningful encounters is seen in Objective 11, ‘Living well with dementia in care homes’. The objective acknowledges that vital meaningful interaction is often missing in institutions: ‘...the typical person in a care home spent just two minutes interacting with staff or other residents over a six-hour period of observation’ (NDS, p. 58). However, the recommendations for delivering improvement in this part of the strategy fail to include any explicit reference to the processes which would support such relating in daily life. It is to these processes, and the improvements they might bring, that I now turn.

The Relational Field

Living well through play

During many observations, it became clear that play was an important entry point into making a connection. Play also involved taking a risk in relating, to be light-hearted in a serious working
environment. Most playful encounters that I witnessed were shared by both participants, which demonstrated people’s desire to make contact, to identify with one another. Play was not used to distract from difficult feeling, but rather as a way of heightening the relating, creating a shared language or experience. In the vignette given a few paragraphs ago, we saw Daphne and the assistant manager making meaning together. They show that they belong to an external space which is created by playfully sharing something of their internal experiences – together forming an in-between space.

As I noted in Chapter 4, play was more frequent at Winston Grove. Although the days at both care sites followed a similar routine, Winston Grove was less orderly than Whittinghall. Space was more fluid, the home more unkempt. Carers often carried out the bureaucratic work of form-filling while sitting at tables with residents having tea; dogs, chickens and rabbits had homes there, too. Whittinghall adopted a way of working that relied on compartmentalisation, a tidy organisation. My first impressions of the home prompted me to write in my diary:

How neat it is here. It feels organised, quiet – a calm. But then there is the old woman and she seems so alone here despite the material comfort, the presentability.

( Diary entry, 12 May 2015)

Drawing on Winnicott, we might imagine that in an institution anxious to do things correctly there may be less capacity to play. Play involves the sharing of unconscious, disorderly spaces, and this may feel too risky in a procedurally run care home.

Objective 11 points to the need for ‘readily available guidance for care home staff on best practice in dementia care’ (NDS, p. 57). Whittinghall seemed to be receiving guidance on best practice: staff had colour-coded uniforms, residents were given life story boxes and clear signage was everywhere, but I wondered if doing the ‘right’ things got in the way of spontaneous moments where contact is made through physical or expressive movement.

Objective 11 does point out that it is important to foster a ‘good-quality social environment … the possibility for self-expression where the individuality of the residents is respected’ (NDS, p. 58). However, the National Dementia Strategy does not specify what this would mean in the context of a care home. Play seemed to afford people with advanced dementia a ‘potential space’ (Chapter 1 and 4, Winnicott, 1971) for self-expression, in which they could be seen. It seemed to offer possibilities for quelling the anxiety of being alone with muddling thoughts and feelings. The potential space that opened up may have allowed residents and staff to (re)experience, through a shared process, a time – maybe lost or forgotten – when shame,
judgement and embarrassment were absent. However, given the neoliberal frame which foregrounds individual autonomy over collective and relational engagement, the notion of play, in a Winnicottian sense, might be a challenging notion to entertain in the national UK dementia policy domain.

Living well and noticing

If play provides some possibilities for living well with dementia in a care home, another may be found in the process of recognition and noticing. Here is a scene where no one noticed Dorothy.

She is not seen. Now four members of staff are by the trolley discussing who is having what. Dorothy lets out a noise and raises her hand again, birdlike gestures. The carer comes along and says that it is soon lunchtime. ‘Lunch, lunch, lunch,’ says Dorothy. The carer looks at me and asks if it’s all right to move her for lunch. I say I am not sure. The carer tells Dorothy the food is ready and starts pushing her to the table.

Dorothy is given a glass of orange juice by a nurse. Dorothy is now alone on a table. She makes a noise as if trying to get someone’s attention but nobody notices. She pulls her face back as if to make a scream but nothing comes out and tears come to her eyes.

....

She pushes the orange juice away, rejected.

(Observation, Whittinghall, 12 May 2015)

In institutional care, it struck me that living well was always linked to the subtle dynamics involved in relating. To live well here had something to do with the instances in which you were noticed, in which the person with dementia is acknowledged as a separate centre of subjectivity (Benjamin, 2006), experiencing a full range of feeling.

The recommendations for care homes contained in the National Dementia Strategy focus on the appropriate use of anti-psychotic medication and the development of in-reach services for community mental health teams and senior staff dementia care leads. Although the strategy quotes the Alzheimer’s Society ‘Home from Home’ report, which recommends more staff time and more activity in care homes (NDS, p. 58), it doesn’t make explicit the possible links between behavioural problems in people with dementia and the absence of being noticed.

What I observed was that living well for Daphne and Dorothy was more likely when their complex emotional worlds were recognised and tolerated. In the above vignette we see that
Dorothy needed to be seen. Her sense of being unheard, unknown, leads to her increasing anger and ultimately a feeling of despair, of withdrawal, a lack of capacity for taking anything good in. Even food.

Recognition is also important for carers. At the beginning of my fieldwork Dorothy barely noticed me as I came to sit with her each week as an observer. At times I wondered whether Dorothy had ingested something of an organisational culture, which turned a blind eye to the full human experience as social policy seems to do so. This was unusual in my experience of working with people with dementia, who often began to recognise and to respond to regular visitors. After one observation late on in the process, I recorded in my fieldwork diary how Dorothy had noticed me, speaking to her as she existed in my mind:

It was a surprise that you recognised me and called me your “new friend”. It was sweet, and at last I was there for you. It’s funny, though, as I hadn’t thought you’d noticed me at all. But you have.

*(Diary entry, 9 June 2015, Whittinghall)*

I realised how important it was to me, even as a weekly visitor, to be acknowledged. This made me think of the members of staff who carried out the work each day, and how vital some recognition, noticing, was from the residents. This was part of the reward of working with people whose capacity for recognition was changing.

Noticing at Whittinghall seemed more tentative than at Winston Grove. The question, of course, is what makes noticing possible in an institutional setting. As Hoggett (2009) points out, referring to public officials working closely with human suffering, ‘Different kinds of defences tend to be used to manage the problems of seeing, feeling, and thinking. Depersonalisation is a defence against feeling’ (p. 165). I wondered if Whittinghall’s focus on professionalism and routine were in part unconsciously designed to close down the organisation’s capacity for noticing.

Paradoxically, as I noted in Chapter 4, staff members there were more able to notice the reality of death in their work than was the case at Winston Grove. I think the staff’s distance may have afforded some residents the possibility to retreat into their rooms, and into dying, but I feel certain that this distance was not necessarily able to support people’s need to continue to live (well or unwell) in an increasingly dependent state.
One of the residents at Winston Grove named Suki (see Chapter 3a, p. 89) was particularly demanding. She called out daily from her place in the lounge, asking for biscuits, cups of tea and then the toilet. Almost in a loop. This kind of neediness, to be looked after around the clock, seemed to be hard to tolerate. What this neediness stirs up for professional carers is perhaps one of the most important questions we ought to ask.

We all know that care work involves responding to need but when need is relentless and loud, demanding and transparent, and in the body of an older person, it seems that neediness can be overlooked. The National Dementia Strategy does not characterise need in this way. Need is re-imagined as a manageable experience.

In fact the word dependency does not feature in the strategy at all, perhaps reflecting a wider social anxiety that pushes need out of the collective mind. In this vein, Foster (2010) quotes Hoggett (2000) saying:

There is a deep-seated hatred of dependency within our culture which needs to be understood; I fear that otherwise it will leave an irredeemable scar upon the project of creating a better world. (p. 166)

Caring professionals can easily be drawn into this widespread ambivalence about caring for the most dependent people, particularly if there aren’t opportunities to reflect upon it. Harassed and overworked, partnered up with new temporary carers, some on zero hours contracts, faced with the looming threat of death on each shift and the introduction of new systems of surveillance, carers, who are managing their own precarity and vulnerability, sometimes found it hard to take in all the demands of residents. If we are to expect so much from care staff – particularly if they are young, like those at Whittinghall but also older carers, like those at Winston Grove, who are perhaps imagining their own decline, or their parents’ – then we must account for their needs too.

Objective 13 (NDS, p. 65) of the strategy envisages the meeting of staff needs in a straightforward way, by offering core competencies and vocational skills training. For messy work like this, creative systems of support that give space to the emotional labour involved in the work are necessary. Sonia, the senior nurse at Whittinghall, who spoke at length about dying residents in Chapter 3b alluded to the importance of giving further thought to the kind of refuelling professional carers need in this line of work.

27 Note the iPod care note system that was introduced in Whittinghall, Chapter 3b.
Living well at the end

As I have implied above, this line of work is inevitably bound up with the finality of human life. Carers will have to nurse people who struggle to swallow, turn fragile bodies indescribably light from weight loss, move corpses and clear out rooms of those who have died. End-of-life care for people with dementia is raised in the strategy under Objective 12 (p. 61) but the focus is on planning, advance directives and ‘workforce development’ (p. 61). As such, it is difficult to avoid the impression that the strategy seeks to take control of a process that brings us face to face with our ‘inescapable helplessness’ (Froggett, 2002, p. 126). As we have come to expect, the idea of equipping staff to notice the pain of the work, the losses, the fears of dying, is not touched upon. Noticeably thinking about resilience, stress and compassion fatigue, holistic, psychological and spiritual care of the type you might find in palliative care policy is also missing (NICE End of Life Care, 2013). Again, aspects of the relational – upon which all care is based – are overshadowed by the procedural.

Despite the fact that the strategy notes that dementia is a ‘severe and devastating disorder (p. 16) and that people in care homes are part of a ‘vulnerable population’ (p. 60) the document seems unable to acknowledge the intense mix of feeling that might be encountered in dementia care homes in the face of death. For instance, there is nothing in the strategy that echoes the following entry I came across when going through my field note diary.

Part of me wants to shout, to ask someone, anyone, ‘What is this fucking place?’ And part of me wants to be a little more gentle, and say, ‘I get it, I do, it’s hard.’ And then I see something else and want to congratulate each person involved. But what is this place where feelings shift and come so powerfully to the surface and then dissipate with little recourse to thought? In one short hour, I found myself anxious, lost, furious, touched, alive, content and dying.

(Diary entry, 4 December 2014, Winston Grove)

Though I was able to feel in that moment what it might be like to live and work at Winston Grove – the way feelings leaked out into daily life – my response demonstrates just how difficult

28 The word ‘death’ is not mentioned in this section. The strategy refers to the National Council of Palliative Care’s work on dementia. The NCPC talk of achieving a ‘good death’ (http://www.ncpc.org.uk/dementia), perhaps a need to prettify, as per living well, experiences which can be harrowing. In death, some people are raging, bodily fluids leak and pain can be intense.
it might have been to think about decline and death there. The National Dementia Strategy doesn’t look any closer either, mirroring an ontological anxiety about dying and perhaps a neoliberal concern with the active, economically viable living. Until now, I have discussed what living well may or may not mean for people with dementia living in a care home context, I will now consider how the care worker is conceived in the strategy before concluding the chapter.

The Workforce

As we have seen, the relational field is not entirely absent in the strategy. It is made explicit in Objective 11, but in reference to relatives: ‘Maintaining good relationships between relatives... and people with dementia, (since it) benefits both parties’ (p. 58). At the introduction of the Living Well chapter, someone with dementia is quoted saying, ‘That was a wonderful feeling; to know that there were people... who absolutely cared for you’ (p. 43). Objective 11 also supports the use of life story work as a catalyst for ‘developing relationships’ (p. 58) between care workers and people with dementia. Here there is a sense of the care-ful work that can go into care; the involvement, the ‘getting-to-know.’ Memory work demonstrates the temporal complexity involved in caring, hinting at the difficulty in connecting with someone with dementia in the later stages.

Interestingly, though, this tentative nod to the relational, to the sensitivity involved in good care, is undermined by the language chosen to represent carers, described as the ‘workforce’ (pages 57, 61, 65). This has connotations of the labour pool, even manual work. The body work of care is perhaps foregrounded over the emotional. In contrast to the individuated voices of people with dementia and family carers, carers are constructed as a ‘mass’. How, then, if we think of Benjamin’s (2006) work on mutual recognition, is the care relationship constituted in the strategy? By using the word ‘workforce’, a certain distance is implied.

The following extract from an interview with Dr Dhillon, a resident in Whittinghall, points to a situation where the ‘workforce’ is experienced as a distant separate body.

Dr Dhillon was a former academic, whom I met only once. He had worked in marketing for many years. He was suffering with a cold, and sat outside his bedroom, a tall man dressed in a round neck green sweater and brown chords, blue eyes, white hair, life in his eyes. His semantic losses were noticeable and he tended to speak in metaphors. Here he watches the staff team at the end of the corridor

D: What are they all doing there? I think it must be about to be a large political protest. Radical. Or something. All just congregated. Very slightly... there... I remember when they
first started... all of these things. America and in advertising. But it was a good idea. I mean it did produce a new produ, a new car or something... It could have been such and such now...

We get them... that’s ten years ago now... for a tenth of the price but more like a hundredth...

ioioioio ah (inaudible). I suppose there’s a lecture going on over there, all about it, or ...
because they keep on going in there (he focuses his eyes off the staff at the end of the corridor. It looks like they are stopping by the nurses’ station). I must have seen like twenty lots going in there... Morning, afternoon and evening from yesterday...(he takes a big sniffle).

I can’t keep track of my contemporaries (he laughs). I’d be very hurt if I thought I was going backward to discuss laid eggs or something while one discovers something new. Yah. Somewhere very (he chuckles) bang. One or the other. We ought to rescue here, oughtn’t we.

Oh dear oh dear have a big sniff now.

(Interview, 11 August 2015, Whittinghall)

Dr Dhillon notes the group of staff, and positions himself outside them, looking in. He feels that he cannot be part of it, but tries to makes sense of the comings and goings. But notice, he talks about the possibility of being hurt and I wonder if what hurts him is a felt-split between himself, outside and going backwards, and the younger carers, inside, discovering something new. Two sets of people within close proximity yet clearly out of touch.

It was at Whittinghall that the task-focused practice implied in the concept of ‘workforce’ seemed to play out more obviously in daily life.

Interviews with staff members at both sites alluded to the very real tensions between the daily practical care tasks involved in the work (which had to be routinized to avoid chaos), constraints on resources and the emotional realities of the work. However, as already discussed, care at Whittinghall was more proceduralised than at Winston Grove, seeming drained of emotional life. Perhaps Dr Dhillon’s observations, as well as contrasting his own ‘going backward’ to the young carers’ discovery of the new, hint at this proceduralisation. Although he does not refer to it directly, the way in which he positions himself on the outside looking in on staff in the distance seems to convey a sense of the staff as a disconnected, distant crowd. Is it possible that the idea of an instrumentalised, undifferentiated ‘workforce’ implicit in the National Dementia Strategy had found its way into the relating at Whittinghall?

It would be reductive to suggest the National Dementia Strategy portrays staff teams only in terms of a homogenised workforce engaged in proceduralised tasks. Objective 13, for instance, clearly states the need for an ‘informed and effective workforce’ (p. 65), going on to say that
adequate support and training is likely to improve staff morale and ease retention problems...’ (p. 66). The strategy thus acknowledges, if implicitly, that the work is not always easy.

Objective 11 recognises further constraints on staff: ‘...staff enjoy providing opportunities of activity and occupation ... but do not feel they have the time’ (NDS, p. 58). Indeed, as interviews with Bridget, Diane, Gemma and April demonstrated, linear clock time was experienced by staff as a barrier to much-needed intimate encounters. Difficulties around time are echoed in the strategy particularly around home care: ‘Current practices of specifying tasks rather than outcomes, not having the time or consistency of worker to develop the relationship ... and the care workers being rushed and visiting for short (eg. 15 minute) periods are particularly problematic for people with dementia’ (p. 47). Rushed time is understood to objectify both sets of people involved in the relationship.

Nonetheless, the strategy’s tendency to describe carers as a mass and care in terms of efficient procedures is striking. In the case of Whittinghall, this tendency seems to have infiltrated the organisational culture. Not only were working practices and relationships to them instrumentalised, this instrumentalisation was possibly used by staff as a retreat from the anxiety of working with ‘dementing’ people. The question for policy, then, is three-fold: what does a focus on efficiency do to the emotional contact involved in care work and, secondly, why is it so difficult to consider the emotional contact involved in the work? If policy were to give value to this component of the work, what would it mean for society as a whole?

The impermeability of the staff at Whittinghall was also evident in observations with Dorothy. Most striking was the sheer number of times she repeated herself. This repetition was a feature of Dorothy’s relating, as if she had to force herself into the ‘workforce’, just to be noticed. I noted:

The nurse is in the nurses’ chamber, and she sits across. Dorothy repeats words as if it is a verbal symbol of her repetitive experience; anxiously holding on to words while simultaneously evacuating them ...

(Diary entry, Whittinghall, 9 June 2015)

On the other hand, as we have seen from earlier vignettes, when relating was open and responsive the construct of the ‘workforce’ seemed ill-fitting. Genuinely co-affecting moments took place in observations. In interviews many members of staff were preoccupied on some level with relating. They understood their work in terms of the relational, often talking about
specific residents who had affected them deeply. Members of staff at Winston Grove lamented the fact that they didn’t have more time to conduct one-to-one care with the residents; and at Whittinghall Sonia spoke about residents she would one day lose. Of course there were contradictions within these beliefs – for instance when there was a freeing up of time (as witnessed in Whittinghall) staff didn’t necessarily spend it sitting with residents.

However, we only have to think of Chaya, who imagined her mother in so many residents, expressing her joy when a resident, palms open towards her, calls her, ‘…an angel on this earth’; Gemma who talked at length about the efforts she made to find out the minor personal details of the residents, in order to plan meaningful activities for them; Michelle, a carer, who was touched by one resident who always asked her about her son; and Nancy, who felt so attached – sometimes ambivalently – to Dorothy that she couldn’t imagine working in the home once Dorothy died. This is not a nameless ‘workforce’, but people with families and partners and lives who are always affecting and being affected by the residents. This is why the relational field is entitled to more space in dementia care policy, and why staff needs are a vitally important part of it.

A sense of how little staff needs figure in current dementia care was strongly conveyed by April, one of the workers at Winston Grove. She commented:

A: If you’re working your staff, like a candle at both ends, eventually you’ll burn them out and they’ll be sitting at home ill and what you think you’re saving you won’t be saving because you’ll have to pay out because depending on where you work you’ll have to pay sick leave. You’re paying them while they’re at home sick because whatever it was at work made them sick and you still have to call the agency supply staff and you have to pay so where is the economics in it?

I don’t know, I don’t know. You can’t blame managers for certain things, managers in some cases just have to go with whatever resources are provided, whatever instructions they get because you tell people here, yeah managers here have a manager and that one there have one over their head and it just comes in a ripple, a ripple and it’s very, you know, but then who feels the brunt of it, is always the ones at the bottom end of the ladder

E: Yeah

A: … I just hope they can wake up, those that sit where they sit and come up with all those ideas and see where, sitting there, coming up with these ideas aren’t the practical way about it, and I think it’s not until some people are caught up in a situation that then the reality hits
them that wait so I think it is just saving money, saving money but sometimes to provide things in a proper way you have to spend to get, um um.

(Interview, Winston Grove, 24 March 2015) April directs this criticism at national government and policy-makers. She speaks to the experience of care workers as she sees it – exhausted and burnt-out – and reminds us all that there are lessons to be learned about care from those ‘at the bottom end of the ladder’; a place at the bottom which is not given voice in policy.

The autobiographical ‘Is’ that introduce the strategy’s major themes, reflect an increased valuing of interiority, of individual subjectivities, of the confessional, as a way into understanding lived experiences and improving lives. But the I is also a construct of the marketplace, the individual consumer expressing his wants and desires. The fact that the autobiographical voices of clinicians, professional carers, domestic helpers are absent suggests that the relational is constructed in an asymmetrical fashion. Implicitly the consumer-patient is cast as the most needy in the partnership, which is in contrast to the general narrative of empowerment. There is a paradox at play: the consumer-patient (emerging from a business model) is both vulnerable but also in the driving seat, the professional responsive and receptive to various demands. This is interesting because it partially sanctions care staff to locate unthinkingly their own split off vulnerabilities in their charges, perhaps wielding power over them as a result. A reversal of the asymmetry found in policy, but a relational asymmetry nonetheless.

In lived experience, sometimes something very different takes place that involves the complex interplay of experiences and subjectivities: it involves, when all is going well, dialogues and not monologues in order that experiences can be given meaning in the context of a relationship. Moments of good care seem to involve a kind of subtle mutual recognition at a deeply intimate level. There were times when both Dorothy and Daphne related to carers and carers related to them in ways that sustained both sets of personhood: a co-affecting, a dialogue.

I remember watching Daphne, tearful, angry, in the lounge. She cut a lonely figure. Erica her then keyworker walked towards her and listened to her for a few minutes. I noted in my diary (7 October 2014) that Daphne said, ‘The backing from the parents. Without the backing of the parents, the children would be lost’. At that point Erica got closer and told her she would like to help. Daphne told Erica that she was one of the ‘good ones’. Erica wrapped her arms around Daphne and said, ‘I know you have given your life to the children. They are so important for you.’ After that, Daphne stopped crying, and asked if she could help Erica in the kitchen.
Daphne and Erica had co-produced some meaning between them. There was a joint receptivity, with Daphne able to express gratitude and Erica able to empathise with Daphne enough to contain her fears. This is not the image we might take from the notion of a shadowy, silenced ‘workforce.’ Rather it is the carefully responsive voice of the carer that allows Daphne to continue. *Living Well: A National Dementia Strategy* was presented as a collaborative, carefully co-constructed document, so it seems all the more unimaginable that the experiences of staff teams are left out.

**Conclusion**

The reclaiming of identity and identities of people with dementia has involved challenging what Kitwood (1997) identified as an old culture of care, in which basic needs were met but psycho-emotional ones were not. The living well agenda has, undeniably, had an important role to play in improving the way that care is practised.

However, as I have sought to demonstrate in the course of this chapter, the endless pursuit of living well has not successfully embraced the ability to tolerate feelings of loss experienced in dementia, to acknowledge increasing disability, or to allow a trusting dependency to develop in relation to another person able to care. Is it all right to have bad, debilitating days? These are questions overlooked in the rhetoric. It seems possible that the idea of living well has been co-opted by the well, those who do not yet have dementia because it allows us to pretend that dementia can be dressed up to look good in some way, that it is not quite as devastating as we think.

At the same time, neoliberal forms of government have also integrated notions of well-being into a network of discourses and practices that begin to support the dominant political ideology of our time. Living well, in neoliberal terms, can become a concept against which people, even the sickest and most incapacitated, can be judged. Incapacity, living unwell, in need of support – all this becomes shameful. In the *Prime Minister’s Challenge on Dementia* (2016) the ‘wellness’ discourse really takes hold with sections titled, ‘Living Well’, ‘Supporting Well’, ‘Training Well’, ‘Dying Well’, ‘Diagnosing Well’. There is no room for failing here.

There is a contradiction at the heart of the neoliberal agenda. It advocates autonomy and self-reliance on one hand but also promotes an endless consumption. The neoliberal subject is invested in the idea that this process buys-in well-being, a kind of choosing that generates an ‘appetite for appetite’ (Phillips, 2005). Arguably this is about neediness, hunger, marketed and reframed as desire. This is perhaps the acceptable face of dependency, a dependency on the
marketplace rather than on each other through processes of noticing, play and meaning-making.

Of course, it is vital that we can make demands, have desires/wants, but the basis of our demands might need examining; what kinds of sustenance do we really need, particularly as our lives become more precarious?

The rational, self-possessed I, making choices and taking control, itself is mobilised in part to make policy more palatable. The notion of interiority is left unquestioned assumed to belong entirely to the person with dementia/family carer. This is a problematic area. Butler and Athanasiou (2013) suggest that possession is written into the basic structure of the neoliberal subject (I am in possession of myself, my rationality) but, as they argue, human subjects are always already dispossessed in the sense that their own minds, bodies and experiences belong to and are given meaning through and with their relation to others.

For someone with dementia, a secondary dispossession takes place as mind becomes even further out of reach, and a need to trust increasingly another mind able to bear one’s own emerges. Yet in current policy, the subject with dementia is implicitly conceived of as owning his or her mind continually throughout this wildly dispossessing journey. And those he or she relates to, the workforce, are seemingly untouched by him.

For me, the relational field as constituted in Living Well: A National Dementia Strategy, presents difficulties because it doesn’t make space for recognising the irrational, messy, uncertain and confusing affective flows found in relating, or for the movement of dependencies between carers and people with dementia. The work of care is presented in a vocabulary that makes the experience more presentable, as if it is imperative that the difficulties be pushed out of view. Relationships shift in and out of asymmetries and symmetries, dialogues and monologues. Carers are both powerful and vulnerable in the same way that people with dementia are. Without reflecting upon the complex external dynamics and internal landscapes that lie between and within each party, the dangers are that relating becomes a fixed form and that organisational cultures close down to the wide range of experience involved in human encounter-events. It seems to me that meaningful encounter-events, which involve processes of self-fragilisation, between people sustain both the person with dementia in care homes and the person who cares for him. It seems vital that there is ‘a re-evaluation of vulnerability as so much an essential part of human learning and living that far from evoking pity or contempt, it is respected as an ingredient in the glue of interpersonal solidarity’ (Froggett, 2002, p. 125).
In this chapter, my aim has been to point out some of the inconsistencies in the *National Dementia Strategy* itself and how it is inadequate in its consideration of the relational field that exists, in all its complexity, in dementia care. Having spent time with Dorothy and Daphne, and having spoken to care staff, cleaners, managers and residents in two homes, I would argue that for living well in a care home context to be meaningful to residents and staff, policy must address the following:

a) That in order for someone with dementia to live well there must be due consideration in dementia care policy of what it can be like to ‘live unwell’;

b) That when someone is ‘living unwell’[^29] this does not necessarily signal a failing of care;

c) That noticing and bearing witness is part of the work of the carer and of the organisation in relation to its staff membership[^30];

d) That there is an unavoidable pain in bearing witness to disintegration and dying, and there ought to be ample opportunity for reflection about this pain;

e) That momentary encounters can be both beneficial and significant, and ought to be acknowledged as such;

f) That play[^31] is as an important entry point into connection as structured activity provision;

g) That, given the complexity of this work, care workers be entitled to better pay;

h) That time and resources be made available for the above to be supported[^32]

[^29]: Dementia is a progressive condition that is uniquely experienced.
[^30]: Through reflective practice, clinical supervision – offering staff a containing (Bion, 1962a) space in which experiences are validated.
[^31]: Feeling able to risk stepping out of a professionalised mode of caring.
[^32]: This study was conducted during part of the UK Coalition government’s (2010-2015) term in office and of the subsequent Conservative government (2015). Some respondents (Chapter 3a) noted the changing socio-economic context.
Conclusion

‘You cannot rush care; you cannot compromise care.’

April, 24 March 2015, Winston Grove

Writing the final words to this piece of work is almost as difficult as saying goodbye to Daphne, to Dorothy, to Melie, to all the residents whom I have had the privilege to spend time with. As a professional carer, as I once was, the people you care about and for sometimes hold on to you as you try to end your shift. In my case, even today, residents hold on through the hauntings of memory. Saying goodbye in dementia care is one of the most challenging parts of the work, when all has gone well and a friendship has formed. A carer can become for a resident, as Nancy had been during those early weeks with Dorothy, an anchor in all the confusion. A carer might know that saying goodbye will disrupt, dislocate and unsettle those s/he cares for, and yet to carry on doing the work s/he has to pull away. Opening up to the experiences of other people, good and bad, can be engulfing and sometimes debilitating. Time and space to refuel is essential. Yet at home, after a busy day, a carer might continue to think about a Daphne or a Dorothy, and become anxious that some component of the work was left undone, that at some point s/he was unable to help put back together someone in distress. So s/he is left distressed herself, guilty. On other days, the joy of sharing a moment, arranging napkins for the lunch table while laughing about the imperfection of the triangular-shaped folds you’ve done together, provides a sense of meaning and reward.

When I think of this piece of work, and its conclusion, I am struck by what Yalom (2008) might describe as ‘rippling.’ Dreamily written, the existential psychotherapist, uses the ripples in a pond as an analogy for the way each of us creates ‘concentric circles of influences that may affect others for years, for generations (p83).’ I know that residents and carers with whom I have worked will continue to have some impact on the way I steer my life.

Both care home sites I visited were imperfect places. Winston Grove had the quality of being at times both managed and unmanageable in the sense that the manager cared and got involved, but that some of the very difficult feelings within the organisation couldn’t be harnessed and reflected upon. Often those who had a valency for anger and anxiety were not embraced in the same way that more grateful, playful residents and staff were. Like the social policy context, the emotional complexity of the work could be avoided. Yet there was something warm and community spirited about Winston Grove, which simultaneously made room for risk-taking and spontaneity, both important factors in creating and preserving relatedness.
Whittinghall was quite different. The neat luxurious surrounds meant that people were physically comfortable and staff knew more clearly where their roles began and ended. The procedural management of the home, and related compartmentalisation, meant that contact with residents and staff was more distanced, colder. Yet this distance provided an opportunity to acknowledge more openly the reality that people would die. There was not the manically defended functioning – the parties, the frequent noisy activity, the animal life – found at Winston Grove, but rather lots of quiet space. This quiet space was double-edged. It may have been needed for those receiving end of life care, but for many residents this quiet possibly reinforced the painful isolation of being out of mind and out of home.

The real absence in both sites, though, was the formal or informal space for staff teams to be able to process the work they were doing. It seemed clear that the people who worked in both sites were at times filled up with the emotional labour of the work. Diane (Chapter 3a) felt brutalised by its relentlessness and, interview over, Bridget (seen in Chapter 3a) discussed her continued anxiety about an incident that had happened years before around the breakfast table. Nancy (Chapter 5) explained that she would have to leave Whittinghall when Dorothy died because they had become close against all odds; and Sophia (Chapter 3b) knew that touching death in her work made her reach out to life – and to holidays.

Because neither organisation provided a space for a more reflective kind of practice, staff inevitability held much in. Social care policy is behind in its thinking about the support of and identities of staff teams. National palliative care policy is more developed in its understanding of the unmet needs of its workers. For instance, in March 2015, Hospice UK launched its framework, Resilience, for supporting staff teams in hospices, particularly to mitigate stress. Here supervision, training and compassion fatigue are considered in some detail. There is a focus on fostering a culture in which honest conversations within organisations can take place. Even in the End of Life Care Strategy, published in 2008, just before Living Well: A National Dementia Strategy, there is some acknowledgement that care staff might be distressed by the work (p. 53) and that reflective practice is beneficial (pp. 66, 140). It also explicitly states that the work involves ‘physical, social, psychological and spiritual’ (pp. 7, 28, 33, 82, 95, 120, 160) components.

I hope to have shown that, in borrowing from psychoanalytical thinkers, not only can we come to better understand the dementia care field, but that there are actual practices that might help us to better support it, too. Staff, like residents, need to be held. Holding, in a Winnicottian sense, involves the simple yet challenging process of being heard, of making room for the
bearing witness of experience by an-other who is able to sit with the full range of emotional content. This is not skills training, which involves a seeming expert offering up theory or fact to those not in the know. The work of psychoanalytically informed reflection is about the connections and meanings that can be formed in and through a process of jointness-in-differentiation (Ettinger, 2006).

This all sounds too abstract, I would agree, which is why in the end I might turn to Bion, who made it clear that we learn about ourselves, or in this case, about ourselves in our work, through a steady process of reflecting upon emotional experience alongside others. This is an intimate act. Learning is not about theorising here, but about carefully unwrapping ourselves, exploring the act of avoiding Dorothy as she cried out; of forcing Melie to brush her teeth; of bringing Daphne to bingo when she is tearful; of turning a corner when Suki needs the toilet... Exploring the feeling behind these acts honestly and in such a way to be able to recognise our imperfect humanness, our failings. This then allows room for thought, the rational and logical. This is not about getting it right, but rather about being able to find a third space within the work that allows teams to recognise the pulls and pushes of the work, without relying on rigidly defensive and protective practice, and without withdrawing. It allows something generative to take place where connections form in the mind and then in the work and back again. This is about finding a space (and a protected space which ripples through the culture) within the institution, where ‘meanings can be discovered... In the third space, the meanings of the situation can be explored. What are the areas of generativity? The short answer is thinking and thought... the capacity to think is the major asset of the people in any enterprise’ (Lawrence, 1994, p. 94, cited in Foster, 2010).

To do this successfully in care institutions, policy must notice the emotional cost of the work, it must recognise the ‘who’ of its workers. Time must be allocated to listening and to feeling and to thinking. Further research into processes of supervision— which give thought to the emotional toll of care work and the way this intersects with categories of class, race, gender, as discussed in Chapter 4 –and the impact on daily practice, and intimate relating, is imperative. We are also talking about monetary investment to provide the resources and time within a shift to do so; about the leadership taking an active role in supporting the psychological going-on-being of the team; and an investment in the relational which at least matches the technical and procedural investment.

This study has been about the experience of dementia, and about the experience of working with people with dementia, in the care home site. It is also about our widespread anxiety about relating to dependency. Dependency in older people is particularly problematic because it
reminds us of our own fear of decline; our fear that there will be no one there to catch us when we fall. It stirs up the nameless dread of fragmenting in isolation and returning to places we have possibly known but struggle to find words for. It feels all the more frightening because the political landscape that we know in the Western democracies is at present precarious, and the dependent are positioned as unlovable and insatiably needy. But as Cooper & Lousada (2005, cited in Foster, 2010) point out, ‘It is not dependency that is the problem, but fear and hatred of dependency which destroys the link to the source of support that may be the ground of our well-being’ (p. 195). This source of support is arguably the relational. Our relationship with others, the huge potential for coming together when we share something of our fragility, is at stake. And our relationship with ourselves as human, with very real limits, too, also hangs in the balance. My learning here has allowed me to conclude, for now, something akin to Lynne Segal’s claim that,

Acknowledging the habitually disavowed mutual dependence necessary for sustaining the human condition, while querying our cultural obsession with notions of ‘independence’, just might help us to see that those most disparaged in the circuit of human interdependence, or largely abandoned within it, call into question the humanity in all of us. (Segal, 2013, p. 37)

By hating dependency we also shame our infantile dependent self and shame ourselves as we age and move towards death. This is, quite simply, no way to go.

References


Analysis. 43. pp/ 306-310


Davenhill, R. (2009) ‘Psychodynamic observation and emotional mapping: A tool for continuing professional development and research in services for older people.’ In Quality in Ageing and Older Adults, 10(1), pp. 32 – 39

Dementia. A state of the nation report on dementia care and support in England (Department of Health, 2013)

Dementia, Rights and Social Model of Disability (2015) Mental Health Foundation


Judah, Ben (2016) This is London: Life and Death in the World City. London: Picador


Klein, M. (1930 [1975]) ‘The Importance of Symbol Formation in the Development of the Ego.’


Lowe, F. ed. (2014) Thinking Space: Promoting Thinking About Race, Culture, and Diversity in Psychotherapy and Beyond. London: Karnac


Matthews, FE et al. (2016) ‘A two decade comparison of incidence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function Ageing Study I and II.’ Nature Communications; DOI 10.1038/ncomms11398


**Panorama: Nursing Homes Undercover (21 November 2016) BBC1**


*Prime Minister’s Challenge on Dementia* (Department of Health, 2012)

*Prime Minister’s Challenge on Dementia 2020* (Department of Health, 2015)

*Putting People First: a shared vision and commitment to the transformation of adult social care* (Department of Health, 2007)


The Things between Us. Living Words: Anthology 1. Words of people experiencing dementia. (Edinburgh: Shoving Leopard, 2014)


Appendix A
Appendix B

Information sheet for residents: The observational study
I am inviting you to be part of an interesting research project that is trying to understand what the experience of being cared for in a residential home is like, and what it might be like to work there.

Before you decide if you want to join in, it’s important to understand why the research is being done and what it will involve for you. Please consider this leaflet carefully. Talk to your family, friends, keyworker or home manager if you want to.

**Who is the principal researcher?**

My name is Esther Ramsay-Jones and I am a postgraduate student. I am conducting this research as part of my PhD study, supervised by Dr Gail Lewis and Dr Peter Redman. The study is being funded by the Open University. I have also worked with older adults in local government in the past.

**Why is this research being done?**

64% of older people living in a care home also have a condition known as dementia. This can be an unsettling experience for someone, and very often receiving good care from a family member or a professional can help someone to feel more comfortable and at ease. This research is trying to understand what being cared for feels like on a daily basis, and how professional keyworkers manage their caring roles. Evidence gathered from this research will help me to think about how people with dementia and professional care workers can best be supported in the caring relationship.

**What will be tested in this research?**

There will be no tests. I will sit quietly in a public space, watching the everyday interactions between you and your carer/s, for an hour each week.

**Why have I been invited to take part?**

You have been invited to take part as someone who is over 65 and living in a care home for older people with dementia. I will come along each week for an hour to see what your care is like, and what your carers’ work is like.

**Do I have to take part?**

No. It is up to you, participation is voluntary. I will ask you for your consent and then ask if you would sign a form to say you agree to being involved in the research, if you would like to. I will give you a copy of this information sheet and your signed form to keep. Before I begin the observation each week, I will also speak with you to see if you are happy on that day for me to observe. If you say no one week, we will talk about making arrangements on another day or at a time more suitable for you. You are free to stop taking part at any time during the research without giving a reason – in this instance, any recordings from the observations will be destroyed. If you decide to stop, this will not affect the care you receive.

**What will happen to me if I take part?**

Your everyday life will not be affected. You might notice me in the room sitting quietly each week. I will visit the home for an hour each week for up to three months. You will be able to do all the things you usually do at that time.
What will I be asked to do?
You will not be asked to do anything, and will be able to get on with your day as you normally would do.

What will you be recording?
I will not be recording anything during the hour-long observation, although I will take notes of what I observed once the hour is over. This will be based on what I am able to recall.

Will I get to talk to you?
We will have met and talked with one another before I start the observations to make sure that you are happy with participating.

Will I be identifiable?
All observations will be recorded using pseudonyms (false names) and any obvious personally identifying information will be changed or removed. Sometimes individuals wish to be acknowledged in studies and, if this is the case, I will speak with you to find out how you would want this to be done.

What about confidentiality?
All data will be kept on a password protected computer and anonymised for confidential purposes. I do have a duty of care towards the older people involved in this study; therefore if I were to witness abusive behaviour it would be necessary for me to discuss the matter outside this boundary. This would involve the following advice gained from Action on Elder Abuse and the Age UK’s August 2013 Factsheet, ‘Safeguarding Older People from Abuse’.

Abridged version.

Appendix C

Residential Care Home:
CONSENT FORM – INTERVIEW COMPONENT, Staff Members

Project title: A Psychosocial Study of the Care Relationship in Residential Care Homes for People with Dementia

Name of Researcher: Esther Ramsay-Jones

I confirm that I have read and understand the information sheet dated [DATE] for the above study. I have had the opportunity to think about the information and ask any questions of the researcher. I feel these have been answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my working life being affected in any way. Any information kept about me will be destroyed if I withdraw.

I understand that all information will be stored in a secure place with only the researcher having access.

I understand that, unless I wish to be directly acknowledged in the study, information I give will be anonymised and confidential.

However, I understand that the researcher, following Age UK’s safeguarding advice, will have to break with confidentiality if there is evidence that an older person is at risk of verbal or physical abuse.

I agree to take part in the above study.

Name of Participant Date Signature