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BECOMING-DEMENTIA AS AN IMMANENT CONDITION OF CO-DWELLING IN EVERYDAY LIFE

AN ETHNOGRAPHY OF BECOMING IN A CARE HOME FOR AGEING JEWISH PEOPLE IN LONDON

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Humanities

2017

Jong-min Jeong

Social Anthropology, School of Social Sciences
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ACRONYM

PCC: Person-centred Care  GSFCH: Gold Standard Framework for Care Home
DCM: Dementia Care Mapping  MS: Multiple Sclerosis (MS)
MCA: Mental Capacity Act  CCA: Community Care Act
MCI: Mild Cognitive Impairment  NRES: National Research Ethics Service
URES: University of Research Ethics Committee

A NOTE ON PSEUDONYMS

I use pseudonyms throughout the thesis.
ABSTRACT

Becoming-dementia as an Immanent Condition of Co-dwelling in Everyday Life: An Ethnography of Becoming in a Care Home for Ageing Jewish People in London

The University of Manchester, Social Anthropology, School of Social Sciences
Jong-min Jeong
Doctor of Philosophy in the Faculty of Humanities, 2017

What have those living with dementia lost? If they have lost aspects of their mind and self, who are they now? Are they ‘normal’? Prevailing medical, therapeutic and sociopsychoanalytic interventions and studies on dementia, largely influenced by Tom Kitwood’s person-centred approach, have focused mainly on revealing and evaluating the remaining intact bodily abilities and functions beyond loss. In contrast to this predominant understanding of dementia, my decade-long involvement in a Jewish Care Home as a volunteer and researcher has raised ontological, epistemological and practical critiques, acknowledging that we are never beyond loss but always alongside it, and that we simply do not know how to dwell well with it. Although the expressive and performative words, gestures and behaviours of those with dementia are often regarded as inarticulate, repetitive and nonsensical, these are the lived worlds of dementia that those affected feel, experience and live through, whilst continuously making relations and familiarising themselves with people, things, and their surroundings.

This demands a paradigm shift in the ontological, epistemological and practical horizon within the study of dementia. Critically developing Canguilhem’s notion of the normal and the abnormal, Ingold’s dwelling perspective and Deleuze’s concept of becoming, I redefine dementia not as a fixed mode of being but as a continuous process of becoming-dementia through an attentive engagement with one’s immediate surroundings. In more detail, this study explores the ways in which people challenge the taken-for-granted concepts of loss and abnormality in five different dementia contexts: ethics, repetition, time, agency and emplacement. By rejecting medical preconceptions or categorisations, this study focuses on uncovering what loss does in everyday life rather than asking what loss means or what people lose. In particular, this study emphasises bodily movement, sensory perception and affect, not because of the language deterioration during dementia trajectories but because of a new way of understanding and new reality that those affected practise in daily life. Consequently, this study illustrates the immanent potential of the anthropological view for thinking and dwelling with those living with dementia alongside their limits and implications.

This study is thus an autobiographical ethnographic testimony of my past decade living, learning, volunteering, studying and most importantly co-dwelling with those living with dementia. This is a collaborative co-production created with those involved, as without the participation of those affected and the co-presence of significant others, my work could not be done. Accordingly, there is neither a beginning nor end to this study, but a moving forward and generating dementia becoming as the lives of those affected and those who care for them unfold.
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ACKNOWLEDGEMENT

Placing a full stop at the end of this thesis only opens another beginning. There is no ending, only a moving forward, and thus my mycelial (or rhizomatic) lines of relation, desire and expectation in relation to this study keep growing. But, without the support of others, this work could not have come into being. I would like to take the time to show my appreciation.

My thanks goes first and foremost to a woman I first encountered, researched and failed to understand as an anthropologist in Korea in 2001. Despite my unsophisticated and challenging interview questions, she showed unfathomable precision in speaking about her untold suffering and hardships, which had remained unvoiced for more than six decades. It was an invaluable time in that I learned anthropology was the art of starting and maintaining relations with others by making the unfamiliar familiar and the familiar unfamiliar. Of course, without Professor Myung-hye Kim’s continued support and encouragement, this could not be possible. Above all, her endless questions about my research proposal and thoughts led me to reconsider my taken-for-granted worldview, although at the time, I could only partially understand what she had been trying to say.

My intellectual journey continued with my study of the oral history of the Korean War from 2001 to 2003. I was passionate about subjective memory and the idea that depending on an individual, historical, political and ideological situation, people tried to remember, restrain or even forget historical events commonly witnessed and experienced by others. In particular, I was one of the luckiest research assistants in that I was given a chance to follow and shadow Dr Jung-seok Park’s anthropological fieldwork, although it was a long and tedious process of living and working together with the subjects we studied. Likewise, I am particularly indebted to Professor Kyung-hak Kim and Professor Sung-heup Hong for developing my anthropological knowledge, attitude and orientation, and Professor Kyung-soo Na and Professor In-ju Pyo for their ethnological approaches. More than anything else, without the support of my supervisor, Professor Hyeop Choi, I could not have accomplished all this work. Furthermore, he willingly wrote me a letter of recommendation, encouraging me to study Medical Anthropology abroad.

In 2008, my intellectual curiosity in subjective memory was in full bloom at UCL in London thanks to the guidance and intellectual inspiration of Professor David Napier and Professor Susanne Kühler. I am very grateful to Florence House (anonym), which has been kind enough to allow me to join them as a volunteer and researcher from 2005 onwards. Sadly, over the past decade, I have known many people who passed away in the Home. My special thanks and condolences go to those and their families who remain anonymous while sharing their experiences for my PhD project. Needless to say, there are always far more people, including those living with dementia and their significant others such as family members, friends, staff, volunteers and medical specialists, who have contributed to the project. I acknowledge them first and foremost and thank them individually. At the same time, to respect the ethical protocol and confidentiality of this research, I ask to be excused from naming those who have given me company, helped, befriended, encouraged and even forgotten me as a result of their mental and physical capacity throughout this process. I cannot emphasise enough that my engagement was only possible due to their incommensurable generosity, interest and concern about me and my project. They gladly became my English teachers, friends, grandfathers, grandmothers and mentors, as I am a student, researcher, volunteer, grandson and foreigner.
Of course, my journey was not only composed of happy moments. I have acknowledged that today may be the last day I am able to talk with those living with dementia. I have painfully witnessed their gradual bodily and mental deterioration over the course of living with dementia and simultaneously I have learned about how to live with such personal, familial and social suffering with wit, smiles or tears. We not only live through but also experience such unfathomable, unpredictable and agonising illness experiences, ageing with our feelings, emotions, senses and imaginations that have continuously layered themselves upon our bodies and ‘hearts’, although some may forget or fail to retrieve them. Of course, these experiences include unwitting remarks, gestures and behaviours, which I no longer remember or have not noticed, but which nonetheless affect the formation of an atmosphere and mood. Therefore, these are not necessarily limited to human activities, but extend to nonhuman entities including the weather, the sky, animals and so forth, noticed through an attentive engagement and correspondence. I am grateful for them all. I may not attentively listen, see, smell, taste or feel them, but they are always co-presences that affect and are affected. I am constitutive of such a world, making the world I attend to.

At this moment, I must thank my supervisory team: Professor Andrew Irving and Dr Anthony Simpson. While Irving has passionately introduced new concepts and theories to me and guided my intellectual journey in a provoking and encouraging way throughout the PhD process, Simpson has always welcomed me, listening to my minute questions and curiosities beyond the intellectual. More than anything else, I wholeheartedly thank them for reading my inarticulate, unsophisticated and ungrammatical drafts with great patience and supporting my potential for further improvement. Needless to say, I thank Melissa Brakel, Noreen Akhtar and Fadumo Ali who have kindly proofread my drafts.

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INTRODUCTION: DEMENTIA THAT BECOMES CO-DWELLING

1. An Encounter with Ayla

*I do not know. I am frightened. I am very miserable. They [the care staff] will put me away. I am not allowed to refuse* (Ayla).

Ayla’s hands tremble and she blushes. Eyes lined by fine wrinkles were clear once but now become vague. She complains that the other residents are no longer friendly, elegant or sociable. They should be in a hospital rather than here in a care home (Florence House, simply the Home). Her gradual loss of memory of being in a residential room make her feel more confused, disoriented and displaced. She cannot find her valuables, nor does she have an emotional or physical attachment to her new environment. Although she tries to ring her daughter for help, she cannot get through. Since she moved to this unfamiliar place, her life has become miserable. She has lost her appetite, partially because she does not think the food tastes of anything at all and it has not been cooked in the homemade Jewish way. Putting four spoons of sugar in her tea and coffee, instead of one, reflects the loss of her sense of smell and taste. She asks the staff whether they can take her home but they say ‘This is your home’. She desperately asks the same questions of the staff again and again but they just keep writing and writing and do not listen to her voice. Staff members do not give her any hope, comfort or support.

It has been a long time since Ayla gave up wearing her glasses because they no longer fit her. Recently, she had to have eye surgery for her senile macular degeneration and cataract. Her recent fall also forced her to have hip surgery. After the surgery, her walking has become wobbly and she finds it difficult to walk without her Zimmer frame. Some teeth have recently fallen out and she no longer remembers the last time she saw her dear friends from her home community. Although she often resists and fights back against rude and unfamiliar people and her surroundings by repeatedly banging things, murmuring and yelling, these expressions bring negative feelings of hopelessness, helplessness and anxiety. What is worse, as her dementia\(^1\) progresses together with her physical deterioration, she more often experiences, and others witness her language, judgement, cognition and memory becoming fragmented and inconsistent. There is nothing she can do at the moment and there is no one for her to

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\(^1\) Although as to the new revision of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)* (American Psychiatric Association 2013), the term ‘dementia’ has been categorised under the term ‘major neurocognitive disorders’, in this study I use the former because people use it in day-to-day conversation. As an umbrella term dementia includes Alzheimer’s disease, Vascular Dementia, Dementia with Lewy Bodies, Frontotemporal Dementia, Creutzfeldt-Jakob Disease, and other rare causes of dementia such as HIV-associated Neurocognitive Disorder, Huntington’s Disease and Parkinson’s Disease Dementia.
rely on either. She feels more depressed. ‘Why me?’ she asks herself, but she does not get an answer, except from the fact that her mother suffered from depression too. She is withdrawn, crouching in the corner on a sofa, ceaselessly looking at her surroundings and listening to the world around her.

What has she lost? If her mind and self is lost, who is she? Is she normal? Over the past decade I have been involved in the Home both as a volunteer and as a researcher for this study. To my surprise, I have experienced, witnessed and learned that there is no language that denies the existence of dementia, but people perceive and understand the illness experience very differently, simultaneously altering the way they treat and care for those living with dementia. In other words, people involved in living, caring and volunteering alongside those affected in the Home have continuously challenged the taken-for-granted-concepts of loss and abnormality and practised the immanent potential of dwelling with them.

Through interweaving ethnography and continuous reflexivity, this study is an ethnographic testimony based upon my decade of involvement with the Home. More specifically, it explores how people contest and negotiate prevailing perceptions and understandings of loss and abnormality in a dementia context by critically redefining them and paving a new way of making a dementia-friendly community in care home settings. It focuses on the bodily movement, affect and sensation of those affected in relation to five different domains: ethics, repetition, time, agency and place. In doing so, it attempts to explore how an ethics of co-dwelling is embedded in everyday (care) practices not only in terms of individual biographical and medical conditions but also in terms of entangled relations and engagements with the lives of others, the policies of the Home and its surroundings. It challenges the established medical understanding of repetitive and routinised behaviours, which are managed and controlled through medical, pharmaceutical or therapeutic interventions, by revealing the minute bodily actions and responses that differentiate every repetition. It tries to illustrate the bodily expressive and transformative movements of those affected in response to the ever-changing social and physical surroundings while waiting for time and people. It critically rejects the predominant concept of agency based on a personal capacity with language, cognition, consciousness and memory, arguing that agency is a creative entanglement emerging through a collaborative engagement beyond the loss of bodily abilities and functions. It demonstrates lived experience and its transformations for those living with dementia, emphasising multiple and idiosyncratic dementia-becomings in the making of a home within the Home.
What all those research questions and motivations have in common is a fundamental doubt and critique about the ontological, epistemological and methodological basis of previous dementia studies mainly based on transcendental and relational personhood which is inherent and treated as a given (Kitwood, 1997; Buber, 2013). This calls for a shift in the approach to dementia by ‘reconfiguring the forming of dementia’ (Baldwin and Capstick, 2007, p. 17) and applying different perspectives and practices. This is a ‘transcendental empiricism’ in the Deleuzian sense (Deleuze and Guattari, 2014) that problematises established conceptions, theories and practices and seeks alternatives by continuously intersecting, inter-referring and integrating the virtual (immanent potential) and the actual (results). Here, I methodologically and epistemologically problematise dementia, based on my participatory engagement with the lives of others, the Home and the biosocial surroundings. Methodologically, this study aims to shift our attention from what dementia is to what dementia does in everyday life by applying anthropological methods of living and working together with those affected in a co-dwelling condition, rather than simply observing, interviewing and surveying. Epistemologically, this study attempts to redefine the concepts of loss and abnormality not only by drawing upon ethnographic evidence but also by revisiting the concepts of the normal and the abnormal from Canguilhem’s perspective (1998). It continues to develop in dialogue with Ingold (2011) and Deleuze’s (2004b) understandings of co-dwelling and becoming. Consequently, this study sheds new light on dementia as a becoming that continuously emerges as lives with dementia unfold in the process of encountering, interacting and responding to the immediate surroundings, revealing the potentialities of co-dwelling in a mode of reflexive ethnography. In what follows, I first explain what dementia means in relation to the perception of loss from the perspectives of Kitwood and his successors, identifying their contributions and limits and problematising ideas that need to be further elaborated.

2. What have Those Living with Dementia Lost?

(1) Tom Kitwood: Beyond Loss
Since German physician Alois Alzheimer first discovered the dramatic shrinkage and abnormal structures in the brain of his patient Auguste D. in 1906, and what was coined as Alzheimer’s disease by psychiatrist Emil Kraepelin in 1910, dementia comes into being through our medical knowledge, discourse and experience. It is true that those affected experience certain changes in behaviour, personality, language, memory and cognitive function during their dementia trajectory that are unexpectedly challenging and embarrassing for them, as well as for those who care for them. These behavioural and psychological signs and symptoms have drawn attention as
pathological markers which ought to be controlled or ameliorated through the application of biomedical, psychological and social interventions. In this sense, dementia is equivalent to loss (Brown, 2016, p. 1).

Tom Kitwood is one of the central figures in the field of dementia care, who provides us with a theoretical and practical ground for Person-centred Care (PCC) for those affected as well as those who care for them (Kitwood, 1997; Brooker, 2007; Mitchell and Agnelli, 2015). He strongly criticises such medical-centred paradigms based on the cognitive capacity of personhood, arguing that dehumanised and depersonalised care is mainly caused by the misunderstanding and confusion about what a person is. More specifically, Kitwood (1997, pp. 45-47) asserts four depersonalising care practices in terms of ‘bestialisation, the attribution of moral deficit, warehousing and the unnecessary use of a medical model’ and particularly criticises its causes embedded in our culture of care, or in what he calls a ‘malignant social psychology’. It consists of seventeen elements: treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, outpacing, invalidation, banishment, objectification, ignoring, imposition, withholding, accusation, disruption, mockery and disparagement. Instead, he redefines personhood as ‘a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being’ stressing ‘recognition, respect and trust’ (ibid., p. 8). Furthermore, by drawing upon Martin Buber’s concepts of ‘I-It’ and ‘I-Thou’ in terms of distance and relation - meaning separateness towards an object and an inseparable living relationship with Others respectively - (Buber, 2013), Kitwood re-identifies an inherent human condition that is relational and ethical.2 Perhaps the most remarkable and controversial legacy of Kitwood for me is his assurance of rementia, meaning that there could be the possibility of regaining not only the physical but also the neurological properties in the brain ‘if circumstances were favourable’ (Baldwin and Capstick, 2007, p. 16). Although his thoughts on rementia have not been further explored by other scholars (c.f. Kitwood and Bredin, 1992, pp. 278-279), his person-centred paradigm provides an invaluable conception of ‘otherness’ that sits in contrast to the prevailing perception and representation of dementia, which is one of ‘loss and tragedy’ (Baldwin and Capstick, 2007, p. 19).

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2 Although the I-Thou relation provides ethical grounds for the necessity of a meaningful relation with and care towards those affected, Kitwood shows an ambivalent attitude towards Buber’s transcendental relationship with God. It is interesting to note that despite its theoretical and practical contribution, Kitwood hesitates to concretise it because of its spiritual and religious connection with the ultimate (Baldwin and Capstick, 2007, p. 187). This is partially caused by his disowning Christian belief after returning from Uganda. Consequently Buber’s transcendental concept has not been fully developed by Kitwood and his followers.
Accordingly, he advocates a new paradigm of PCC that is relational, contextual, processual and embodied in-the-world (Kitwood and Bredin, 1992; Kitwood, 1997), emphasising the dialectical understanding between the personal, psychological, social and neurological. Later, his dialectical framework is described as an equation, D=P+B+H+NI+SP (dementia = personality + biography + health + neurological impairment + social psychology) (Brooker, 2007, pp. 47-51). He also develops an evaluating tool for day care services based on observation called Dementia Care Mapping (DCM) (1999) in association with Kathleen Bredin who initially introduced the Rogerian humanistic approach (Rogers, 1995) from which PCC originated. He extends his interests to organisational culture, publishing The New Culture of Dementia Care (1995) together with Sue Benson and his original award-winning book Dementia Reconsidered (1997). In doing so, Kitwood claims that people may finally lose their bodily abilities and functions, yet the person-centred approach argues against this claim on the grounds that people remain inherently situated in a social context, and so they continue to possess both relational and ethical agency. Since then, his legacy based on a new concept of personhood has been diversified and specialised across three different spheres: embodiment, citizenship and process.

(2) Limitations and Implications of the Legacy of Tom Kitwood

A. Embodiment

Kitwood uses the concept of embodiment to synthesise the work of the physical and the psychological beyond the mind body dualism. However, he largely relies upon ‘neurological events’, focusing on the plasticity of the brain organ - in his terms the ‘neurology of personhood’ – as, for him, the body is a mere ‘vehicle of expression’ (Kitwood, 1997, pp. 16-19). Recently, many scholars have critically developed Kitwood’s concept of personhood by elaborating his understanding, which is considered ‘necessary but insufficient’ (Phinney and Chesla, 2003; Kontos, 2005; Baldwin and Capstick, 2007, p. 183; Kontos and Martin, 2013; Hughes, 2014). They claim that personhood is socially constructed (Sabat and Harré, 1992; Herskovits, 1995) and experienced ‘in and through’ the lived body (Baldwin and Capstick, 2007, p. 183). The former emphasises the very existence of the self from diverse philosophical perspectives, such as from those of Descartes, Locke, Hume, Kant, Merleau-Ponty, Parfit and Wittgenstein (Sabat and Harré, 1992; Sabat, 2005b). Criticising the traditional concept of cognitive ability-centred personhood which is characterised as conscious, rational, reciprocal and communicable, they redefine personhood as applicable to social beings within a personal, social and environmental context (Hughes, 2001; Davis, 2004). Accordingly, this social constructionist perspective highlights that bodily deterioration is not just caused by the neuropathological but rather by the ways
those affected are perceived, understood and treated (Sabat and Harré, 1992; Hughes, 2001; Woods, 2001; Hughes et al., 2006). Furthermore, they not only demonstrate how the lives of people with dementia can be extended through a psychosocial and spiritual lens but also provide philosophical and ethical grounds for treating them as human beings with intrinsic value and dignity.

Developing social constructivist perspectives, a substantial body of work sheds new light on the lived experience of an embodied self with dementia by interweaving phenomenological understandings of the ‘lived body’, ‘embodiment’ and ‘intersubjectivity’ (Csordas, 1990; Taylor, 1992; Merleau-Ponty, 2002) with Pierre Bourdieu’s concept of ‘habitus’ (1984). This phenomenological paradigm contributes to revealing those bodily abilities that remain intact, in particular, bodily memories that are pre-reflective and embodied and which otherwise remain silent. Such pre-conscious bodily movements, which have been biographically and socio-culturally sedimented within, and through, the body provide a singularity of subjective illness experience. This approach shares Kitwood’s understanding of a person who ‘is still an agent, one who can make things happen in the world, a sentient, relational and historical being’ (1993, p. 541).

While Hughes (2001; 2011) contributes to developing the concept of the embodied self, Kontos and Phinney extend this person-centred model in practice, where the embodied self is embedded in the lived world and experiences through the lived body. In particular, Kontos pushes this concept further into day-to-day illness experience, revealing intact skills and abilities within arts-making (Kontos, 2003; 2014; Dupuis et al., 2016) and narrative (Kontos and Martin, 2013) and a remaining embodied selfhood (Kontos, 2004; 2005; 2006b). Above all, she attempts to overcome the limits of the biomedical gaze by criticising ways of looking at ‘disease as a physical entity’ (Carel, 2016, p. 51) and regarding the body of social actors as ‘inconsequential’ (Kontos, 2003, p. 159), like the mere ‘self-in-society perspective’ (Turner, 2008, p. 62). Instead, she stresses that ‘selfhood is embodied and characterised by an observable coherence and capacity for improvisation that is sustained at a pre-reflective level by the primordial as well as the socio-cultural significance of the body’ (Kontos, 2004, p. 831).

In brief, this social constructive and phenomenological lens offers a subjective account of an abstract “objective” reality, namely lived experience that reveals the ‘reality of illness’ experience (Toombs, 1987, p. 236). As within Merleau-Ponty’s concept of ‘body memory,’ a person’s lived experience is ‘mediated’ by and then ‘sedimented’ in the body throughout one’s lifetime and these reservoirs play significant roles as ‘implicit predispositions’ (Fuchs, 2011, p. 69). In addition, these are not merely private activities
but ‘intercorporeal’ and ‘intersubjective’ practices rooted in specific socio-cultural, political and historical contexts (Csordas 2008). Namely a person living with dementia is ‘still’ a human being as ‘the situated embodied agent’ (Hughes, 2001, p. 87; 2011, p. 227) that reflects the very nature of ‘embeddedness’ and ‘embodiment’ of human experience in a particular time and space (Hughes, 2001, p. 89). However, although this perspective contributes towards a rescuing of the remaining intact bodily functions and abilities, it stays silent towards the loss, which is still regarded as a pathological and negative side effect.

**B. Citizenship**

Despite the increasing recognition of a personhood that is relational, embodied and ethical in a social context, the way in which the dementia illness experience is perceived, approached and understood in relation to a broader social, political and environmental context has been less developed. Criticising Kitwood’s ‘apolitical concept’ of personhood, a new perspective based on (biological) citizenship has paid more attention to issues such as the power dynamics of daily experience and social inclusion (Baldwin, 2008, p. 223; Rose, 2009; Bartlett, 2010; Brannelly, 2011a; 2016; Baldwin and Greason, 2016). While Kitwood’s personhood recognises the intrinsic value of a person with dementia, his approach pays less attention to the social issues, such as the influence of familial structures, age, gender, class and ethnicity (Bartlett and O’Connor, 2007). Above all, the personhood perspective has been criticised on the grounds that persons with dementia largely remain the receivers of care services rather than capable persons with power and agency. Although we have to some extent successfully made people living with dementia subjects in care and research, they are still treated as Others different from those without dementia. Often this results in their prevention from participating in day-to-day engagement with society and research projects. In fact, they are often regarded as people who express their feelings, suffering and emotions but are not necessarily considered co-producers of the formation of society with the same rights (Bartlett and O’Connor, 2007; Bartlett, 2010; 2014a; 2014b). In other words, being a citizen is not inherently and automatically conferred on them in reality, but experienced, practised and recognised by their engagement and participation in broader society.

Accordingly, a growing body of research shifts the paradigm of concern from whether or not they have personhood (Davis, 2004; Hughes, 2001) to ‘how to maintain personhood’ (Bartlett and O’Connor, 2007, p. 114) and more fundamentally ‘how the issues of capacity and competence influence how one views oneself’, namely within ‘decision-making’ (Sabat, 2005a; Hughes and Baldwin, 2006; O’Connor and Purves, 2009, p. 15; Elliott et al., 2009; Boyle, 2013a; 2013b; Miller et al., 2016). By integrating
the concept of (biological) citizenship into dementia practice and research, the focus of this perspective has evolved from the (transcendental and ethical) status of being to social practice. The former recognises citizenship as a bestowed property ensuring all people have equal rights and responsibilities and thus rightfully concerns itself with any discrimination toward those affected, for example, inclusion/exclusion criteria for accessing surgical services (Graham, 2004), social and spiritual life (Manthorpe et al., 2004) and democracy (Sonnicksen, 2016). However, this citizenship perspective is criticised because such unfair practice is deeply ‘entrenched’ and ‘embedded’ in our social, political and even personal life, making it difficult to recognise and change (Baldwin and Greason, 2016, p. 290).

Meanwhile, citizenship as a practice pays more attention to the ways in which people living with dementia are facilitated in care and social activities (Brannelly, 2011b; 2016); hindered by negative perceptions (Behuniak, 2011); how they participate in social and political movements as active citizens (Sabat, 2003; Brannelly, 2011a; Bartlett, 2014a; Dupuis et al., 2016); and express their needs (McColgan, 2005) in the course of daily practice. Proposing the notion of ‘narrative citizenship’ Baldwin (2008) demonstrates that persons with dementia continuously contribute to forming the world by making their own narrative as well as by shaping ‘the narratives of others’ as ‘joint authors’ (Baldwin and Greason, 2016, p. 297). Nikolas Rose draws attention not only to the public but also to academia in terms of his idea of ‘biological citizenship’ based on the human gene and pathology in the study of dementia. He argues that ‘there were simply “not enough genes” for the sequence to be regarded as a “code of codes” or the digital instructions for making a human being’ (Rose, 2009, pp. 70, 76). Most importantly, as he shows, diagnosis and knowledge of genetic dementia do not lead those with the likelihood of being affected with dementia to be passive, but to active forms of biological citizenship through participating in research funding, political campaigns and other associations.

A significant shift has also been made in the research process in that those affected are no longer perceived as mere objects of research but as collaborators who actively engage in research throughout the process (Wilkinson, 2002), for example through creative methods such as walking (Phinney et al., 2016; 2016) and the arts (Dupuis et al., 2016). Furthermore, much recent research highlights decision-making, in particular when capacity fluctuates or is no longer validated, questioning the ways in which those affected engage with care and daily activities (O’Connor and Purves, 2009), particularly in consideration of couples (Boyle, 2013a; Boyle, 2013b) and the family (Elliott et al., 2009; Miller et al., 2016) and through representatives (Jox et al., 2012).
In brief, people with dementia become significant not just because of their social, economic and political concerns, but also because of their contribution to making social change and to forming narrative and society. Similarly, a recent campaign for building Dementia-friendly Communities, in association with the British government and the Alzheimer’s Society, provides a platform where those affected can ‘have high aspirations and feel confident’ by acknowledging and empowering their potential contribution to, and participation in, society (Alzheimer’s Society, 2013, p. 41). Further research regarding the way in which those affected dwell in communities would be worthwhile.

C. Personhood as Process
Not only those affected but also those who care for them experience complicated and dynamic transformations during dementia trajectories in terms of role, relationship, illness process, identity, and perception of dementia. In this respect, Kitwood’s theory has continued to be elaborated over the past three decades.

Davis and his colleagues (Davis et al., 2011) describe paradoxical familial concerns and guilt caused by the inability to care for kin with dementia, losing their personhood and their previous relationships throughout the dementia trajectory. Based on an interpretative phenomenological approach, Nowell, Thornton and Simpson (2011) identify the ways in which those affected respond and react to their worldly surroundings from their own perspective. Drawing upon the concept of liminality, the dynamic transformative experiences of those affected as well as those who care for them are highlighted, focusing not only on their emotions (Kelly, 2008), but also on their positions, roles and responsibilities from the perspective of subjective experience (Shomaker, 1989) and family caregiving (Gibbons et al., 2014). In addition, this procedural lens allows researchers to explore the dynamic process of how those affected as well as those who care for them negotiate and adjust their transformative personhood, roles and responsibilities (Adams, 2005; 2006; O’Connor and Purves, 2009), illustrating the transition from home to care homes (Paddock, 2015) and from hospitals to homes (Plank et al., 2012).

It is interesting that although these studies shed new light on the changing experiences of illness and care, their analyses fail to illustrate the transformative process of change. This is mainly a result of the methods of collecting data and analysis that are based on phenomenological and interpretive approaches and secondary data collection, such as surveys and interviews (Adams, 2006; Davis et al., 2011; Nowell et al., 2011; Plank et al., 2012; Gibbons et al., 2014) rather than participatory engagement (Kelly, 2008). Furthermore, dementia as loss is still to some extent embedded in this social
phenomenon. Despite these limitations, the aforementioned previous studies and approaches contribute to reshaping the concept of personhood to one that is neither given nor fixed, but which emerges in the process of engaging with the lives of others, things and the surroundings.

(3) Not Beyond Loss but Along with Loss
Kitwood’s legacy on personhood has been elaborated over the past three decades through social constructive, phenomenological, political and procedural perspectives. It is true that the introduction of the theme of personhood has contributed to bringing those living with dementia to the centre of the study of dementia, highlighting their subjective experiences from their own perspectives. They no longer remain mere objects for medical treatment and research but become subjects, making their own voices heard. For example, the embodied and narrative self opens up a new territory where those affected still participate in the making and remaking of their own stories as well as contributing to the stories of others. More importantly, this perspective on personhood has provided the driving force for shifting the culture of dementia care from task-oriented to person-centred by providing the hope, though controversial, that those affected can to some extent recover from loss, if the conditions of care are met. Accordingly, it offers a substantial body of research, stressing that the relation between neurological deterioration and individual subjective illness experience is not a simple causal relation but is much more complex (Rose, 2009). Individual illness experience is not solely determined by pathological loss but also by dialectical relations between the personal, social and the environment in a given time and situation (Kitwood, 1997). Consequently, this personhood lens has supported the development not only of medical knowledge about the cause, diagnosis, treatment and process of dementia but also of other medical, therapeutic and environmental interventions, including assistive technologies (Bartlett and O’Connor, 2007).

The person-centred approach is extended to other people and is community-oriented, demanding a person-directed, relationship-centred and becoming-centred perspective. According to the Dementia Care Mapping-based audit for PCC over the past three decades, there is currently a considerable disparity between theory, policy and practice (Martin and Younger, 2001; Elaine, 2012; Colomer and de Vries, 2016). The findings show that notwithstanding remarkable improvement in the quality of care and life for those affected, the shortage of staff training and communication between the institute and staff is commonly reported. Above all, contrary to Kitwood’s theory and expectation, people practice PCC not in a person-CENTRED way, but a PERSON-centred way, demanding more realistic relational and interpersonal approaches which include
staff and families (Greenwood et al., 2001; Sutton, 2003; Nolan et al., 2004; Brown Wilson, 2009; Sellevold et al., 2013). Needless to say, the concept of personhood itself is still controversial and disputable due to its ambiguous and multiple implications depending on cultural and philosophical traditions (Higgs and Gilleard, 2016). As Graham points out (2015b, p. 7), the person-centred approach is fundamentally an ‘outside-in perspective’ and thus PCC varies depending on the perspective of personhood. Due to this reason, Power (2010; 2014) alternatively suggests a ‘person-directed’ approach based on a person’s direct expressions and perspectives.

Above all, despite different approaches and perspectives, what they all implicitly share is a perception and hope that those affected could revitalise and regain intact and ‘remaining agentive abilities’ through a range of dementia-friendly approaches and practices, and by living in environments ‘beyond loss’ (Hydén et al., 2014, pp. 1-7). However, I argue that this is a paradox in the legacy of Tom Kitwood on the grounds that it blinds us to seeing the value of the other side of loss. It calls for a reconsideration of loss that is not merely pathological but a differentiating force that continuously brings something into being through the process of everyday illness experience. In the following, I attempt to reconceptualise ‘the normal’ and ‘the pathological’ in dialogue with Canguilhem’s understanding so as to rethink dementia not as loss, but as a becoming that is essential and constitutive of life.

3. Are Those Living with Dementia Normal?

I am never half full or half empty, I am always me. And I can never be accurately characterized as having observable, distinct, and mutually exclusive levels of anything with me... I am always becoming, always resisting, always embracing and always influenced by my past (Taylor, 2007, p. 106).

As Richard Taylor, a retired psychologist with five years’ experience of living with Alzheimer’s disease, claims, the current understanding of dementia does not embrace the ‘half empty’ in our bodily functions and abilities, which is that of loss. What makes Taylor’s remark invaluable to me is his way of problematising dementia. One of the main problems we face today does not merely include identifying the cause, condition and features of dementia but is more importantly about ways of perceiving, approaching and understanding. He insists that in order to improve the quality of care and lives of those affected we need to change our perspective, and that invites us to rethink loss not as something you have but as co-dwelling; not as a noun, but as a verb: becoming. In fact, people living with dementia do not just have dementia, but feel, suffer and endure through their bodies as others do. Here we witness how deeply such a taken-for-granted attitude is embedded into our value judgements, medical
knowledge and epistemology, implying that loss needs to be excluded, controlled and managed because of its abnormality. It is not surprising that we often confuse ontology (what dementia actually is) and epistemology (a way of seeing what dementia is) (Baldwin and Capstick, 2007, p. xix). Consequently, it raises ontological and epistemological questions concerning what is normal (what is lost) and what makes the normal normal or abnormal (what make loss abnormal). It problematises how biology forms the social, and vice versa.

In his *The Birth of Clinic* (2012) Michel Foucault asserts that the advent of a new medical experience and its transformation of the epistemological horizon have evolved in line with the development of medical knowledge (particularly, modern pathology) and the medical gaze. In his view, the birth of modern medicine is neither pre-designed nor publicly agreed, neither led by a collective consciousness of clinicians nor motivated by the discovery of new medical knowledge. Instead, it is driven by what Foucault calls ‘episteme’, that is to say, ‘historical a priori’ (Foucault, 2005b, p. 172) which is the unconscious and immersive knowledge and its discourses within a particular historical time. More specifically, episteme grounds ways of articulating, defining and classifying illness experience and thus reveals the possible existential condition of disease in any given epoch (Foucault, 2005b). In this sense, it is possible that a doctor diagnoses and treats the same disease differently according to an epistemic shift, or various epistemes simultaneously exist, contest and negotiate in the process of forming knowledge/power system. This is the reason Foucault uses ‘birth’ in the title because ‘the clinic’ emerges in the process of acknowledging meaning and the value of its experience.

Meanwhile, with modern biomedical reductionism based on Enlightenment thought and Cartesian dualism, the dehumanised ‘medical gaze’ comes into being in the 19th century onwards (Foucault, 2012). The arrival and accumulation of modern medical technologies and tools, such as pathological autopsy, physiology and the stethoscope, even allow medical doctors to identify the inner states of their patients. This results in objectifying the human body as a thing rather than a living being, and ignores subjective illness experience. Yet, as Drew Leder states, the Cartesian body does not clarify the essential difference between ‘lived body’ (*Leib*) and ‘inanimate or dead bodies’ (*Körper*), nor can it capture lively experience by using Cartesian language and concepts (1992, p. 122). Furthermore, from the personal level, illness experience is to some extent ambiguous. For example, as Robert Francis Murphy points out, the body frequently seems to be ‘forgotten’ and to ‘disappear’ (2001, pp. 111-112). It is often felt as ‘dis-embodied’ and even ‘concealed’ from lived experience until bodily dysfunction is explicitly exposed (Leder, 1990, p. 22). Likewise, dementia is not just a
disease of the physical brain, nor is it the breakdown of psychosocial processes. Even
the ‘dementing’ brain is not separate from the rest of the corporeal body, but its
functions are exposed through the entire body (Phinney and Chesla, 2003). It calls for a
concept of ‘lived experience’ (Merleau-Ponty, 2002). Namely, the lived body is ‘bound
up with, directed toward, an experienced world. It is a being in relationship to that
which is other: other people, other things, an environment’ and that ‘helps to
constitute this world-as-experienced’ (Leder, 1992, p. 123) even though frequently we
do not recognise this due to its feature of ‘present-absence’ (Leder, 1990, p. 21). As
Ernest Becker says, the person is both a self and a body that is porous and interactive
while existing beyond the ontological mind/body dualism (1973, pp. 41-42).

It is ironic that as modern medical technology evolves, the modern pathological
approach encounters a new form of individual living being that emerges in the process
of coping, enduring and suffering disease. In other words, in contrast to the nosological
approach of the 18th century, in which individuals are always treated as identical, the
individual is no longer a static entity but constantly interacting with their immediate
surroundings, being affected and affecting throughout the course of a life. Needless to
say, even sick persons continuously attempt to integrate this living force within their
abilities and capacities; that is the logic of life (Foucault, 2005b). Here we encounter a
dynamic and complicated relationship between disease and life, in which disease takes
place in the course of life; disease is a ‘pathological form of the realisation of life, or as
life’s pathological form’ (Raffnsøe, 2003, pp. 23-24). The pathological is, as it were, a
part of life which cannot be isolated or separated from the social, environmental and
historical, as the way it is in-the-world. Accordingly, pathology can be defined as a
discipline that finds, treats and recovers abnormal bodily functions as identified by
physiology. However, this concept of the pathological implies a negative sense of
something in life being abnormal, anomalous and deteriorated. For the same reason, I
am opposed to Phinney and Chesla’s proposal that dementia should be seen as a mere
‘breakdown of a deeply embodied sort,’ although they acknowledge that dementia is
not just ‘loss’ of cognition, language, memory resulting from the deterioration of
bodily functions (2003, p. 296).

It is worth noting here the work of Georges Canguilhem, On the Normal and the
Pathological (Canguilhem, 1998) that demonstrates a positive relation within the
‘dynamic polarity of life,’ that is between the normal and the pathological, between
physiology and pathology and between the biological and the social. Considering our
fundamental body mechanisms, the pain, suffering and feeling of illness and disease
make the development of medicine, therapy and therapeutic techniques possible by
informing the necessity of treatment and the process of retrieval. Within the context
of nosology in the 18th century, the purpose of medical and therapeutic treatment was to return to the normal. These were norms that were already established as a universal standard. Whereas within the epoch of pathology in the 19th century and early 20th century, disease and medicine are inseparable from the individual due to their diverse, complicated and different medical tolerances, resilience and endurance. In this process, Canguilhem becomes aware that medicine requires us to integrate the individual, their environment and social relations because the individual body constantly redefines, re-establishes and re-attunes its bodily condition in response not only to its own bodily condition but also to its biosocial surroundings. The relation between the normal and the pathological, between biological norms and social norms, and between the natural and the social are mutually constitutive by engaging with each other in the formation of life (Canguilhem, 1998; Foucault, 2005a; Das et al., 2014, p. 16).

Consequently, Canguilhem assures us that being healthy does not just mean being normal, in that the former refers not only to the state of being able in a given situation, but also to the ability to endure the given, and upcoming situation, and at the same time to establish a new state of normality in a new situation (Canguilhem, 1998, p. 130; Raffnsøe, 2003, p. 29). Disease indicates the reduced ability to cope with life challenges by way of losing bodily tolerance and a vital life force, yet at the same time it also signifies continuous interactions and reactions within bodily functions and abilities. From this understanding, life is in a constant state of becoming, establishing new forms of the normal in response to ever-changing circumstances, what Canguilhem calls ‘normativity’ (1998, p. 127). Therefore, the conception of disease is defined as ‘the capacity to set new norms for oneself more adequate to the loss one has borne’ (Das et al., 2014, p. 16). Disease is ‘an integral part of life; perpetuating life, forcing it to come to further expression’ (Raffnsøe, 2003, p. 30). Life is inherently with loss and loss is essentially constitutive of life.

In brief, Canguilhem’s perspective would be remarkable enough on its own. From his perspective, dementia and even death become an essential constitutive part of life, allowing us to express the individuality of those affected by making and remaking ourselves in the process of suffering, enduring and attuning. Accordingly, I strongly disagree with seeing and dealing with illness experience as a malignant or harmful phenomenon, arguing instead that loss is another way of life in the form of the pathological, which is often unpredictable, uncontrollable and unavoidable. It offers a new perspective that allows us to explore dementia as a new form of life in a mode of co-dwelling beyond the dualism between the normal and the pathological, between the individual and the social, and between biology and the social. It calls for shifting
questions from what it means by living with dementia to what life with dementia is becoming in the condition of co-dwelling.

4. Becoming-dementia as a Way of Co-dwelling

The understanding of normativity is an essential feature of dementia in that loss is fundamentally a part of life emerging in the process of attuning health within the bodily condition and abilities without damaging the significance of loss itself. In dialogue with the works of Julian Hughes and Tim Ingold, in this subsection, I demonstrate that dementia is already and always immersed in our life as a form of co-dwelling. Consequently, I argue that the interactions and encounters I have experienced over the last decade should be considered in the context of a co-dwelling that is situational, relational, ethical, generative, reflexive and improvisational.

(1) Co-dwelling

Hughes develops the concept of a ‘dementia-in-the-world’ (2011, p. 215) that is inherently relational, situational and caring, reflecting Heidegger’s concept of ‘being-in-the-world’ (2010). He is particularly interested in revitalising Heidegger’s notions of ‘being-with’ (mitsein), ‘taking care’ (besorgen), ‘concern’ (fursorge) and ‘care’ (sorge) on the grounds that humans ‘thrown’ into the world are vulnerable and anxious and thus are required to care for themselves and others (Hughes, 2011, pp. 215-219). Likewise, acknowledging such a human ontological and existential condition, he asserts that persons with dementia are intrinsically vulnerable and thus demand the need for care and concern based on their transcendental situatedness in-the-world. More importantly, he points out that the fundamental reason for those affected being alienated and estranged from society is not the value of the human itself but the way in which we perceive, understand and approach dementia. Alternatively, he suggests that we need to reflect ‘worldly embedded practices’ that embrace ‘normativity as a constitutive, immanent, and irreducible feature’ of being-in-the-world by developing our existential condition of this from a realistic ‘human-person-perspective’ (Hughes, 2011, pp. 227-228). In other words, our perspective reflects our values and concerns within the particular historical time and culture we partially share and, at the same time, we shape the world by engaging with the experiences of others. In this sense, we are co-producers of the formation of society and co-authors of narratives from the perspective of ‘the situated embodied agent,’ although there are always different intensities and capabilities of participation and involvement (ibid., p. 227).

From this understanding, it is reasonable to say that dementia experience reflects our perspective of personhood. In other words, in Graham’s words, personhood embraces ‘the personal, relational, existential and the moral as embodied day-to-day negotiation.
of self’ (2015b, p. 7). That is to say, dementia experience is always and already enmeshed with the lives with others, things, and the surroundings in a form of co-dwelling. Here, the term *co-dwelling* thus implies the situated, relational and ethical features of dementia which are embodied in bodies and embedded in-the-world. It allows us to explore dementia in a more inclusive context where those affected engage in and with their worldly surroundings.

While Hughes’ human-person-perspective offers the philosophical and ethical grounds by which to explore dementia, *co-dwelling* also signifies the generative ontological features of people living with dementia-in-the-world. It is particularly worth noting the work of Tim Ingold, who extends the concept of dwelling to a ‘dwelling perspective’ in which all beings are invited to ‘a world that is inhabited by beings of manifold kinds, both human and non-human’ (2000, p. 5). His perspective allows us to understand not only the social but also other modes of living, things and the physical environment in an ecological system. Animal life and the natural environment are never predetermined, nor isolated from human life, but they emerge in the process of interaction and engagement with the worldly, particularly human surroundings. While Hughes adopts a human-person-perspective, Ingold extends his concern to the ecological, attempting to integrate the biological and the social (Ingold and Palsson, 2013). What is invaluable to me in Ingold’s work is his critical development of the concept of lines of movement and lines of becoming in dialogue with Heidegger’s notion of *dwelling* (1971), Jakob von Uexküll’s notion of the *Umwelt* (1982) and Deleuze’s concept of *becoming* (1983). I trace his approach in order to understand its relevance within dementia.

Following Heidegger’s footsteps, Ingold explores the etymological origin of dwelling. Dwelling is *wuon* in Old Saxon, *wunian* in Gothic, and *bauen* in German, which means *to build*. In his essay ‘Building Dwelling Thinking,’ (without commas), Heidegger demonstrates the essential fluid relations among being, building, dwelling and thinking and Albert Hofstadter, who translates the book *Poetry, Language, Thought* into English, summarises in his introduction:

*Bauen*, to build, connects with *buan*, to dwell, and with *bin, bist*, the words for “be.” Language tells us: to be a human being is to be on the earth as a mortal, to dwell, doing the “building” that belongs to dwelling: cultivating growing things, constructing things that are built, and doing all this in the context of mortals who, living on earth and cherishing it, look to the sky and to the gods to find the measure of their dwelling (Heidegger, 1971, pp. xiii-xiv).
Heidegger continues that ‘if man’s [sic] being is dwelling, and if man must look to the way the world fits together to find the measure by which he can determine his dwelling life, then man must dwell poetically’ (ibid., p. xiv). In this way, he revitalises the forgotten meanings rooted in the word ‘dwelling’ which include not only constructing, cultivating and building but also maintaining and caring. Regarding Heidegger’s contribution to the study of dementia, what is remarkable to me is that he regenerates the term ‘dwelling’ as an ongoing poiesis within the human condition or as an ‘ongoing poetic journey’ that is extended from the ancient Greek poiesis (Worley, 2001, p. 12). Such ‘poetic or creative dwelling is being-in-the-world in such a way that as part of that world one is intimately intertwined with and concerned for it and its constituent parts’ (Zigon, 2014, p. 757). In doing so, Heidegger advocates that life is always immersive in dwelling-in-the-world and at the same time all possibility of ontological existence is open. The uncertainty, ambiguity and unpredictability of the present and the future become an embedded condition of co-dwelling.

Based on Heidegger’s concept of dwelling, Ingold attempts to synthesise von Uexküll’s thought on the Umwelt and Deleuze’s lines of becoming. His dwelling perspective offers an ongoing creation, a building of creative care that invites us to live in poetic dwelling. The term Umwelt is particularly useful to link to the dementia context in that every creature has their own subjective world that no other can easily access. He cites von Uexküll’s spider’s web, in that the spider can intersect with the life of the fly through the web, yet the spider does not know the fly’s world (Ingold, 2011, p. 79-80). In the same manner, the partial understanding of the lives of people living with dementia remains unfulfilled and thus our intersubjectivity and mutuality remain unfulfilled, requiring continuous interaction and encounter with them in an ethical and empowering way.

(2) **Resonance: Beyond Words**

This partial understanding raises a fundamental question of how to communicate with and understand people living with dementia when their language, reasoning and memories are compromised during the dementia trajectory. Do we, as anthropologists, need a particular fieldwork method to communicate, or a new epistemology to interpret and understand? How do we guarantee we are able to know the way in which those affected experience the illness?

In his essay, “‘From the Native’s Point of View’: On the Nature of Anthropological Understanding,’ Geertz (1974, p. 30) strongly rejects the knowableness of others through the psychological and perceptual perspectives, insisting that what the ethnographers perceive is ‘what they perceive “with,” or “by means of,” or “through,”
or whatever word one may choose.” Instead, he suggests the ethnographers need to regard culture, as well as human behaviours as text to be interpreted through, what he calls ‘thick description’ (Geertz, 1973, p. 6). Yet, despite his contribution to revealing the ‘dangers of ethnocentrism and projection of one’s own feelings and experiences’ onto research subjects, his method is also deeply embedded in ‘the European or North American-like view’ which considers cognitive, emotional and sensory ways of perceiving and knowing as separable and even hierarchical (Hollan, 2008, p. 478). More fundamentally, his approach is based on symbolic and interpretive understandings of expression as almost impossible in a dementia context when language is compromised.

Wikan further explores the limitations of Geertz’s anthropological knowledge-making based on thick description and symbolic and interpretive analysis in ‘Beyond the Words: the Power of Resonance’ (1992). She rebuts the idea that people do not (or cannot) always express what they feel and want to say, either because it would be socially and morally improper or they do not know how (or lose the capability to) respond. Needless to say, silence is no less complex, meaningful and expressive than spoken words. It does not mean, however, that descriptive ethnography is wrong but acknowledges that we pay less attention to other possible ways of exploring, while intensifying ‘the felt, embodied aspect of empathy’ (Hollan, 2008, pp. 479-480). Accordingly, Wikan asserts that in order to understand others we, as ethnographers, need to try to:

[r]efine our ways of attending, thus better to grasp what people are up to, their multiple, compelling concerns, and what is at stake for them, against a backdrop of the social relations in which they are engaged, and the resistance life offers to them (Wikan, 1992, p. 467).

That is to say, she calls for ‘learning to attend’ to the world surrounding us through an on-going ‘painstaking engagement’ with people in everyday social life, what she calls ‘resonance’ that is neither ‘field technique’ nor ‘epistemology’; rather referring to it as a ‘down-to-earth concept grounded in practical action’ (ibid., p. 471), seeing it as ‘an ongoing intersubjective process’ (Hollan, 2008, p. 480).

Furthermore, Wikan’s concept of resonance can be extended beyond human relations and activities. Considering Ingold’s ‘constitutive acts of dwelling’ (2000, p. 195), landscape as well as other non-human entities do not just incidentally or automatically exist in our perception, but continually resonate with one another. From the perspective of dwelling people, as well as things, weather and atmosphere are ‘neither given in the world nor placed upon it, but emerge within the self-transforming
processes of the world itself’ by ways of affecting and being affected (Ingold, 1993, p. 169). In this sense, what one does ‘is not action as such but experience, and to enact an experience’ makes it ‘something one undergoes, and yet this undergoing is active and not passive’ through attentive ‘correspondence’ (Ingold, 2017, p. 16).

(3) **Becoming-dementia**

Problematising the taken-for-granted perceptions and understandings of loss and abnormality, I have critically developed and proposed dementia as an immanent condition of co-dwelling through perpetual attentive resonance and correspondence. It is a corollary that this understanding calls for critical reconsideration of Kitwood’s essential features of human relatedness that are ‘given’ as ‘a status’ in relation to one another (Kitwood and Bredin, 1992, p. 275). It emphasises that as the loss of the adaptive, personal, physical and social is progressive, the person with dementia deteriorates and becomes vulnerable, yet the given social relations offer a moral ground for humanistic relational care with dignity by improving (or maintaining) quality of life and by preventing further deterioration based on remaining abilities (Brown, 2016, p. 2).

However, although Kitwood’s notion of personhood is relational, it is too static and only reflects a bestowed dimension upon those affected. In other words, it does not sufficiently reflect the dynamic relations and processes of being bestowed and bestowing personhood. Consequently, Kitwood’s personhood makes the person living with dementia more dependent on those who care for them. Yet, as Ingold’s relational and dwelling model of personhood shows, ‘persons are continually coming into being – that is, undergoing generation – in the course of life itself’ (Ingold, 2000, p. 142), implying that life is not only determined by genealogical attributes, but rather emerges in the process of continuous engagement at the level of the biological as well as the social (Ingold and Palsson, 2013; Brown, 2016). Needless to say, as dementia develops, those affected become more vulnerable, yet are continuously transformed across time whilst acting and responding to their immediate surroundings. At the same time, relationality does not mean belonging to someone. It does not exist in the state of ‘being’, but always in the middle.

In this moment, from the perspective of the person living with dementia, resonance allows them to embrace not only the human emotional, affective and empathetic dimensions of social life, but also captures the different temporalities and modalities of the constituents of the world in which one dwells. That is the ‘lived reality’ (Mol, 1998, p. 275) those affected actually experience, no matter how minute, and no matter how confused. The life lived with dementia consists of continual bodily
expressive movement and action in response to the ever-changing surroundings by orchestrating perception, affect, bodily practices and socio-cultural expectations. Likewise, the identities of those affected, even after death, still reside in-between related individuals, things, and physical environments in the mode of the ‘postmemory, postlanguage self’, reflecting ‘the plasticity of identity’ (Brown, 2016, p. 6).

In this sense, using Ingold’s term, they are wayfarers whose lives are fundamentally ‘lines of movement’ continuously resonating with and corresponding to worldly surrounding within their bodily abilities and functions, generating ‘lines of becoming’ (Ingold, 2010a, p. 4; 2011). Here, again, the wayfarer does not just move through the world but continuously engages and interacts with the world through their bodies, through feeling, sensing and moving which is creative, relational and improvisational. A sensing, experiential and affective being, which is a situated and embodied being-within-the-world, actually and always exists in the process of becoming. In this respect, Ingold’s concept of wayfaring provides an insight of becoming within the study of dementia through movement, sensation and affect; what I call ‘becoming-dementia’.

(4) Becoming-researcher
The term co-dwelling indicates that I also play a role not as a mere observer, but as a co-producer and constitutive member of the community of the Home by directly and indirectly engaging with the lives of residents, the Home and its surroundings. Fundamentally, anthropological intervention cannot be realised without interaction and engagement with research subjects in a specific time and place. This signifies that I am continuously affecting and affected throughout the research process. In contrast with laboratory experiments, it is impossible for anthropologists to isolate, disconnect and distance themselves from the people they study. Frankly speaking, I am often perceived as one and multiple in the Home. My identity varies depending on residents’ familiarity and memories of me, ranging from being a student, a volunteer, staff member or grandchild to being a foreigner. My identities, as well as those of others, are transformative in the process of everyday interaction and encounter. They are continuously co-presented and negotiated in day-to-day practice. Above all, I find that I do not wish to do research in order to discover a truth, nor do I approach my research subjects just by ‘following the flow of people, following the things, following the metaphor, following the story, following the life and following the conflict’ as George Marcus says (1995, pp. 97, 106-110); rather I realise that I continuously familiarise and engage with the lives of residents and significant others by talking, doing and learning.

3 Here, significant others refer to those dwelling with people with dementia, such as staff, family members, consultees, volunteers and friends.
Moreover, I notice that I reflexively integrate my personal experience into the research and the research also becomes my life. It is a ‘meshwork’ of entangled and entwined lines of life and research (Ingold, 2011, p. 83). My field notes become my diary and vice versa. I cannot isolate myself from the reality that I describe in my ethnography.

5. Outline of Chapters

This ethnographic study consists of six chapters exploring becoming-dementia as an immanent condition of co-dwelling, and aimed at providing anthropological ways of thinking and conducting practice. Each chapter deals with ordinary encounters with becoming-dementia, particularly focusing on ethics, repetitive behaviours, time, agency and emplacement. In doing so, they suggest new possibilities and potentialities for thinking and dwelling with people living with dementia alongside its limits and implications.

I begin with a brief portrait of those living with dementia in care facilities in the UK, focusing on British Jewish people, followed by a history of the institution and my research design. I demonstrate the way in which the institution has managed its complex, relational and dynamic transformations alongside its stable and routinised repetitive activity. In doing so, I highlight the transformative forces and processes of the institution, stressing the performativity of the dynamic and procedural features of institutional routines.

In Chapter 2, I provide insight into the ethics-in-practice within the co-dwelling condition that allows us to explore the complexity, ordinariness and relationality of the ethical dimensions of daily life. Beyond the normative ethics of how we should live, work and research, I engage with the lives of others to look at the way in which people dwell, suffer and endure their lives. The findings are notable in that ethics emerge through striving to make relations, connections and networks with one another in the name of family, carer and friends and in the form of love and care.

In Chapter 3, I challenge the established perception, perspective and understanding of the repetitive behaviours of those living with dementia, particularly focusing on the affective and sensory dimensions of having breakfast. Drawing upon Deligny and Deleuze’s cartographic approach and microanalysis, I trace residents’ individual itineraries from their own room to the dining room and the way they have meals. The findings show the singular mode of lines of movements and gestures that are closely related to their own sensory and affective dimensions of experience in the formation of subjectivity.
Chapter 4 attempts to reveal the multiple and heterogeneous subjective experiences of waiting in a communal area by enunciating minute bodily responses and expressive action and enactment. By unveiling dynamic interaction and communication among those engaged in waiting, I argue that waiting is not wasteful but generative. Furthermore, I demonstrate that those affected play a significant role in the formation of narrative by engaging with the narratives of others.

Chapter 5 explores the dynamic and complex processes of works of dementia focusing on art-making, arguing that the question of whether or not people with dementia have agency is inappropriate. Understanding art-making as creative entanglement, I illustrate the reality of art-making that has many different forms in practice because of its openness and interwoven relations, while also being conditioned by the way those affected are situated in the here-and-now, and particularly within their different medical conditions. Accordingly, I insist that the question is not who, but how. Lines of becoming can only guarantee indefinite possibilities of art-making with people with dementia.

In Chapter 6, I explore the ways in which those affected emplace their new home and environment. Rather than disregarding the social practice of the Home as pathological, I understand such expressive action and response as lived experience so as to uncover residents’ diverse ways of place-making at Home and its transformation as their dementia progresses.

The conclusion addresses the limitations and implications of the legacy of Tom Kitwood and suggests an alternative understanding, perception and approach from the perspective of becoming-dementia.
CHAPTER 1 - CONTEXTUALISING THE ETHNOGRAPHIC PRESENT

1. Demographic Fact and Implications

(1) First Encounter with Dementia and the Home

Although I carried out intensive fieldwork for a year from May 2014, my first encounter with Florence House goes back to May 2005. I was taking English Language classes in London and exploring my intellectual curiosity about subjective memory. This led me to become a volunteer befriender in the Home, which is located near the language school. Over the past decade, my involvement with these residents has grown and deepened, and eventually resulted in the development of a Master’s thesis in 2008: *Recapturing a Sensory Daily Life with the Jewish Elderly through Their Sensory Experiences and Belongings*. Sadly, as time has passed, the residents I came to know have either passed away or their dementia has deteriorated. In 2011, this drove me to undertake a PhD in order to explore the human capacity for living well with dementia, focusing on arts-based sensory and tactile activities such as drawing, singing, dancing, reading, talking and knitting. The research proposal developed into a project - *London Diaries: Dementia as Capacity and Responsibility* - over the first year of the PhD, and during the time of my ethical clearance, became concentrated on *Decision-Making in Everyday Life*.

In what follows, I briefly illustrate people living with dementia in care homes in the UK, focusing on British Jewish people. The second subsection shows the dramatic demographic change of dementia and its implications in more detail, followed by the ‘routine dynamics’ (c.f. Aroles and McLean, 2016) of the Home over the past 170 years. It demonstrates the way in which the Home has managed and endured complex, relational and dynamic transformations alongside its stable and routinised repetitive activity, highlighting the dynamic and processual features of institutional routines. The third subsection details my research design, including its methods, the heterogeneity of participants and its procedures. The last section illustrates the ethical dilemmas encountered throughout the research process, including those of ethical approval, fieldwork and writing, making a suggestion for ethics as an art of co-dwelling.

(2) Jewish People with Dementia in Care Homes

The ‘unprecedented,’ ‘pervasive’ and ‘enduring’ consequences of population ageing impacts multiple facets of our everyday life, having ‘profound implications’ (United

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4 I was involved in several research projects about the oral history of those who experienced the Korean War in 1950-53, and the life history of Korean Comfort Women during my MA in Cultural Anthropology in Korea (2001-2003).
In mid-2015, the UK population reached 65.1 million with the ratio of 49% male (32.1 million) to 50.7% female (33.0 million), and the older population continues to grow with over 11.6 million (17.8% of population) aged 65 and over and 1.5 million (2.3% of the population) aged 85 and over (Office for National Statistics, 2015). While those aged 65 and over and residing in care homes has remained relatively unchanged - 291,000 compared to 290,000 in 2001 - despite an 11% increase in this population in the total population, those aged 85 and over living in care homes has gradually increased from 56.5% in 2001 to 59.2% of the total care home population in 2011 (Office for National Statistics, 2014). Recent increased longevity, with advances in bio-medical technology and government-initiated community-based care, has led to dramatic changes in care homes. In particular, while the average age of people entering institutional facilities has increased, their condition upon entering is often more fragile and vulnerable, so methods of caring have changed dramatically (Paddock, 2015).

Meanwhile, dementia has become a national priority for health policy in England, as the launch of the challenge on dementia by the UK’s former Prime Minister David Cameron shows (Department of Health, 2012). As illustrated in the Dementia 2014 Infographic (Alzheimer’s Society, 2014a), there were 850,000 people living with dementia in the UK in 2014 and this is expected to increase to 1.14 million by 2025 (Age UK, 2016). The updated Dementia UK Report (Alzheimer’s Society, 2014c) also estimated that one in fourteen people aged 65 and over, and one in six people over 80 experienced a form of dementia. In 2014, there were 42,325 people diagnosed with early-onset dementia (before the age of 65) and 773,502 people diagnosed with late-onset dementia (after the age of 65) in the UK. While two thirds of those with dementia resided within the community, the rest (311,730 people) lived in care homes. Of these, there were 180,500 people in residential care and 131,230 in nursing homes in the UK. Meanwhile, 80% of people living in medical and care facilities experience a form of dementia or another form of cognitive and memory deterioration (Alzheimer’s Society, 2014b). Dementia is now the leading cause of disability and death in England (Office for National Statistics, 2016).

According to the initial finding from the 2011 UK Census, there were 263,346 Jewish people (0.5% of the total population) living in England and Wales, and more than 60% of those lived in London (Graham et al., 2011). One quarter of UK Jews were already aged 65 or over and the proportion of Jews aged 75 and over was twice that of the UK: about 14% and 7% respectively. In addition, while there were 3,525 Jewish people living in medical and care facilities in the UK in 2011, which had declined from 4,355 in 2001 by 19%, a higher proportion of ageing people in general lived in these facilities. In
other words, while 8.8% of people aged 75 and above lived in communal care facilities, this proportion has increased by 6% for those aged 80 to 84, 10% for those aged 85 to 89, and 29% for those aged 90 and above (Graham, 2015a). Furthermore, among those living in medical and care facilities, there were over half (56%) of Jewish people living in care homes without nursing and a further third (34%) of those lived in care homes with nursing in England and Wales, with women residents twice as likely as men to dwell in these institutional settings. Concomitantly, these statistics show that as of 2011 there were about 27,400 Jewish people playing the role of unpaid carer for family members or friends in the UK. This relatively high proportion reflects the attitude of Jewish people towards care homes and ageing based on their cultural and religious beliefs. More specifically, the majority of Orthodox Jews aged 65 and over expressed their strong preference for a specific care home operating within Jewish religion and culture, and employing strict kosher rules. However, in 2011 two out of three respondents in a National Jewish Survey showed no sign of particular dietary requirements, but still looked for places with a Jewish ethos (Graham et al., 2014, p. 39). In particular, the survey reports that there were 36 Jewish care homes out of 2000 in the UK, and 22 out of 35 of these were located in North-West London. A report, Key Trends in the British Jewish Community (Abramson et al., 2011), also illustrates that one in twenty-five British Jews aged 65 and above lived in care facilities provided by Jewish voluntary organisations, and that in London, their average age reached almost 90. Also, only about 28% of residents in London care homes were male (Valins, 2002). These demographic trends are reflected in Florence House.

2. From Poorhouses to the Home for Ageing Jewish People

(1) Destitution and the Birth of Jewish Poorhouses

A Parliamentary Ruling (1772) and the New Poor Laws (1834) failed to meet the expectations of Jewish people. In particular, these relief policies and government-run poorhouses (also known as workhouses) were heavily criticised by the Jews not only because of insufficient relief, but also because of their cultural blindness (Bermant, 1976). For example, under the strict rules and regulations, inmates of poorhouses were segregated into male, female, the young and the old and were forced to undergo harsh labour; child labour routinely took place, the family was split up and no consideration was given for kosher dietary requirements. There was also no appropriate place for praying or for performing Judaism. Likewise, although there were local councils and other aid organisations running in London in the Victorian era, they did not meet the rapidly increasing needs and demands of the Jewish poor. It was a group of successful Jewish working class individuals, mostly shop-keepers and
tradesmen, such as grocers, greengrocers, clothes salesmen and butchers, who established a range of charitable organisations in order to cope with economic crises and preserve Jewish identity and culture.

As an independent Orthodox Jewish charity, Florence House can also be traced back to three small poorhouses founded in the East End of London in the Victorian era: the Asylum Home for Jews (1840), the Asylum Home for Widows (1843) and the Jewish Warehouse (1871). Over the past 170 years since then, they have dramatically transformed in response to social demands and ever-changing cultural, economic and political crises.

(2) Pogroms, New Influxes, Mergers and the Birth of Florence House

From the 1880s to the early 20th century, London faced huge Jewish immigration of Ashkenazi Jews mainly from Eastern Europe and with a distinctly Yiddish culture, who were fleeing political persecution and economic hardship in their home countries (Dekel-Chen et al., 2010; Johnson, 2011; Klier, 2011). The new arrivals settled down and worked near East London, which was already occupied by other immigrants. The Jewish population quickly outnumbered earlier settlers, such as Sephardic Jews, Huguenots and Irish immigrants and soon reached about 125,000 people with 65 synagogues within two square miles. In the 1880s, the area soon became known as the ‘Jewish East End’ (Kolsky and Rawson, 2012, p. 11).

With such an unprecedented flux and ensuing aggregated social problems, the three poorhouses faced extreme financial difficulty and desperately needed more patrons. These new patrons, from the wealthy aristocracy instead of from the successful working class, drove tremendous changes in the character and management of the institutions. In the 1870s, Frank Kermode, a retired banker, established the ‘modern system of entry by abolishing unfair forms of patronage’ and set up the ‘voting law’, in which inmates were no longer chosen according to their relations and backers, but upon their life conditions (Roberts, 2001, p. 35). Accordingly, direct participation of working class sponsors was no longer possible and their involvement reduced.

Meanwhile, the Jewish Warehouse moved onto the old premises at Stepney Green donated by Kermode and was renamed the Home for Ageing Jews. The Asylum Home

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5 For example, this list includes the Sephardic Hospital, Beth Holim, (1747), the Jewish Bread, Meat and Coal Society (1779), the Holy Society for the Adequate Maintenance for Widows and Orphans (1788), the Jewish Hospital, Neve Zedik (1807), the Boards of Guardians, such as the Whitechapel Board of Guardians (1835), Jewish Alms houses (1849), Friern Hospital for mental illness (1851), the Jewish Poor in Spitalfields (1854), the Jews’ Temporary Shelter for Trans-migrants (1885), the Grand Order of Israel (1896), the Shield of David Friendly Society (1896) and their amalgamation (1935), the Victoria Club in Whitechapel (1901) and the League of Jewish Women (1943).
for Jews and the Asylum Home for Widows moved to the neighbouring area in Hackney in 1878 and in 1880 respectively. An amalgamation of the two charities took place at the same time, followed by a merger with the Home for Ageing Jews in 1894. Collectively they were called the Home for Ageing Jewish People, although they remained separate in Hackney and Stepney Green (Roberts, 2001, pp. 37-39). Primarily, they aimed at providing relief for the poor whilst observing and practising Jewish dietary, cultural and religious ways of life, and secondarily to act as a kind of hospice and enable peaceful dying in their faith. With the generosity of Lord Wandsworth Simon Schama, who donated ‘Florence,’ a luxurious dwelling with an estate, the two sites of the Jewish homes were relocated to South London in 1904. A few years later in 1910, Lord Wandsworth opened the Home for Ageing Jewish People, now known as Florence House.

(3) Two World Wars, Modernisation and Ageing Residents

A wide range of new medical professionals and facilities were employed and equipped in the first half of the 20th century. By 1924, eye, ear and dental care facilities were made available in-house. In 1949, an occupational therapy department was founded to (at the time) provide advanced therapeutic practice, such as making rugs, lampshades, handbags, wallets, stools, scarves, soft toys, lace dinner sets, bath mats, tray cloths, and baskets. After the Second World War, chiropodists regularly visited and by 1952, their own department was established. Throughout the 1950s, physiotherapists practised some experimental and controversial treatments, such as faradism, infrared stimulation and wax-baths. In 1956, the charity first accepted residents referred from mental hospitals, and the ‘weekly group musical circle’ became a regular programme in 1958. In the 1950s, the Home built the foundation of today’s care practice and philosophy. Subsequently, by the 1960s a full-time medical staff comprising a matron, deputy matron, twelve qualified staff and thirty state-enrolled nurses and orderlies were working in the Home. Indeed, this was a dramatic change in that only half a century ago there were only two medical officers, a master and two matrons, expected to routinely care for 105 residents.

From the second half of the 20th Century onwards, the Home transformed greatly through major building works and care practices, and has become the largest Jewish care home in the UK. Residents no longer come merely as a consequence of poverty, but to enjoy the quality of care in the later stages of life. The increasingly diverse needs and demands of residents require more personalised care, and this has driven dynamic

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6 As a nursing method, faradism uses electric currents to stimulate damaged or paralysed muscles and nerves.
architectural changes despite financial difficulty. When the Home first opened in its current location, it had capacity for 80-100 residents. In 1954 a single-storey building was constructed to house nurses, resulting in extending resident capacity to 169. This was followed by the building of Crawford Wing in 1957 and the Barnes Wallis Wing in 1958, boosting its total capacity to 224 residents, including 134 beds specifically allocated for the severely infirm. The remodelling of the nurses’ bungalow in 1965 allowed capacity for eleven independent residents and the purchase of Whitworth House in 1967 provided twenty-six flats for independent elderly residents located just across the road. In 1976, the Prince of Wales opened a new four-storey Red Brick Extension which was renamed the Arthur Lewis Centre (ALC) in May of 2001- with 160 en-suite single rooms. It consists of four different units; each unit has three wings, and the middle of each unit comprises a large communal area together with a kitchen, a dining room and a staff desk. Each wing has its own small utility space for creating a social area.

Figure 1-1 Florence House Today

7 The Home purchased the land from the Inner London Educational Authority in 1973. It was formally used by the Jews' Deaf and Dumb Home (later known as the Residential School for Jewish Deaf Children) since 1899.
The number of infirm residents requiring nursing care increased by half in 1967, then from 60% in 1968 to 75% in 1971. At the same time there were 35 out of 279 residents who were over 90 years old. The average age for a resident already reached from 83 in 2000, to over 90 in 2015 with around 10% (13) of residents being over 100 years of age. The government also continued to introduce and revise their health care policies and regulations. In particular, the Registered Home Act of 1984 drove the Home to standardise quality of care and services in terms of recording, staffing, staff training and accommodation. Accordingly, the Home was transformed to being dually registered as both a Nursing Home and a Residential Home. In 1990, the number of residents had reached its peak of 430 with 350 care staff. Once again, since the introduction of the new Community Care Act in 1990 (CCA), the type of residents has dramatically changed, resulting in an increased burden on management, funding and care practices. More specifically, the CCA encouraged the elderly to stay in their own homes or communities as long as possible so admission to newcomers has been even further delayed.

As the needs and demands of residents become more diverse and complicated, the Home has systematically, geographically and medically divided its building into five different units, of which the ALC houses four different units: Barry Unit is mainly used for those who need nursing care due to physical disability; Meir Unit is for residents with advanced dementia who need nursing care or end of life care; Abraham Unit is mainly occupied by residential residents with Mild Cognitive Impairment (MCI) to moderate dementia; Joel Unit is mainly for independent residents. The Christie Wing offers nursing services for those with less advanced dementia. A resident there for respite (short stay) is given the same options as permanent residents, depending upon the availability of rooms and their medical needs, interests and adaptability.

Table 1-1 Fee, Demography and Type of Care (July 2014)

<table>
<thead>
<tr>
<th>Unit</th>
<th>Type of Care</th>
<th>No = 171*</th>
<th>Sex (M/F=48/123)</th>
<th>Fee/week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barry Unit</td>
<td>Nursing</td>
<td>27</td>
<td>18/9</td>
<td>£1290</td>
</tr>
<tr>
<td>Meir Unit</td>
<td>Nursing (advanced) Dementia</td>
<td>14</td>
<td>6/8</td>
<td>£1440</td>
</tr>
<tr>
<td>Abraham Unit</td>
<td>Residential (early to moderate) Dementia</td>
<td>45</td>
<td>12/33</td>
<td>£1130</td>
</tr>
<tr>
<td>Joel Unit</td>
<td>Residential</td>
<td>42</td>
<td>10/32</td>
<td>£980</td>
</tr>
<tr>
<td>Christie Wing</td>
<td>Nursing: less advanced Dementia</td>
<td>34</td>
<td>10/24</td>
<td>£1130</td>
</tr>
</tbody>
</table>

Note: * = 2 on respite care
A decade ago, there was only one Dementia Unit housing about 40 out of 200 residents. As of 2015, more than 80% of residents have a form of dementia. These demographic changes have driven a fundamental transformation in care practices and building plans. The Home demolished the Rutherford Wing and built the state-of-the-art Christie Wing, which was specifically designed for people with dementia and opened by the Prince of Wales in 2011. At the same time a memory garden, including a 1940s/50s landscape complete with a Morris Minor car, a bus shelter, a red K6 phone box and water features, was opened to create a more dementia-friendly environment.

In 2014, the Meir Unit was remodelled and renovated to provide quality of care with the appropriate medical supplies and equipment for residents with advanced dementia and the terminally ill.

The Home now provides for the whole spectrum of residential, nursing, dementia and palliative care together with a respite option. As of July 2014, there are 171 residents alongside about 250 volunteers, 370 staff, and more than a thousand family members...
and friends. They come from all around the world to live, work, volunteer or visit. Culturally and religiously appropriate care and service becomes more and more important to meet the interests and needs of residents living with dementia as well as their significant others (Botsford and Dening, 2015).

As Figure 1-3 shows, the Home is equipped not only with medical and therapeutic facilities but also with cultural, religious and other social facilities on the ground floor. When entering the Home, visitors find a reception within an elegant hall. This is directly connected to a shop, a cafe and a dementia-friendly garden. In particular, the sounds and smells from the cafe along with fresh air from the garden invite people into a friendly, home-like atmosphere. Several arts and crafts pieces made by residents are displayed in and around the shop and the cafe, and several couches and tables are arranged for private family meetings. A hairdresser, a therapy department, a synagogue and a concert hall are located to the right of the reception. On the other side are the NHS facilities, the activity centre, a library, a lounge, Sukkot (Feast of Tabernacles) and several offices for staff. The long corridor is dementia-friendly with a handrail and adorned with several portraits of residents and artworks made by themselves and volunteer artists. Likewise, all facilities are built so that residents can
easily access the open garden and take the maximum advantage of nature. Most social and arts activities take place in this area.

Lifts and stairs connect each unit, and the atmosphere in all units is cosy; gentle music plays and the rooms are full of seasonal decorations hanging beside residents’ artworks and photographs. Of course, medical and therapeutic information can also be found on the wall. The weekly programmes of therapeutic and social activities are advertised on the notice board in each unit and on the internet homepage. Table 2 is a sample for residents on the Abraham Unit as of May 2015.

Table 1-2 Abraham Unit Weekly Programmes

<table>
<thead>
<tr>
<th>Mon</th>
<th>Tue</th>
<th>Wed</th>
<th>Thu</th>
<th>Fri</th>
<th>Shabbat</th>
<th>Sun</th>
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<td>AM</td>
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<tr>
<td>Art</td>
<td>Cooking</td>
<td>Cooking</td>
<td>Pottery</td>
<td>Pottery</td>
<td>Religious</td>
<td>Visits</td>
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<tr>
<td>Cooking</td>
<td>Pottery</td>
<td>Body Exercise</td>
<td>Flower</td>
<td>Reminiscence</td>
<td>service</td>
<td>from family</td>
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<tr>
<td>Discussion</td>
<td>Body Exercise</td>
<td>Art</td>
<td>arranging</td>
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<tr>
<td>Reading</td>
<td>Drama</td>
<td>Discussion</td>
<td>Men’s Group</td>
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<td>Group</td>
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<td>Discussion</td>
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<td>Music</td>
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<td>therapy</td>
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<td>(Shopping)</td>
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<td>Pottery</td>
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<td>Drama</td>
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<td>Discussion</td>
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<td>Walks</td>
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<td>Film (Choir)</td>
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<td>Tea party</td>
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<td>Bridge</td>
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<td>Poetry</td>
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<td>Tea &amp; chat</td>
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<td>Religious</td>
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<td>leader</td>
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</table>

Intergenerational programmes are also included. From a new born baby to secondary school students, the Home encourages local youths to mingle with residents, and they are often invited to seasonal events and Jewish Festivals. They also organise other social activities in partnership with outside organisations, either for a limited period of time or for longer-term projects up to ten months.

During the welcome weeks, GPs, care staff, family members and an activity coordinator develop an individual care and activity plan together with the resident based on their individual needs and wishes. Following the Mental Capacity Act of 2005 (MCA), in the case of a person with dementia, a legal representative is also invited to

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8 For example, in 2011, New Voices was a certificated young volunteer activity programme over six months for those 16 to 25 years old including training, supervision and mentoring sessions.

9 For example, in 2014 there was the Pots of the Past project with the Museum of London, and since 2012, the Inmind project with the Royal Academy of Arts, a Mapping Workshop, a Composing Opera and a Visual to Vocal project with Dulwich Picture Gallery. Drama Therapy took place thanks to funding for ten months from February to November 2015. Two graduate students held music therapy as an internship in 2013-14. The Royal Academy of Dance ran a six-week Dance Therapy course for selected residents in 2012-13. Depending on the funding source and size, most collaborative projects are given to designated residents; for example, Drama therapy in 2015 was only allocated to Holocaust survivors and their family members or relatives.

41
the meeting. Their daily life is closely monitored and recorded, and the individual care plan is discussed (on demand) at a yearly Multidisciplinary Team Meeting (MTM).

Over the past 170 years, the Home has not only changed, but the character of its residents has dramatically transformed. While the original institutions of the Victorian era provided temporary relief from harsh economic and spiritual situations, in 2015, the Home has transformed into one of the most advanced, state-of-the-art care homes, with about £13 million spent on its renovation. Residents today do not come because of poverty, but to move their home to another home in order to receive the quality of care and enjoy the rest of their lives with dignity.

(5) From Dementia-Friendly-Home to Community

Operating and governing the Home of around 180 residents and 300 staff involves more than just a balancing of income and expenditure. In particular, since the introduction of the Community Care Act in 1990, both local authorities and care homes have struggled to meet their needs and responsibilities. This has resulted in them always competing between several priorities with limited resources (Hadley and Clough, 1998). For example, the annual operating loss of the Home amounted to £2.7 million in 2011, £3.4 million in 2012, £3.8 million in 2013, and £3.2 million in 2014, meaning that income from residents and local authorities is unable to cover the costs of the institution. In order to make up the running cost and seek new income sources, as well as sharing the skills and experiences of their care practices, the Home has had to adapt diverse strategies. This has included amalgamating with Hampstead House (a care home) in 2012 and Camden Lodge (sheltered housing) in 2015, renting unused care facilities to a local Hospital in 2015 and integrating local services by opening a nursery in 2017. In particular, providing a second site for the Jewish nursery on its premises is mutually beneficial, offering an opportunity for intergenerational activity while also providing nursery services to families in the community. However, this income combined with residents’ fees covers only around 70% of total expenditure, which means that another 30% of income falls short. The Home is unable to survive without the contribution of communities through legacies, donations, gifts, voluntary work, fundraising campaigns and other societies.

Therefore, it is essential for the Home to maintain and encourage a good relationship with its communities by negotiating with them and responding to their interests, needs and demands. For instance, this relationship has led to a new state-of-the-art...
dementia-specialised wing in 2011, the refurbishment of a kosher kitchen in 2012, the redevelopment of the Meir Unit in 2014, the Avenue cafe in 2015 and will lead to the £36 million redevelopment of Hampstead House in 2017-2018. Above all, over the past half-decade the Home has passionately tried to meet residents’ needs, choices and preferences with dignity and respect, not only by establishing excellent facilities but also by providing well-planned staff care training and carer development programmes based on Tom Kitwood’s ‘person-centred care’ (1997). Accordingly, diverse dementia-related care has been implemented and transformed the culture of care from task-centred to person-centred. The recognition of personhood, which is often ignored and stigmatised by illness conditions and behavioural challenges, is re-validated and re-addressed according to the person’s unique personality, biography, life-history and present situation (Sabat and Harré, 1992; Kitwood, 1997; Hughes et al., 2006).

Needless to say, the Home has also continued to maintain and strengthen its relationship with local councils, other voluntary organisations and celebrities through collaborative work in terms of on-the-job training, apprenticeships and the day care centre, in turn providing various services and staff training.12 Residents not only enjoy engaging with diverse social activities provided by those from the outside but also contribute to enriching its history. Of particular note are the visits of public celebrities. Inviting the Prince of Wales to open the new dementia-specialised wing in 2011 was a pivotal point of the ceremony, and was not the first time he had opened a new section of the Home. In February 2015, Princess Anne also visited for the unveiling of a plaque, honouring Britain’s Special Operations Executive, which was based on the current site of the Home during World War II. In addition, the visits of the Duke of Edinburgh in 1980 and Princess Diana in 1983 will never be forgotten in the history of the Home. Of course, the Home has also contributed to society by inviting and working with political parties, politicians (such as the visit of Health Secretary Jeremy Hunt in December 2013) and academic,13 including myself. Furthermore, residents may have ordinary encounters with celebrities through everyday social activities, such as tea parties, literature groups and guest talks. As Deborah Moggach, author of The Best Exotic

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12 For example, with hospices (Trinity Hospice and St Christopher’s Hospice), hospitals (St George and Wandsworth), Universities (King’s College London, Kingston University, University of Bradford), colleges (College of Occupational Therapists and Royal Academy of Dance), schools (Yehudi Menuhin School and Bolingbroke Academy, Magic Moment Israeli Youth), a nursery (Apple & Honey Nursery) and other cultural and religious facilities (National Portrait Gallery, Dulwich Picture Gallery, National Theatre, The Wallace Collection, the British Museum, Tate Modern & Tate Britain Gallery, the museum of London, local synagogues based in Wimbledon, Marble Arch and Kinston synagogue, and so on)

13 For example, residents participated in a range of practical art sessions and workshops as part of a larger study called ProVACAT- Practicing or Viewing Art Cognitive Ability Trial - supported by the University of Sussex. In particular, since 2011, in partnership with the Bradford Dementia Group, the Home has not only provided excellent provision of care for those living with dementia, but also jointly created and offered a model, service design and guidelines for dementia care across the UK.
Marigold Hotel, mentioned at the literary lunch at Claridge’s in London in 2012, her experience at the care home has inspired her to write about the lives of older people. Other celebrities such as the Sun’s former boxing correspondent Colin Hart, English actor and comedian Stephen Fry, presenter and activist Edwina Currie, and a former MP and celebrity speaker are among those who have shared their talents and stories with residents at the Home. These events provide a sense of connectedness and togetherness which undoubtedly improves the quality of life of those who live there.

The Relative Committee, which meets twice a year, has played a significant role in improving care practice and the care environment. For example, it contributed to the introduction of casual clothes instead of staff uniforms in 2011, larger name badges in 2013, and upgraded laundry collection and distribution in 2015. Above all, improving meals has always been at the centre of the Committee’s interests. Various social, regional and cultural backgrounds mean that, as the ex-chief executive has said, their recipes for gefilte fish are very different. The soundscape has become one of the most essential concerns and noise control has been a top priority since the Meals Matter Committee in July 2014. Consequently, all the chairs and tables in the dining rooms were altered with rubber tips on their legs to avoid them making noise.

Linking with and responding to the larger society does not stop here. The voices of Jewish elderly residents are heard in parliament and by the public through diverse routes; for example, by writing letters to MPs\textsuperscript{14} (Elgot, 2012), giving opinions in newspapers\textsuperscript{15} (Jackman, 2015a; 2015b), TV interviews\textsuperscript{16} as well as blogging and tweeting. In terms of human resources in particular, looking for the right person is always a priority when meeting their limited budget. It was about twenty years ago that the Home personnel travelled to Israel to find new employees who had the skills and passion for caring for the elderly as well as the language competence in both English and Hebrew. At that time a lot of Asian immigrants, particularly from the Philippines, were recruited and some of them still work here. These days, many Eastern European immigrants work in care, as the former chief executive highlights in an interview. Similarly, Simon Morris, the chief executive of Jewish Care also points out in his interview with the Jewish Chronicle that recent movements and decisions on Brexit put pressure on independent Jewish charities where 15% of staff are non-British 15.

\textsuperscript{14} For example, about reforming the Andrew Dilnot Commission in 2011 which proposed a contribution cap of between £35,000 and £50,000, which would not cover any assets under £100,000, resulting in increasing an extra £1.7 billion of expenses annually.

\textsuperscript{15} For example, there were opinion letters about the unrealistic cut in the nursing fund from the NHS and the Minimum Wage increase in 2016.

\textsuperscript{16} An interview about the need for immigrant staff has now been released on YouTube under the name of Care Home Chief Executive: Romanian Staff ‘Genuinely and Naturally Care’: https://youtu.be/DtATrDCjapc
EU nationals, not only in terms of raising new funds, but also in losing a high quality workforce and their support (Oliver, 2016).

Last but not least, it is hard to ignore what Dominelli and Hoogvelt (1996) complain about in terms of the recent changes in social work from needs-centred to budget-centred. This Care Home is no exception. It could be a direct example of the prioritisation of management that in 2013, a new chief executive with a background in charity finance but not of Jewish descent was appointed for the first time in over 170 years. It occurred after the retirement of a Jewish chief executive who had served for four decades. Although a new Jewish director of operations had been appointed within executive management at that time, it was nevertheless seen as a seismic decision from the point of view of residents and community members. I assume that recent structural reform, property investment, and amalgamations cannot be explained without the influence of the new chief executive. Of course, the recent transfer of her office from the isolated administrative fourth floor to the ground floor and her active involvement in diverse committees, such as the Meals Matter Committee and Relative Committee, also reflect the dynamic tensions and negotiations within Jewish communities.

3. Research Design

(1) Researching as Co-dwelling

It took me almost two years to get ethical clearance from the NHS’s National Research Ethics Committee (from July 2012 to May 2014) and this process led me to rethink a somewhat deterministic approach to dementia illness experience. While continuing to engage with residents as a volunteer, helping out and facilitating daily activities with them, I reviewed the previous methods and approaches and developed a critical ethnographic approach to exploring the lived experience of becoming-dementia. This was founded in an Ethical Protocol which includes Informed Consent as an ‘ongoing consensual process’ (Ramos, 1989, P. 61), together with two Distress Protocols, a Consent Protocol and a Consultee Declaration.

To my regret, during the process of ethical approval, several initial creative fieldwork methods, such as Phonography, Collaborative Life History, London Diaries and Dementia Artwork Mapping were either refused or revised to meet ethical regulations. Phonography, a (phone) photo essay, would have been a practice-based collaborative artwork with residents with dementia, handing over a phone/camera to them and letting them take photographs themselves. It was designed to extend inclusion to those who had experienced a deterioration of language, memory and cognition but
also to provide a platform for them to participate in a new activity, to express their feelings, emotions and other experiences that would otherwise remain unvoiced. The images were expected to be used as talking points as well as sensory representations so that they could talk about, remember, feel and express the world around them in a particular time and space. Based on co-presence and co-suffering, Collaborative Life History would have focused not on the content of the story told by residents and significant others, but on the process, the situation and the ways in which they make a joint story alongside ‘walking and talking’ (Ingold and Vergunst, 2008) and ‘photo elicitation’ (Harper, 2002). Of course, it would emphasise not only a joint account of illness experience, but also its situational and relational meaning through intersubjective and intercorporeal interaction and communication (Csordas, 2008). London Diaries would have attempted to explore the ways in which individual residents make ‘connections, associations and putative relationships’ in the process of arts-based social activities by developing Marcus’s practice of ‘following’ (1995, pp. 97, 106-110). Dementia Artwork Mapping would have been developed upon the established ‘Dementia Care Mapping’ (Innes, 2003) which is a codified observational evaluation of bodily behaviours and mood changes of individual residents with dementia. However, I realise that trying to approach, perceive and understand the lived illness experience of residents with dementia through rigorous anthropological theory, epistemology and methodology may come at the cost of losing their voices. This called for revisiting the validity and scientific rigor of ethnographic evidence and fieldwork by asking about the ways in which anthropologists perform fieldwork, and collect and justify their ethnographic data. Bearing this in mind, I took my decade of involvement with the Home as an ‘anthropology as practice’ that provided not only ‘the occasion, the pretext and the locus of the drama that is the source of anthropological reflection’ but also the ethnographic presence, ‘the coevalness of fieldwork’ (Hastrup, 1990, pp. 45, 51) and the creative process of a ‘reflexive performative ethnography’ (Turner and Turner, 1982).

In more detail, this ethnography is firstly rooted in everyday life by co-dwelling with people, the institution and its surroundings. While rejecting predefined pathological conceptions, categories and classifications, I performed participant-observation by playing a role as a member of the community (see, Brown Wilson, 2009) who talked, helped, walked and was befriended by residents just like ordinary volunteers. This method became more concrete when I encountered the work of the French anti-psychiatrist Fernand Deligny (2015) who carried out a residential research programme for children and adolescents with autism by living and working together with them. Drawing upon the cartographic method, he drew lines of bodily gestures and
movements which continuously interacted with and responded to others, things and
the physical environment, excluding any kind of reflexive and conscious representation
from the maps. Therefore the lines on the maps signify ‘tracks and traces,’ in Deligny’s
terms, which are ‘networks’ of the ways persons with autism live in the world (Wiame,
2016, p. 44). His method offers a non-judgemental and person-directed approach (for
more detail, see Chapter 3). In particular, his perspective combined with a Deleuzian
microanalytic sensitivity to bodily movement, sensation and affect (e.g. Biehl and
Locke, 2010; Deligny, 2015) in relation to the social and physical surroundings,
strengthens and concretises my performative methodology of co-dwelling in mundane
experience. Needless to say, collaboration became a fundamental condition for the
fieldwork. In particular, Ingold’s thoughts on integrating the concepts of co-dwelling
and becoming offer not only a theoretical but also a practical ground for this study. For
Ingold, dwelling involves the continuous generative engagement with how human
beings make, build and produce in an intransitive way. It is a corollary that the
meaning of life is embedded in the process of dwelling, and thus dwelling is
fundamentally about ‘movement’ (Ingold, 2010a, p. 3). Beyond loss of bodily functions
and abilities, this dwelling perspective focuses on the continuous interactions and
engagements with the lives of others, things and the environment. Namely, co-
dwelling is about collaborative work, movements of becoming, and the new modalities
of becoming-dementia. Therefore, this co-dwelling approach calls for ‘an itinerary
rather than a map’ in that the latter offers us a position, while the former tells us
about the ‘direction,’ orientation, relation and processes of movement (Hastrup, 2013,
p. 8).

In addition, this critical ethnography synthesises ethnography and autobiography in
the process of anthropological knowledge-making (see Okely and Callaway, 1992;
Reed-Danahay, 1997; Behar, 1997). In fact, as I indicated above, the fieldwork is deeply
embedded in my life and vice versa. This is a continuous ongoing reflexive process
(Nadin and Cassell, 2006) that has been developed upon a decade of personal
relationships with the Home, its residents and significant others, as well as a
continuous intersubjective and intercorporeal method of ‘learning’ developed through
a ‘process of gradual familiarisation in practice’ (Hastrup and Hervik, 2003, p. 8).
Accordingly, ethnography is an autobiographical co-dwelling project that is a co-
authored record of ‘a mode of striving against the social world’ entailing ‘the
possibility of doubt and disappointment with the worlds we dwell in’ (Das, 2015, p. 17).
While demystifying the process of fieldwork and ethnographic writing, I use myself as a
‘resource of ethnography’ (Collins and Gallinat, 2010) in conjunction with ‘reflexivity’
(Davies, 2012), oscillating between ‘moderate participation’ and ‘complete
participation’ (DeWalt et al., 2000, pp. 262-263). In this sense, Spry’s autoethnography shows an experimental and creative attempt to incorporate the experience of ‘being there’ and the self-reflection of ‘being here’ through a continuous process of reflexivity of ‘the situatedness of self with others in a social context’ (Spry, 2001, p. 710). As a ‘fieldwork technique,’ reflexivity aims to use:

scrutiny of the self as a historically and socially positioned actor interacting with others in the field, to reveal how social categories, boundaries, hierarchies and institutions work (Wright, 2004, p. 48).

Furthermore, my experiences of living, caring and researching are not mere biographical happenings, events and narratives, but multiple inner voices laden with such things as emotion, affect, sense and desire. As Tami Spry describes her own experience of losing her son in childbirth, she is unable to separate her feelings from writing her ethnography. Her feelings are already and always embedded in her lived experience through embodiment, and so it is within her writing. Similarly, Renato Rosaldo confesses in his ‘Introduction: Grief and a Headhunter’s Rage’ in *Culture and Truth* (1989) that he did not fully understand the headhunting of the Ilongot people in the Philippines in relation to their grief and rage until he himself lost his wife. Rather than a detachment to what anthropologists experience, Spry and Rosaldo as the ‘positioned (and repositioned) subject[s]’ (Rosaldo, 1989, p. 170) demonstrate the significance of emotional and ‘empathetic scholarship’ based on an ‘empathetic epistemology merging participant-observer positioning with the vulnerability of the feeling and sensing “un-learning” body’ (Spry, 2006, p. 346). This reminds me of Paul Stoller’s *Sensuous Scholarship* (2010a) and Sarah Pink’s *Doing Sensory Ethnography* (2015), which argue that rather than being caught in a web of reasoning and metaphysics, we as anthropologists need to develop an ‘epistemological humility’ (Stoller, 2010b, p. 5). Our sensory and affective ways of making connections with, understanding and perceiving people, things and the surroundings bring a new path to understanding the nature of the human being in terms of embodied and sensory experience. Likewise, Bianca Brijnath shares this perspective with sensory scholars, saying that caring for those with Alzheimer’s fundamentally involves all human activities of ‘eating, moving, toileting and bathing,’ but regrettably ‘tasting, feeding and eating’ as well as ‘urine, faeces, vomit, sweat, pus – a form of care work’ that has barely been discussed (Brijnath, 2011, pp. 611, 616, 618).

In relation to the study of dementia, this reflexive and performative ethnography based on empathetic, sensory and affective scholarship attempts to offer an original ethnographic perspective by looking at the lives of people living with dementia not as victims of a ‘hyper-cognitive’ culture and society (O’Neill, 1997; Post, 2000), but as
lines of movement (Ingold, 2007; 2015; Deligny, 2015; Deleuze and Guattari, 2004b). Co-dwelling with a cartographic microanalysis sheds new light on ways of becoming-dementia, particularly in terms of bodily expressive performance in the framework of the relational, contextual and situational beyond bloodless knowledge and language. Accordingly, this study attempts to uncover the immanent force of movement; life that ‘does not begin here or end there but keeps on going, finding a way through the myriad things that form, persist, and break up in its currents. It is a movement of opening, not of closure’ (Ingold, 2010a, p. 2). In this sense, although residents with dementia may experience the deterioration of language, judgement, cognition, orientation and memory as their illness progresses, we also witness lines of movement, life itself making and unmaking social formations within their capabilities. Although their expressive words and actions are often regarded as fragmented, repetitive and inexplicable, making connections, relations and familiarising themselves with people, things, and their surroundings continues.

Lastly, in this study I use the ethnographic present. It is not simply because ‘only the present tense preserves the reality of anthropological knowledge’ (Hastrup, 2013, p. 14), but also because ‘ethnography is historically determined by the moment of the ethnographer’s encounter with whomever he [sic] is studying’ (Crpanzano, 1986, p. 51). The ethnographic present as a literary technique does not merely represent or translate reality from A to B, but demonstrates the ethnographer’s co-presence sharing the time, space and reflexive co-creating process beyond a chronological time paradigm (Hastrup, 1990, p. 57). That is to say, the persons, the ethnographic data and my autobiographical ethnography used for the writing are produced, interpreted, and reproduced throughout the creative and reflexive process beyond an ‘anthropological performative paradox’ (Hastrup, 2013, p. 14).

In brief, based on co-dwelling in day-to-day practice in the Home, this study critically develops reflexive performative ethnography through cartographic microanalysis to explore the minute transformation of bodily movements, the senses and affect. It differs from established phenomenological approaches which mainly focus on revealing remaining intact embodied memory, movements and skills (Hydén et al., 2014), resulting in paying less attention to anticipated, future-oriented creativity and desires. Consequently, this ethnography sheds new light on becoming-dementia as an emergent force of co-dwelling beyond loss by revealing a continuous process of individual differentiation and transformation in response to an ever-changing world.
(2) Procedures

The Director of Care Services at the Home initially identified potential participants from the resident body. In compliance with the MCA, this study only included English-speaking Jewish residents who had the ability to engage in daily activities, with the presence of dementia ranging from MCI to moderate dementia. It also included significant others, such as staff, medical professionals, volunteers, family, friends and residents without dementia. However, it excluded those expressing voluntary withdrawal as well as those identified by the Home as incommunicable or being in a critical health condition, including advanced dementia. As a result, potential participants were screened and limited to those living in the Abraham and Joel Units. Then, with ongoing liaison with two unit managers and after consulting staff, the researcher approached the residents, ensuring that no coercive pressure influenced potential participants or those who did not want to join. Recruitment was carried out through face-to-face contact and I re-introduced myself as a PhD student. Potential participants were then provided with written information sheets to give them ample time to consider participation. In the event that a person lacked or had begun to lose the capacity to give informed consent, the researcher was referred to a consultee and staff, drawing upon their knowledge of that individual in making a decision on participation. When obtaining initial consent, the participants were also asked their preference with regards to continuing in the study and/or identifying a personal consultee should they reach a state in which they no longer had the capacity to decide for themselves. Obtaining consent took place as an ongoing process in ordinary interaction and communication in association with ‘process consent method,’ acknowledging that ‘capacity is situational’ and ‘specific,’ and thus can be ‘present even after the usual legal threshold has been crossed’ (Dewing, 2007, p. 13). Table 1-3 shows the results.

Intensive fieldwork based on co-dwelling was conducted for a year from May 2014 to May 2015, engaging with the lives of residents with dementia and significant others. As a participant observer, I spent most of my time co-dwelling by way of facilitating, walking, eating and doing things together with residents and their significant others, whilst observing the ways in which they engaged in activities, focusing particularly on their embodied experience of bodily movement, sensation and affect. I also conducted overnight fieldwork for one and a half months from August to October 2014 and in-situ and in-depth interviews with significant others in response to the significance of night life and care at night and a general neglect of this time in academia. In particular, I used ‘moderate participation’ (DeWalt and DeWalt, 2011, p. 25) in that I did not directly engage with, but mainly observed, the lived experiences of life and care.
overnight in order not to interrupt the private life of residents. The first half of the overnight fieldwork took place in the Joel Unit and the second half in the Abraham Unit. During this time, I read the medical histories and care plans of residents who had already given consent and did intensive interviews with night-time care workers.

Table 1-3 Key Participants of Residents

<table>
<thead>
<tr>
<th>Table 3. Key Resident Participants</th>
<th>Ratio</th>
<th>Sex (F / M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joel (13/42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With Dementia</td>
<td>2/13</td>
<td>1/1</td>
</tr>
<tr>
<td>Without Dementia</td>
<td>11/13</td>
<td>7/4</td>
</tr>
<tr>
<td>Abraham (15/45)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With Dementia</td>
<td>10/15</td>
<td>9/1</td>
</tr>
<tr>
<td>MCI or early stages of Dementia</td>
<td>5/15</td>
<td>3/2</td>
</tr>
</tbody>
</table>

Table 1-4 Number of Employees and Interviewees (269/34)

<table>
<thead>
<tr>
<th>Nursing Admin 5</th>
<th>Meir Unit 36</th>
<th>Resident Service 3</th>
<th>Accounts 8 / 1</th>
<th>Porter 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management 8 / 4</td>
<td>Abraham Unit 23 / 8</td>
<td>House Keeping 51</td>
<td>Activities 10 / 8</td>
<td>Therapy 9 / 3</td>
</tr>
<tr>
<td>Christie Wing 25</td>
<td>Joel Unit 22 / 3</td>
<td>Maintenance 8</td>
<td>Hairdresser 1 / 1</td>
<td>Bank Nursing 40 / 2</td>
</tr>
<tr>
<td>General Admin 5</td>
<td>Barry Unit 26/1</td>
<td>Fundraising 4 / 1</td>
<td>Volunteer Manager 1/1</td>
<td>Religious Advisor 1/1</td>
</tr>
</tbody>
</table>

*In-situ* interviews were performed by chatting with significant others during and immediately after social activities at the scene. The topics were limited to the social activities of the moment. In-depth interviews with significant others were conducted at a suitable time and place for those being interviewed, including care workers, volunteers, care specialists and family members (see Table 1-4). Interviews were designed to collect narratives about lived experiences of caring for those affected by dementia and the life histories of these individuals as well as their loved ones in the care home. The interviews were non-structured and conversational and took about half an hour to an hour. The interview data was then transcribed. The transcripts, material I collected in the field and everyday field notes, which were written based on my memory in the evenings at home, have become the basis of a reflexive and performative ethnography and have been used for microanalysis. Briefly, the analysis involves a wide range of re-reading field notes and other ethnographic resources from the perspective of becoming.

(3) Key Participants

As Table 1-3 shows, the number of key participants joining the study (n=28/87) had an average age of eighty-nine with dementia, consisting of a majority of women (n=20/28). Of those participants with dementia there were only a small number of
males (n=4/17). These statistics generally correspond to the sex ratio of residents (M/F) in the Home (n=48/123), reflecting the longer life expectancy of women than men.

Briefly speaking, although most residents were second-generation working class immigrants, they had later become successful members of the middle class with relatively high levels of education and some with professional jobs, such as a lawyer, teacher, architect, civil servant, journalist, dress maker, retailer and so on. As Pia Kontos (2003; 2006b; Kontos and Naglie, 2009) already mentions about embodied selfhood and bodily memory (tacit knowledge) in dialogue with Bourdieu’s habitus and Merleau-Ponty’s embodiment, their taste and habitus played an important role in social interaction and communication through their ways of speaking, dress, gesturing and their table manners. Together with the deterioration of their bodily functions and abilities, these were deeply embedded in everyday situations, including in conflict. Although the Home provided Jewish Orthodox practices, there were a small number of residents actually practicing Shabbat and other religious services, not only because of their fragility but also because of diverse beliefs and different modes of practice from the perspectives of Orthodox Judaism, Reform Judaism, Christianity and atheism. Accordingly, they have different degrees and intensity of religiosity. During fieldwork I did not encounter anyone who identified themselves as Israeli, only British (English, Welsh or Scottish) and ‘culturally Jewish’ in their words. Despite such diversity in ways of thinking, they have some things in common, such as prior investment in their children’s education and the recognition of Israel as a nation.

Significant others were also recruited (n= 69) and interviewed: residents without dementia (n=14), volunteers (n=10), friends (n=4), consultees (n=5), care staff including therapists (n=16), GPs (n=2), other staff (n=16) and partnership workers (n=2).

Although some participants are either formerly diagnosed as having a form of dementia or as having already handed all decision-making over to consultees (mostly sons or daughters), the matter of who is capable of giving consent is always ambiguous. The capacity may be ‘decision-specific,’ meaning that an individual may be able to make one decision but not another, and this does not always follow medical diagnosis (Nuffield Council on Bioethics, 2009). For example, Penina has never been formally diagnosed as having some form of dementia but was treated as a person with loss of mental capacity because of her excessive spending which was completely different from her previous consumption behaviour in 2014. At the same time, it is tremendously important to mention that there were a number of residents who were present but could not be recruited due to the impossibility of obtaining informed consent due to a sudden death (n=4), sudden deterioration in their health (n=8),
voluntary withdrawal (n=13) or exclusionary subjects (n=7). However, because of the openness and contingency of social life I cannot isolate participants from non-participants. Although these non-participant residents remained present at ethnographic scenes, they remain anonymous in the mode of co-dwelling and were excluded from the research data.

4. Ethics as an Art of Co-dwelling

Much work criticises not only the current ‘dominant tendency to disembed, exteriorise, and alienate ethics’ from professional practice (Meskell and Pels, 2005, p. 1) but also the gaps between ‘bureaucratic demands and real research ethics’ (Gillan and Pickerill, 2016, p. 2). Retrospectively, for me, the question of research ethics is not just to follow a normative protocol but to engage with enduring and complicated ‘everyday ethics’ (Powers, 2001; Lambek, 2010b) by learning, doing and co-dwelling.

My first two attempts to obtain ethical approval failed on 14th August 2012 at the National Research Ethics Service (NRES) and on 21st March 2013 at the University Research Ethics Committee (UREC). Then, my research proposal and ethical protocol were rigorously revised and approved by the NRES on 8th April 2014, together with a Site Specific Assessment on 8th May 2014. In addition, although Site Agreement from the Home was initially obtained from the Director of Care Services on 23rd July 2013, the final research approval was made via the Care Governance Board of the care home based on ethical approval from NRES and informed by the Board of Trustees. While the ultimate responsibility for observing the Florence House Research Policy in line with the Department of Health Research Governance Framework (Department of Health, 2005) was on the researcher, the Director of Care Services also took responsibility for liaising, checking and helping the research progress and other related administrative work, such as reporting to the chief executive officer and the Board of Trustees. During initial meetings with the Director of Care Services we shared relevant research protocols including the Nuffield Bioethics Framework (Nuffield Council on Bioethics, 2009), the University of Manchester’s Seven Principles of Good Research Conduct, Ethical Guidelines for Good Research Practice from the Association of Social Anthropologists of the UK and the Commonwealth, the Mental Capacity Act 2005, the Florence House Research Policy and the Department of Health Research Governance Framework. We made an oral agreement that I would observe these ethical protocols and guidelines.

Throughout this long process, I not only learned about what ethical research meant and how I should research but more importantly, I witnessed and experienced the way in which ethical research could be achieved. Above all, as Guillemin and Gillam point
out, there is a gap or discrepancy between two dimensions of ethics in research: ‘procedural ethics’ which refers to obtaining ethical approval from a Research Ethics Committee and ‘ethics in practice’ that experiences the process of carrying out research (2004, p. 263). In other words, neither ethical approval nor professional (and organisational) codes of ethical practice can in themselves provide all that is required for handling ethical issues. Likewise, fieldwork based on participant-observation alongside engaging with people and a community for a long period of time no longer guarantees the validity, relevance and ethical practice of ethnographic research. Consequently, ethnography is no longer taken for granted as a scientifically rigorous and objective research method without critical reflection on ethnographic presence, which does not just mean ‘being there’ but a range of interaction and involvement in and with the lives of people, things and the environment. In particular, in relation to health and social care research, anthropological intervention has been increasingly required to present its validity, relevance and responsibility with regard to ethics in order to not only ‘protect and promote’ the dignity, well-being and rights of people they study but also to provide the researched with more opportunities to ‘participate’ in the research within a safe environment (Health Research Authority, 2017). In particular, in relation to people living with dementia, such an ‘audit culture’ (Strathern, 2003) and governmentality require ethnographers to show in detail whether research hypotheses and methods follow the MCA: Is the research purpose, inclusion and methods grounded in accordance with the MCA? Is research carried out in a mutually beneficial, ethical and empowering way? Does anthropological intervention outweigh the risks to and burdens upon of research subjects?

However, anthropologists do not understand their research subjects as ‘spatially, temporally or ethically disconnected’ entities, nor as fixed things that can be objectified; they rather expect the understanding of research subjects to appear through continuous relations, interactions and encounters (Coleman and Collins, 2006, p. 10). There is no way for anthropologists to control and manipulate everyday life. In this sense, the question the anthropologist should ask is not about what is ethics in research but rather fundamentally about doing research differently through problematising. Indeed, the time I spent obtaining ethical clearance involved not only learning about procedural ethics but also involved presenting the research as ethical by negotiating, deleting and modifying. In this sense, I share my perspective with Keane and other Foucauldian ethicists that see ethics not as ‘fixed’ but ‘flexible and as situation-responsive as the subject matter itself’; ethics that are ‘not as the fulfilment of the a priori requirements of a normative theory or a philosophical thought experiment, but as something that emerges out of specific kinds of practices and
institutions, something we can discover empirically’ (Keane, 2014, p. 444). Namely, ethics emerge in practice forming an ethical subject through continuous reflexivity.

However, this ethnography pushes beyond ethical subject-making so as to reveal the everyday ethics embedded and situated in daily life which are difficult to discern due to their openness and entanglement with other dimensions of social life. The reason for this is because I find myself neither being an ethical ‘adjudicator’ nor an ‘expert practitioner’ or a facilitator in ethics-in-fieldwork (Meskell and Pels, 2005, pp. 1-25); rather I am a co-producer of everyday ethics in the condition of co-dwelling, engaging and interacting with the lives of others, things and the surroundings. It is interesting to note that the people I have met during my fieldwork commonly say there is an ambiguity and uncertainty about ethics. Acknowledging Orthodox Jewish ethics based on the concept of the ‘sanctity of life’ that is ‘an intrinsic value as a divine gift of creation’ and the consciousness of the chosen people, individuals are expected to show respect to the elderly and the ill as ‘duties and obligations in addition to rights’ (Jotkowitz et al., 2005, p. 881). However, when I asked significant others about ethics they barely drew a line between life and ethics unless they experienced a ‘moral breakdown’ (Zigon, 2007, p. 133) by ‘crossing the line’ (Hasselkus, 1997, p. 642-645), such as through verbal abuse. Ethics is already deeply embedded and immersed in life through repetitive and routinised work. Accordingly, while they perceive the importance of ethics in care, they do not recognise ‘ordinary taken-for-granted concerns as ethical issues’ in everyday life (Powers, 2001, p. 334). This finding calls for an ethics of the everyday, as it were, the everydayness itself which I understand through Al-Mohammad and Peluso’s work ‘Ethics and the “Rough Ground” of the Everyday’:

> The ways in which life is not only open to the pain, suffering, joy and ennui of others, but also how in the entanglements and relations of lives with other lives in the everyday, lines of care and concern emerge, are fostered, and also frayed’ (2012, p. 44).

In this sense, an ethics which is experientially and sensibly embedded in the body emerges and is practised through everyday interaction and engagement with the worldly surroundings in ways that are uncertain, undetermined and contingent due to the openness and entanglement of social life. This ethnography demonstrates ethics as an art of co-dwelling that is performed in the forms of making, linking and connecting relations. In the following chapter, I attempt to explore this in more detail in the case of Ayla’s sleep disturbance.
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S=Abraham Unit, W=Joel Unit, N*=Christie Wing and S*=Barry Unit; AD: Alzheimer’s Disease; H/W=House wife; D=Dementia; MCA=Mental Capacity Act
CHAPTER 2. ETHICS AND CARE AS WAYS OF CO-DWELLING IN EVERYDAY PRACTICE

1. What shall (can) I do?

I was on duty the other night and she came out. At 2am! I sat her down and asked how she was and why she wasn’t in bed. I talked a bit and tried to get her back to her room but she didn’t want to go (Interview with Silvia, a Senior Care Worker).

No. I don’t think she will [settle down in the Home] because she refuses to accept her situation. It is a sort of personal trait that she is very, very tenacious, she always was. As a mother, she could be a nightmare; I remember when I was a teenager, if she wanted to do something, she never, never, never gave up. But if we move her, it would be so difficult (Interview with Tracy, Ayla’s adult daughter).

I know but some of them are so ill. That nice one I know from here is now in hospital. I am threatened. I am frightened. They are gonna put me away if I am very ill. I cannot refuse that. I really don’t know (Ayla).

Silvia has no problem caring for residents who have disturbed sleep, but it is not a good idea to keep Ayla awake at this time, as the episode will no doubt affect her day, making her drowsy and in turn keeping her awake the following night. She needs to negotiate with the resident to get her back to bed. Tracy is as baffled as ever. It was her mother who chose the Home, but as her dementia progresses, she complains about it more and more. Considering her mother’s personality and character, this will not stop until she moves to another care home. But a move to another place would be more problematic because, as her mother often says, she has doubts as to whether someone is actually putting her away. For Ayla, she has no friends here and trusts no one. She is no longer active and strong enough to endure her lived reality of dementia. Denial seems to be the only thing she can manage now.

What is at stake for me in these three quotations is the ordinary complexity of ethics and more importantly their testimonial values that reflect everyday life and care practice at the Home, but often remain taken for granted, unheard or undervalued. In other words, these unfinished commitments attest to the very human condition of co-dwelling and ‘the complexity and perhaps inconsistency of human action and intention’ in terms of ‘ordinary ethics’ (Lambek, 2010b, p. 9). To put it concretely, everyday life emerges through ongoing interaction and engagement with the lives of others and thus demands a range of moral/ethicalendeavours in order to maintain them,

17 In this chapter, drawing upon Al-Mohammad’s (2010) proposition of ethics as everyday life, I do not distinguish between ethics and morality. For more detail, see the fourth subsection.
flourish within them or endure them. This is what Veena Das calls ‘moral striving’ (Das, 2010, p. 376). Unfortunately, this kind of ordinary striving and its implications have drawn little attention from academia within the study of dementia. In this chapter, I attempt to explore this ordinary moral/ethical striving in the event of Ayla’s disrupted sleep among those involved: the Home, its staff, Tracy, Ayla and the researcher.

Over the past three decades, much work has highlighted the importance of identifying and understanding the ethical issues and concerns of living with, working with, caring for and researching people with dementia (Hughes and Baldwin, 2006; Nuffield Council on Bioethics, 2009; Rai and Eccles, 2009; Oppenheimer, 2009; Hughes, 2014). Daniel Strech and his colleagues’ systemic qualitative review of clinical dementia care demonstrates that there are 56 ethical concerns categorised in seven different groups: diagnosis and medical indication, assessing patient decision-making competence, information and disclosure, decision-making and consent, social and context-dependent aspects, care process and process evaluation, and special situations for decision-making (Streich et al., 2013). It is true that these studies have contributed to raising awareness of ethical practice and providing ethical guidelines, but they are also abstract and inflexible.

Whereas these professional and organisational normative ethics indicate how people should live, work and research, day-to-day care practice and illness experience, which are much complicated and intricately interwoven with the lives of others and their surroundings in any given time and space, are understated. As Julian Hughes (2014) and Clive Baldwin (Hughes and Baldwin, 2006) assert, people are always entangled with others, and thus an ethical dimension of daily life should be perceived as relational, situated and embodied in-the-world. There is no ‘pure’ or predesigned moral norm or ethical practice in reality (Fassin, 2014, p. 432) because it is difficult to discern ethical reflections on moral principles and more precisely, it is experientially indissoluble in everyday (care) practice. For example, the casuistic approach established in the report Dementia: Ethical Issues (Nuffield Council on Bioethics, 2009) is recommended for use in the sphere of bioethics, as it looks at ethical matters case-by-case based on moral theories and ethical frameworks (Hughes and Common, 2015). Like other normative rules and regulations, however, it cannot encompass everyday ethical dilemmas, nor does it reflect the way in which ethical experience and practice emerge, circulate and reproduce in practice. That is to say, ethics is continuously contested and negotiated in the formation of social life. Consequentially, this lacuna calls for an epistemological shift from normative ethics to ‘ordinary ethics’ (Lambek, 2010b) or ‘ethics in action’ (Powers, 2003, pp. 59-99), asking how people act and
respond when facing ethical dilemmas, or in Zigon’s terms, when they face ‘moral breakdown’ (2007; 2008).

Secondly, it is regrettable that previous studies are unbalanced in terms of dealing with ethics in a dementia context. Less attention has been paid to the way in which people living with dementia ethically act, speak and think. This is unarguably a result of doubts concerning their agential abilities, such as their mental capacity and personhood. Because if a person with dementia is not the same person due to loss of language, cognition and memory, previous discourse and arguments about ethics and morality based upon individual autonomous and conscious agency, responsibility and freedom become fundamentally questionable. It is ironic that there is no ethical subject with dementia in most published papers, articles and books except for a few autobiographies (e.g. Bryden, 2005; Taylor, 2007; Phelps, 2012): the ethical becoming without subjects. More precisely, there are only mere ethical beneficiaries or objectified ethical beings with dementia in the study of ethics in dementia.

In brief, the complexity, ambiguity and indeterminacy of ethics in everyday (care) practice and the absence of ethical becoming from the first person perspective calls for a new way of understanding, a new approach and perspective which would otherwise remain unrecognised. In addition, these complexities require us to explore the very context and situation of the everydayness of ethics in the process of continuous and dynamic social interaction and encounters between those involved. In other words, questions about what ethical issues are at stake and what counts as an ethical dilemma need to be considered in relation to the socio-cultural, institutional, biographical and medical context in practice.

Taking the example of Ayla’s sleep disturbance and related care practice, this chapter attempts to demonstrate the ways in which she speaks, acts and enacts in response to her existential crisis in an institutional setting. Beyond the stories of human rights, moral norms or ethical regulations, I compile ethnographic evidence of ordinary endeavour in (care) practice from all parties involved. In doing so, I argue that ethical issues are ‘pervasive’ (Hughes and Common, 2015, p. 42). However, this does not mean they are ‘inherent’ and ‘unproblematic’ in action (Fassin, 2014, p. 432); instead, ethical dilemmas emerge in the process of striving with social interaction and communication (Lempert, 2013) whilst undergoing illness.

Taking a step forward, acknowledging the openness and entanglement of life in relation to the worldly surroundings, I criticise current bioethics based on the concepts of autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress,
2001), mainly with regard to people with dementia as the receivers of care. Then, I argue that the concept of an ‘ethical or moral subject,’ which is based on individual cognitive and autonomous agency, is insufficient in embracing an ethical becoming with dementia. Alternatively, regarding people living with dementia as co-producers of care and ethics I suggest a situated and embodied ethical becoming with dementia in the condition of ‘being-with’ (Al-Mohammad, 2010, p. 427) in dialogue with the Deleuzian theory of becoming.

The following consists of four subsections. The second subsection briefly describes Ayla’s interrupted sleep, including the way in which the institutional structure and subculture of care is implemented in everyday care practice. Furthermore, Ayla’s biography and her illness experience are illustrated as the background of her striving to make connections, relations and establishing familiarity with others and her surroundings whilst coping with her feelings of hopelessness, frustration and anxiety.

In the third subsection, I reconfigure Ayla’s disrupted sleep in the formation of ethical subjectivity from the perspective of those involved. In doing so, I shed new light on the potentiality of becoming ethical in the condition of co-dwelling. In the fourth subsection I revisit the ways in which embedded ethics and care emerge and are practised in dialogue with Al-Mohammad’s everydayness and Deleuzeian thought on becoming and bodily desire. In conclusion, I would argue for an ethics as a mode of co-dwelling.

2. Ayla’s Disrupted Sleep

(1) A Description of Sleep Disturbance and Care

It is only twenty past five and daybreak has not come yet. Silvia, a senior care worker, has already noticed that Ayla has had a prolonged absence from her bed. She keeps monitoring the control board on the care desk, asking Sonnet, a care worker, to check Ayla’s well-being and whether she is moving around. Sonnet looks down the corridor on the way to the medical storeroom to prepare the morning care equipment, and gestures to us that Ayla is walking towards the desk.

Ayla has a sleepy face and dishevelled hair. Her sweater is pulled to the right but she does not seem to care. After her hip replacement surgery, her walk is insecure and wobbly. Whenever she takes a step forward, her body sways both ways. Her Zimmer frame is dragged rather than supporting her. On her way to the desk, she often pushes her walking-frame away. Sonnet hesitates to help but attentively waits until Ayla passes. When Ayla senses Sonnet’s presence, she stops and looks at her several times. As soon as she recognises her, she turns in the other direction, her face showing
disappointment. Sonnet asks Ayla whether she is okay. Ayla says something but it is as though she is mumbling to herself. After a brief encounter, Sonnet advises her to see Silvia at the desk.

Ayla takes one step and then another very slowly, gazing towards the desk. It looks as though she is looking for something or cautiously looking around. Silvia greets her, asking what has happened and showing her concern that it is too early to be awake. Ayla mumbles again in a very low voice and then comes toward Silvia, saying she cannot sleep and wants to talk to Tracy. Silvia asks her whether she has tried to call her daughter using the telephone in her room. Ayla says she has tried but has failed and she asks Silvia to call her daughter. For a while, they quibble over calling Tracy because Silvia says it is not right to call someone at this time of day. Ayla becomes nervous and starts to frown. Silvia recommends Ayla has some tea and calls her daughter early in the morning, but Ayla’s anxiety is getting worse. This negotiation has lasted more than ten minutes. Silvia cannot do any morning work because of Ayla’s persistence and her facial expression of hopelessness. At last, Silvia seems to have no choice but to wait until the sun rises.

A while later, Silvia asks her to take a seat next to Robert who is taking a rest on the sofa in the communal area. Like Ayla, he woke up and could not get to sleep again. He was tossing and turning and left the room in order not to wake his wife. Ayla turns her head to the area but cannot figure out who he is exactly. It is a bit dark because the lights are off in that area. She walks towards Robert. Once she recognises him - an ex-mayor who has been married to an ex-magistrate for about seventy years - she stops to adjust her clothing. He is one of the few in the care home that she feels a sense of friendship with. His way of speaking and his manner reminds her of old friends and colleagues in North London where she lived for the entirety of her middle and later life. Sitting next to him she greets him and tries to talk. Robert opens his eyes after noticing Ayla’s presence. They catch up on each other’s lives very briefly, but the conversation...
does not last long. His voice is slow and weak. She looks at him and tries to listen to what he says, but his voice is overwhelmed by his sleepiness. His eyes are also closed. Only silence passes between them. Her eyelids are also getting heavier. About half an hour later, she opens her eyes again when she feels him leaving for his bed. She is alone again. For a while, she appears to be restless, standing up and sitting down repeatedly and looking vacantly into the distance. She approaches Silvia and asks again about the phone call, but does not get the answer she wants. She withdraws to the sofa again, reclining inertly with half-closed eyes. Silvia asks her to have tea whilst she waits to call her daughter, but Ayla is not interested in drinking tea. At about five to six, Sonnet asks Ayla whether she wants to take a shower so as to start the day earlier than usual before calling her daughter, and Ayla follows her.

(2) Institutional Structures and Subcultures of Care

As Kitwood mentions (1997, p. 102), ‘caring springs from the spontaneous actions of people who are very resourceful and aware, able to trust each other and work easily as a team’. However, depending on individual staff experience, socio-cultural background, skill and motivation, the ways in which care services are delivered vary. Thus, the institution tries to set goals and safeguards in order to provide, maintain and develop quality of care and life. As we have seen in Chapter 1, the establishment and development of Florence House is based upon traditional Jewish (religious) obligations, what is called tzedakah in Classic Hebrew. It means ‘justice or righteousness’ but is generally used as ‘charity, benevolence, gemilut hasadim (bestowing loving kindness)’ in day-to-day life (Roberts, 2001, p. 2). However, this Jewish attitude to charity (tzedakah) differs from other charitable behaviours and organisations in relation to the care of the elderly in that it morally, religiously and culturally enforces Jewish people (including non-Jewish staff) to observe it as ‘an unmistakable priority’ (ibid, p. 2). Needless to say, the Home emphasises the teaching of the Torah and Talmud in the name of charity for the poor, the ageing and the ill, that they should not be blamed but respected as an obligation. Charity is deeply embedded not only in the institutional subculture but also in Jewish daily life as an essential attitude.

It is evident that over the past 170 years the Home has made a huge effort to develop a specific cultural, religious and moral attitude, emphasising that as an Orthodox Jewish charitable institution it is ‘to provide holistic quality care, assistance and support to older Jewish people in a safe and stimulating environment using dedicated and trained staff and volunteers,’ based on five different values consisting of ‘compassion, respect, excellence, dignity and integrity’ (Mission and Values of Florence House as of 2015). This mission and these values are structured in more detail through
Care Governance, ensuring that all clinical and social dimensions of life lived with illness are included in the long-term care facility:

All residents in our care receive services that are person centred, of a high quality, safe and evidence based, where evidence is available, in an environment that provides for open and non-judgemental ongoing assessment of practice for and with all Florence House care employees (Care Governance as of 2015).

Accordingly, individual care staff are assigned personalised care and designated duties depending on their level of training and the development plan, such as Medication, Nutrition, Infection Control, Health & Safety, Fire Marshal & Office Filing, Incontinence Assessor, Wheelchair Lead & Stock Replenishment, Food Champion, Vital Signs and so forth.

While care governance offers a structure of care practice in the care home, Person-centred Care (PCC) and the Gold Standard Framework for Care Home (GSFCH)\(^{18}\) training provide a subculture of care practice with a philosophical orientation. Their training contents are displayed around the Unit and regularly updated in the form of posters or information graphics made by training participants and care staff. In particular, PCC has drawn attention not only to health care professionals but also to service users. It criticises the task-oriented care practices and hierarchical relationships between the service provider and the user. Accordingly, it contributes to changing such unilinear relationships from being ‘to’ or ‘for’ ill people, to being ‘with’ them in delivering care services by allowing the user to make decisions as co-constructors of communities in everyday life (The Health The Health Foundation, 2014, p. 3). The Home implemented PCC as an alternative care practice in partnership with the Bradford Dementia Group at the University of Bradford in January 2011. PCC aims to not only provide excellent provision of care but to produce practical tips for dementia care:

Care is concerned primarily with the maintenance and enhancement of personhood. Providing a safe environment, meeting basic needs and giving physical care are all essential, but only part of the care of the whole person (Kitwood, 1997, p. 136).

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\(^{18}\) GSFCH, as a quality improvement care programme, qualifies for accreditation which is recognised by the Care Quality Commission (CQC), by the National Health Service Choices (NHSC) and by other related care quality provisions. The Home has offered GSFCH training to care staff in partnership with St Christopher’s Hospice in London since 2004. While GSFCH training provides credits, guidelines and criteria for obtaining excellent accreditation, PCC offers practical tips and a philosophical orientation. PCC is regarded as the gold standard care practice not only in the Home but also for all other concerned parties including CQC, the NHS, the government and other care organisations. In this chapter I focus more on PCC in order to explore ethics-in-action.
More specifically, Tom Kitwood, the founder of BDG, adopted and developed the concept of ‘client-centred therapy’ from Carl Rogers' humanistic psychotherapy (1995; 2012) and conceptualised the term PCC during the 1980s and 90s (Kitwood, 1997). He emphasises communication and relationships rather than individual ability in cognition, memory and language. Later, Dawn Brooker concretised the term in the form of an equation: PCC=V+I+P+S:

V: A value base that asserts the absolute value of all human lives regardless of age or cognitive ability.
I: An individualised approach, recognising uniqueness.
P: Understanding the world from the perspective of the service user.
S: Providing a social environment that supports psychological needs (Brooker, 2007, p. 13).

Individual staff members are provided with basic training for PCC and depending on their achievements, care workers are offered Dementia Champion training. This is usually practised together with Dementia Care Mapping (DCM), developed by Tom Kitwood and his colleague Kathleen Bredin (1992) to deliver more efficient PCC training, as well as to evaluate care practice from the perspective of people with dementia. Mapping usually takes place in public areas based on observation. During the session the mappers collect detailed information, evaluate and codify the expressive and behavioural bodily experience of those affected. In Florence House, DCM usually takes place in other Units at least 2 to 3 hours during the day for several days, totalling up to 15 hours. The mapping is only used for care training but the results are reported to the Unit in which the mapping was carried out and discussed among staff in regular meetings in order to improve care practice. Over the past half-decade, PCC alongside DCM has been successfully implemented and continuously developed in collaboration with BDG. As of 2016, most of the team leaders and senior workers have taken this training and become ‘dementia champions’ on the Unit. Recently, palliative care together with the Namaste Care Program (Simard and Care, 2013) has been prioritised in line with PCC due to recent dramatic demographic changes in age and prevalence of dementia.

In brief, the institutional subculture can be characterised by an organisational code of practice based on Orthodox Jewish commitment, charity, which has been captured in the form of PCC. It emphasises care practice based on the service user’s best interests, including their needs, preferences and strengths, considering persons with dementia

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19 It offers simple, practical and holistic end-of-life care for people with advanced dementia based on individual sensory experience. It involves stimulating and aromatic scents, comforting music and hand massages. The Namaste care program was initially implemented in the Advanced Care Unit in 2013 and has since spread to all other Units.
as ‘experts’ on themselves and those who care for people with dementia as ‘facilitators’ (Graham, 2015b, p.6). However, the concept of personhood is always ambiguous, not only because of its diverse usages reflected in different perspectives on different roles and professions, but also because of its continuous development through daily (care) practices and activities (Hung and Chaudhury, 2011). Nolan and his colleagues also criticise the current autonomous individual centred understanding of PCC, suggesting that we need to reflect more on relationship-centred care (Nolan et al., 2004). By developing the ‘six senses framework’ which consists of six vital senses of security, continuity, belonging, purpose, achievement and significance, they insist that care homes need to be built as a community in which all staff, families, residents, volunteers and friends are asked to work together as community members (Nolan et al., 2004). Likewise, the National Service Framework (NSF) for Older People is criticised for its ‘individual’-centred approach (Department of Health, 2001, p. 8). Accordingly, this brings people with dementia away from the social, cultural and political, alternatively suggesting relation-centred or interpersonal care (Nolan et al., 2004; Bartlett and O’Connor, 2007).

To sum up, PCC is neither individual-centred care practice, nor does it offer a grammar of ethical practice that everyone should follow. It should be understood in the context of the relational and situational. More significantly, there is a different intensity in the Jewish way of life, charity, and PCC. In addition, there is less agreement on the accountability and PCC practice between the organisation and persons in action. Namely, in everyday care practice, PCC and other abstract institutional care governance is actualised in the form of bureaucratic accountability by checking, recording and evaluating individual performance (Parker, 2001) through Performance Assessment Frameworks (Department of Health, 1999a; 1999b; 2000) through Personal Care Daily Records and Night Hourly Observation Charts. Consequently, this has a negative effect upon the staff in that they think they are only required to finish work on the checklist.

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20 The form asks the recorder to detail ‘the story of the resident’s experience and care needs, since the last entry. Typically residents experience engagement with activity, food and drink, using the toilet, washing and skincare, each shift. You must record the resident’s well-being and mood during these experiences, and what, if any, support was needed. There may also be additional information to record, such as reactions to distress, a visit from the GP or relative, or if the resident had a fall. If you did not witness the experiences, you must record where the information came from (e.g. ‘it was handed over to me by...’).

21 There are nine different behavioural categories, BS: Sleeping in bed, BA: Awake in bed, W: Wandering, L: Lounge, O: Out, H: Hospital, CS: Sleeping in chair, WT: Watching TV, T: Toilet.
(3) Ayla’s Existential Crisis: Living in a Nauseating Reality

Ayla’s brief biography was collected during fieldwork and based mainly on her autobiographical storytelling. As her medical condition has evolved, her narrative has become more fragmented, confused and entangled. Conversations are often disconnected and abruptly turn to other subjects. However, this does not mean she has no story, nor does this subsection aim to reveal her inability to recollect her biographical memories. Instead, I focus on her generative intention and motivation to tell her story in response to her immediate circumstances (Mills, 1998; Hydén and Örulv, 2009; e.g. Hydén, 2011) which, from her point of view, can be characterised as relational.

Ayla was born in Scotland in 1929 to a Jewish family who emigrated from Russia to escape the pogroms, the persecution of Jewish people in the early 20th century. She has five siblings including her twin brother, whom she is proud of and who always took care of her when she was young. In particular, her sister, Michelle, was always the champion of the family and became a well-known pianist, marrying a Hungarian gentleman. Whenever Ayla has the chance to say anything about the arts, she always boasts about her sister. Furthermore, she has an ‘extended’ family of Jewish refugee children of her age, whom her family lived with during the time of World War II. Initially the children thought they were in America, and later some of them decided to live with Ayla’s family and others did not. One of them, who changed his German name to an English one, became a famous entertainer in Europe and became one of her best friends whom she admires and remembers fondly. Thus for her, the War was not necessarily hostile and horrifying but endurable. Although she often heard terrible news, she was able to live and explore her uncertain future as long as her adolescent life was full of friends and family. Playing tennis and socialising with them were the best memories of her youth. Ironically, the War had an influence on her afterwards in that she could not go to University due to ‘a great number of men who came out of the forces and took the places at Universities,’ in her words. Luckily, she undertook language teacher training in Latin and French instead and became a Jewish primary school teacher in Glasgow and in London, on and off on a full-time or part-time basis. Most importantly, during the training in Glasgow she met her husband-to-be on a blind date. After they married, they moved to Newcastle and then to London, followed by the opening of her husband’s business. She has two adult daughters and a son who have their own successful lives. One of her daughters, Tracy, also works as a teacher in London. It is Tracy who not only gives her emotional, social, economic and legal support but also recently gave her a great grandson. He is named after Ayla’s father.
Meanwhile, the other daughter whom Ayla hardly talks about has suffered from Multiple Sclerosis (MS) for many years.

Although Ayla suffered from minor depression and there were ups and downs during her middle age, she was able to manage as long as she was with those who supported her, such as her husband and other lifelong friends. Although her daughter who has MS is a cause of concern and worry, she knows she is under the good care of her own family. The situation, however, dramatically changed after her husband passed away. What is worse, dementia has slowly taken her previous life and memories away.

Since coming to Florence House in December 2010, Ayla’s illness has gradually worsened. Over the following five years she had two major operations on her hip and her right eye due to falls, cataracts and macular degeneration. She often describes her life as spiralling out of control. Several episodes of verbal and physical abuse towards staff and other residents have been documented in her medical chart and personal care plan. It includes yelling and shouting ‘stupid,’ ‘daft,’ and ‘liar’ together with banging, pushing and shaking tables, throwing spoons and knives and so on. Above all, the most serious concern is her verbal abuse towards other residents, which often triggers stress and anger on their part. From their perspective, she is often described as a ‘clever girl’ who ‘diplomatically’ uses her miserable face and feeble voice to obtain attention from the staff and other volunteers. Staff members also understand her needs in terms of her anxiety management, and they try to divert or distract her from any risk factors. For example, they are aware of her favourable relationship with some other residents and those she often yells at. Therefore, whenever social gatherings such as meals, concerts and daytrips are organised, her seat is tactically arranged in relation to her relationships and preferences. However, against her wishes, the staff and her supporters cannot always be with her. Unexpected encounters in the care home happen. In turn, she also needs to face an uncertain and contingent world around her on her own terms. Unfortunately, this becomes problematic due to her progressive medical condition. Indeed, she has not yet familiarised herself with the institutional setting, pleading to return to her own home in North London. Her friends from North London who used to visit have stopped coming since 2014 and her only friend in the Home passed away in 2013. The only thing she can do within her capability is to find a person she can rely on and make her environment as familiar as possible. This relational and dependent personality is often revealed in her attachment to her old house and personal belongings and her handbag is always full of old photo albums of family gatherings.
3. Ethics as an Entangled Engagement with Worldly Surroundings

This subsection shows an ‘assemblage of ethics and morality’ (Zigon, 2010b) from the perspectives of those involved in ethics-in-action - the Home, its staff, Ayla, Tracy and the researcher - by carrying out a ‘microanalysis’ (Biehl and Locke, 2010, p. 337) of bodily expressive performance. The assemblage offers insights into the dynamic, complex and immanent field of ethics that people live through continuously participating in a formation of the social.

(1) Care Workers: Articulating Embedded Ethics with Attentive Empathy

From a staff perspective Ayla’s episode is regarded as displaying abnormal behaviour which requires therapeutic and psychological intervention. As far as her sleep pattern and history of sleep disturbance is concerned, it is unusual for her. Ayla keeps murmuring, showing signs of depression, agitation and anxiety. Her repetitive and desperate requests to call her daughter are discouraged by Silvia but Ayla does not stop. She asks again whether Silvia knows when her daughter will come. Silvia looks over the daily logbook and Ayla’s Care Plan, but there is no indication of a visit from her daughter. Ayla is perplexed, gazing at Silvia with a desperate face. She does not believe her, as though she has something to hide. Silvia shows her the logbook and weekly schedule and asks her to have a cup of tea to calm her, but Ayla does not want anything but to call her daughter. Ayla becomes worse and in the meantime Silvia cannot do anything else. Finally, she asks Ayla to take a rest next to Robert.

Should Silvia stop the work she has been preparing for the morning, sitting next to Ayla and listening to her whilst offering her tea or coffee? Should she call Sonnet who is in charge of the wing in which Ayla resides and ask her to take care of her? How much can Silvia share with the other staff? Is the rhythm and tone of voice she uses to persuade Ayla enough to convince her? Is it better to help Ayla to call her daughter? Which action would work in Ayla’s best interests without hurting her dignity and feelings? What is the appropriate time and number of staff to help Ayla call her daughter per day?

To summarise, from Silvia’s perspective, caring for Ayla’s sleep disturbance is deeply interwoven with the works and lives of other residents, colleagues and family members as well as the subculture of care in the Home. Unfortunately, normative ethics protocols, regulations and even PCC do not offer practical tips in this particular case. One thing Silvia is sure about is that Ayla needs some attentive and respectful support and she has some work that needs to be done for her morning care. *It never rains but it pours*. She weighs up all the possible actions she could take at this moment.
and the potential outcomes. Regardless of the cause in this situation, once Ayla’s sleep pattern is broken, it influences the rest of the day and night and sometimes may go on even longer. She may be inert and may not want to engage with activities because of tiredness; she may want to take naps during the day, which would potentially interrupt her sleep pattern at night, turning her sleeplessness into a vicious circle. What is worse, sleepiness can cause falls during the daytime. Silvia’s tender and soft voice becomes a bit rigid. Ayla does not move for a while, waiting for another response, but in vain. She appears lost for a moment, not knowing where to look or to go. Silvia leaves a note for the next member of staff, informing them that Ayla should have an ‘ordinary’ day, without too much napping or sleeping. She knows from her experience that putting someone to bed is not the end. Lying down on the bed and sleeping are two different things.

Meanwhile, Silvia also needs to think about her nightshift duties and related achievements. Morning care - what is called ‘setting up’ - such as assisting washing and dressing, cannot be ignored for the day. Night care consists of compulsory things that all residents are assisted with at some point in time. There is more flexibility at night, whilst setting up is a job that requires negotiation and skilful communication to get cooperation from residents. Residents have their own rhythm of life as to when they prefer to wake up, wash and get dressed. Other times, they want to stay in bed. Although nightshift care workers usually know about individual sleep patterns, their preferred night environment, toilet time and its frequency, and the time of callout for assistance from previous experience and the advice of colleagues, it is always a matter of negotiation between the residents and care workers:

_Tziona calls at 5 o’clock every morning. I know what time everybody wakes up and goes to sleep. If Tziona does not call at this time, someone needs to check. Each has their own time, otherwise they wake up and scream_ (Interview with Cecil, a Nightshift Care Worker).

Concomitantly, Sonia also needs to think about the expectations of the dayshift workers:

_If we do not wake residents up and do not prepare for the day in the morning, they [dayshift staff] will complain and I do not like to listen to that_ (Interview with Sonia, a Nightshift Care worker).

Needless to say, prioritising time and the flexibility of caring practices are pivotal (Egede-Nissen et al., 2013) in PCC that require care workers to put the person first, considering individual residents’ unique preferences, needs, ability and life history and treating them with dignity and respect. Ironically, if staff literally respected and followed what residents want to do or ask for, they would receive complaints about
their incompetence, including a personal complaint from senior staff, regardless of how hard they work overnight. Their whole PCC would be de-valued because of respecting the will and interests of residents too much. In practice, as we have seen above, PCC is not something which needs to be instated as a rule or regulation, but is rather an on-going process of negotiation through interaction and communication - ‘a matter of practical tinkering’ in the words of Mol and her colleagues (2015, p. 13).

Finally, Silvia thinks it would be better to be with Ayla. Sonnet also changes her morning schedule of assisting personal care by putting Ayla first.

(2) Tracy: Living in a State of Liminality and Observing Charity

It has been a long time since Ayla was trusted to call her daughter by herself. Her macular degeneration and cataract make it difficult for her to find the numbers on the phone. There was a time when she anxiously, eagerly, and repetitively called her daughter regardless of the time. Of course, answering repetitive calls is not an easy task for Tracy. Working as a primary school teacher, she has her own rhythm of work and life that is more or less divided by work in the day and rest at night. Although the calls were to some extent manageable, it was also difficult, and in particular when Ayla called her at night or at dawn. In fact, there was rarely a scheduled time for a call. One day, Tracy consulted with care staff and professionals in the Home about this matter. This consultation was interpreted as her wish to no longer get calls from her mother at inappropriate times.

It was a surprise as well as a relief that Ayla’s repetitive calling did not last long. For some reason, Ayla stopped calling her daughter and Tracy did not pay much attention to why. To be precise, Tracy sometimes got a call from her, so she did not doubt her mother’s capacity until she heard from the staff and researcher that Ayla’s capacity fluctuates and thus is unpredictable. Tracy thinks positively that repetitive calling may be a typical behavioural symptom of dementia, which she needs to endure as her mother’s illness progresses. But when she hears about Ayla’s deterioration, and that she has difficulty using electrical items, such as the TV, radio, electric light stand and the telephone, it is a completely different matter and it is not hard to image her feelings of distress. The telephone in Ayla’s room has already been changed to a dementia-friendly one. Tracy asks for more attentive care from care staff. Visiting every Saturday is reasonable, but she says that in her mind there is always a feeling of guilt she cannot escape. Ayla’s fluctuating capacity makes it more confusing and difficult in terms of Tracy’s responsibility and her roles as an adult daughter, a legal representative (a power of attorney) and a family carer. As Gibbons and his colleagues (2014) demonstrate, family caregiving is a liminal experience in that while the process
of becoming a caregiver is ambiguous, the end of social and emotional suffering is uncertain. Neil Small and his colleagues (2007) also note in their study of palliative care with dementia that from a caregiving perspective, loss is experienced in a liminal state of uncertainty and ambiguity in that people do not know how long their suffering will last. Above all, as Ayla’s dementia develops, their relationship is transformed and so is Tracy’s role. However, it is far more complex than initially expected. As Ward-Griffin describes (2007), a mother and adult daughter relationship within dementia care evolves into a range of modes, such as custodial, combative, cooperative and cohesive, depending on the levels of support and expectations of care. Chesla and Muwaswes (1994) reveal three types of caregiving relationship with people with Alzheimer’s disease: continuous, continuous but transformed, and radically discontinuous. Brenda Gillies (2012) also demonstrates carers’ ambiguous relations and their efforts to maintain reciprocal relationships in loss through compensatory actions, assistive technology and the care environment. In brief, although there are some differences in their perspectives, what Ward-Griffin, Chesla, Muwaswes and Gillies have in common is that they see caregiving relationships as transformative, and the process as complex, ambiguous and uncertain.

The reason Ayla calls her daughter seems to be obvious in that she wants to secure her safety and support by relying on familial love. Unfortunately, the reality is harsh for both parties as her illness evolves. Tracy cannot remember how many times she has told her mother that she cannot move to her old house in North London in which nobody lives, and that she cannot always be with her mother because she also has her own family and a job to take care of. Above all, moving into the Home was Ayla’s own decision after failing to live in another care home close to Tracy’s house, although now she does not remember this at all. Tracy often feels so frustrated that she does not know what she should, might, could or would do for her mother as well as for herself. She expected her mother’s transition from her home into institutional care to offer some relief and lessen the stress for both parties, but stress and anxiety in relation to her responsibility has hardly lessened. The stress of caring and its responsibility gradually intermingled with her daily life just as before and in ways have become even more intricately entangled (Milligan, 2003). In reality, she cannot disconnect her concern for her mother from her everyday life. Rather, as she mentions in her interview, prolonged exposure to a pressurised caring responsibility and devastating stress lead Tracy to feel hopeless and guilty about her inability to show her mother empathy and love (Day et al., 2014).

In brief, this ambiguity and the uncertainty about her responsibility, role and situation make it more difficult for Tracy to observe her charity as a caregiver, an adult daughter,
a wife, a grandmother and the consumer of a care service. Of course, her way of observing charity based on Reform Judaism cannot be neglected because there is a different intensity of embeddedness in practicing the duty. For her, enacting charity is embedded in her everyday caregiving as an abstract moral reasoning. Charity does not offer her practical ways of doing, saying and making decisions about her mother’s daily care; neither do books, articles or pamphlets about dementia care provide her with a clear idea of how to care for her mother. Needless to say, charity is not predetermined or innate; her charity instead emerges in the process of interaction and encounter, reflecting her striving within the continuous, complex and dynamic negotiations among the ethical questions of what is right or wrong, what is the best option for her mother, how much she should (and can) involve herself in her mother’s daily care routine, in what way she should (and can) behave and take action, and so forth. It reminds me that, as Binaca Brijnath describes in her book Unforgotten (2014), there is always anxiety, social stigma and a feeling of loss in caring for people with dementia, yet at the same time there are always possibilities of connection, love and empathetic relations between carers and those affected. Living not with loss, but in loss, Tracy performs her charity in the name of love, although she has never felt this was ‘enough’. In other words, as a daughter she believes and even anticipates that her mother would recover some day and settle down in the Home, although she knows it is impossible. On Saturday, she may again explain that she cannot come on weekdays and ask for more attentive care from the staff.

(3) Ayla: Existential Concerns and her Striving
Ayla wakes up too early. She tries to sleep again but it does not work. She is likely overwhelmed by her depression and anxiety. She calls her daughter again and again but fails each time. There is nothing she can do but try to find any person she can rely on and be supported by. She seems to find herself in an unfamiliar and insecure environment. She first encounters Sonnet, but Sonnet is neither familiar nor an intimate. Ayla quickly passes by her and walks towards the desk.

Here I pay attention to the ways in which she strives to obtain what she wants, focusing on her bodily expressive performance as ‘embodied memory’ (Kontos, 2005; 2006a; 2012) and ‘body techniques’ (Mauss, 1973; 1979; Goffman, 2008) including ordinary language. Unlike her interaction and encounter with Sonnet, Ayla performs diverse ways of speaking with different intensities of tones and rhythms for example, mumbling, crying out, appealing, repetitively asking and silencing - whilst rejecting any alternative suggestion, such as taking tea. She also shows different ways of acting and bodily movements such as showing signs of her emotion and affective feelings through
withdrawing, gazing and staring. It is worth noting Alan Rumsey (2010) and Jack Sidnell (2010)`s study about “the Ethics of Speaking” in Ordinary Ethics (Lambek, 2010b). In responding to Wittgenstein and Austin`s arguments on ordinary language, they identify that ethical insight is:

[embedded in the categories and functions of language and ways of speaking, in the common-sense ways we distinguish among various kinds of actors or characters, kinds of acts and manners of acting; in specific nouns and adjectives, verbs and adverbs, or ourselves intelligible to one another, in “what we say when” (Lambek, 2010a, p. 2).

Ayla`s ways of interacting and communicating with Sonnet, Silvia and Robert are quite different from one another. The intensity of her voice, her gestures and bodily movements vary. Unlike engaging with the staff, when she recognises Robert, she stops to rearrange her clothing. Her tone of voice and attitude towards him are friendlier.

Pia Kontos` concept of embodied selfhood allows us to re-evaluate Ayla`s singular ways of speaking and doing that are characterised not only as socially embodied bodily practice but also as `intersubjective and intercorporeal` (Csordas, 2008) in the making of connections and relations within her limited language, cognition and memory. However, while Kontos successfully demonstrates embodied bodily practice in the context of the situational, relational and creative, her interpretation is limited to immediate social action and situations. In other words, her ways of approaching the embodied self ignore bodily desire, which is future-oriented. As Kitwood says, interaction is not just `responding to signals, but of grasping the meanings conveyed by others; it involves reflection, anticipation, expectation and creativity` (1997, p. 87). It is worth drawing upon Erving Goffman`s theory of body in (his) Relations In Public (2009) which develops upon the concepts of `body techniques` from Marcel Mauss (1973; 1979) and `intercorporeality` from Maurice Merleau-Ponty (2002). Goffman demonstrates the `interdependency and relational constitution` of those two concepts, what he calls `corporeal-cultural techniques` (Crossley, 1995, pp. 134-135) through socialisation. How Goffman`s concept differs from Kontos` is that, as Goffman shows with the notion of `pedestrian behaviour`, he opens up a new horizon of interactive, contingent and forward-looking body techniques. He demonstrates that ways of walking are continuously transformed and transforming in relation to the walks of others, reflecting not only individual physical and psychological conditions but also the social context at any given time or space. Likewise, Ayla uses her embodied techniques that are socio-culturally embedded in her body to make a connection with Robert. At the same time her body work shows a `moral order` which demands `sound character`
and ‘reasonable competence’ (Crossley, 1995, p. 139) in the process of her interaction and communication. Goffman’s body techniques do not only provide co-produced, co-ordinated tacit bodily conversations, but also offer bodily moral dispositions that reflect Ayla’s striving to make a desired network and relation.

Taking one step further, her experience is not a mere assemblage of temporally constructed episodes or events. To have an experience means something is enacted in and through her body as a bodily experience. As Heidegger notes, the experience of becoming other via a technique of the self includes a dramatic bodily change in being-in-the-world, namely ‘to undergo an experience with something - be it a thing, a person, or a god - means that this something that befalls us, strikes us, comes over us, overwhelsms and transforms us’ (Heidegger, 1971, p. 57). Likewise, Ayla’s bodily expressive movements and gestures should not be taken for granted as an ‘authentic, intensely human, existential given’ (Desjarlais, 1994, p. 898). Her bodily memory and technique are constructed not as a ‘discrete analytic element’ but as ‘enacted assemblages’ with ‘interconnected cognitive, affective, and transpersonal processes’ (Kleinman and Kleinman, 1994, p. 719). In particular, her bodily expressions of suffering and existential concerns remind me of Veena Das’s work on pain and its intersubjectivity:

Pain... is not that inexpressible something that destroys communication or marks an exit from one’s existence in language. Instead, it makes a claim on the other – asking for acknowledgment that may be given or denied (2007, p. 40)

As Ayla’s dementia progresses, she loses her capacity for language, reason, memory, cognition and other bodily functions, such as vision and movement. It is true that her established neuro-connections are slipping away or deteriorating in her brain. Nevertheless, she is continuously making new connections within her limited illness capacity so that she can make sense of the world around her and make life meaningful (Canguilhem, 1998).

(4) Researcher: Researching and Writing as Co-dwelling
Overnight care on the Unit is provided by three care workers, including a senior worker who is in charge of administering medication on the shift. During overnight fieldwork, I carried out interviews with nightshift staff and read the Personal Care Plans of residents who gave their consent for this research. I also shadowed care staff and observed the nightlife of residents alongside keeping extensive field notes. Overnight fieldwork has been carried out for one and a half months and Ayla’s ethnographic vignette is one of the episodes I recorded.
It is important to note that Ayla’s episode is not representative in terms of the ethics of every illness experience and care practice in the Home. The reason I chose it is because her case is ethnographically rich and involves diverse ethical engagements from all parties concerned, allowing us to explore the complexity of entangled relations and interactions between people, the institution and morality in the process of becoming ethical. More honestly, although there are many episodes and occasions, such as calls caused by pain and falls, they all take place within residents’ private rooms, which I do not have access to.

Ayla is diagnosed with a form of dementia with chronic depression. Robert lives with his wife and is relatively healthy except for his age-related fragility and vulnerability. The unexpected encounter with Robert which is a mundane happening brings up the first ethical dilemma in terms of the ambiguity of obtaining research consent. Unlike clinical laboratory experiments, ethnographic fieldwork takes place in open-ended settings where the daily lives of individual participants are always to some extent intermingling, interacting and encountering the lives of others who are not participating in the research. Of course, without these people this ethnography cannot be done, not only because of their ethnographic presence but also because of their (in)visible and (im)material effects. It is literally impossible to exclude non-participant contribution. They contribute to making diverse social environments and atmospheres and bring things into being by directly and indirectly participating in continuous interaction and engagement as members of a co-dwelling community. Robert is not a participant in my research. Although he is interested in my research, he hesitates to become involved due to familial concerns. The questions I thus need to ask concern how far I can regard such mundane encounters as ‘ordinary’ without damaging the will of non-participants and how much I can ethnographically engage with non-participants’ lives in writing. Ironically, it is neither ethical to distinguish participants from non-participants in day-to-day interaction and communication, nor is it practically possible to isolate them.

Secondly, as contributors to the edited book *Ordinary Ethics* note, ethics is embedded in our daily life, so also within the life of the researcher in terms of not only carrying out the fieldwork but also by dwelling within it:

Ethics is part of the human condition; human beings cannot avoid being subject to ethics, speaking and acting with ethical consequences, evaluating our actions and those of others, acknowledging and refusing acknowledgment, caring and taking care, but also being aware of our failure to do so consistently. As a species, given our consciousness, our
socialization and sociality, and our use of language, we are fundamentally ethical (Lambek, 2010b, p. 1).

However, because of this openness and entanglement with the experiences of others it is difficult to demarcate the boundary between practice, conceptual work and writing. This means that unlike previous studies which have said and done much about particular ethical professionalism or methodologies, it demands an alternative approach and perspective to explore ethics in practice and the ways in which people strive to make right or good in the process of interaction and encounter. In doing so, this study finds that ethics already take place not only when I engage with Ayla’s situation but also when taking field notes and writing ethnography. Ethics is immersive yet only emerges through bodily situational, relational and embedded endeavours. In more detail, when I see Ayla I hesitate as to whether I should say hello as usual and be with her or away from the scene. This only takes a second but I feel time flows extremely slowly. For a second, I think of all the possible choices I could make and their potential consequences. It is because of time that I observe Ayla only from a distance. It is still dawn, but watching her unhappy face and bodily performance makes me reflect on whether I should change my mind and what is the right action or the best thing for Ayla. But as Silvia says, this single event does not finish here. It affects her whole day, causing sleepiness and inactivity due to insufficient sleep at night. In addition, it is ambiguous to distinguish private life from public life. As I briefly mentioned before, doing fieldwork with dementia in a care home setting requires many ethical protocols and guidelines I should follow, and one of the key practices is that I do not interrupt their private lives or enter private areas. Needless to say, visiting and entering participants’ private spaces, such as their rooms, is fundamentally excluded in my research design except when it occurs by their invitation. Ayla and Robert are both resting in the communal area, wearing a dressing gown and pyjamas respectively, which make the place private, or in-between. Fundamentally, I think my engagement would not help the situation in the long run and that there is still a possibility she may go back to her room and sleep again like Robert.

Thirdly, the way in which I take field notes regarding this episode and its contingent situations is complex in terms of whose voice and with what perspective. This reflexivity continues while I am writing about this episode in my thesis. There is no radical break between being there and being here. Note-taking and writing ethnography both awaken in me some level of ‘ethical demand’ (Zigon, 2007, p. 138) that I immediately listen to and attend to. Consequently, I decide whether or not to engage with Ayla and observe how she gets along with her early wake-up. By not -engaging with her, I enact another method of engagement by staying back and
watching closely and attentively. At the same time, I take this ambiguous and complex situation into account not only through writing about what happens, but also feeling, reflecting and experiencing as a co-producer of ethics in action and writing.

4. The Complexity and Ordinariness of Care, Ethics and Anthropology

This chapter does not seek moral judgements or ethical decisions, nor does it suggest an ethical guideline for the case of Ayla’s sleep disturbance; instead it attempts to demonstrate which aspects of everyday experience and practice can be regarded as ethical or moral for anthropological exploration; the way in which anthropologists use ethnography to explore ethical (moral) matters in everyday life; how anthropologists perceive and engage with day-to-day care practices while carrying out fieldwork; and the way in which ethics take place in daily care, life and fieldwork. In this section, I demonstrate a brief anthropological history of everyday ethics and its potential application to the study of dementia whilst establishing a new perspective for its exploration. It is followed by a reconstruction of ethics, in Ayla’s case as an ethical and moral entanglement.

(1) Ethics, Morality and Anthropology

Anthropologists once criticised the lack of a theoretical foundation in ethics and morality (Faubion, 2001; Laidlaw, 2002). In fact, it is generally considered because of the influence of Durkheim that all social actions are regarded as ethical, and ethical matters have not been paid much attention to by anthropologists (Laidlaw, 2002). However, over the past three decades a substantial body of study in morality and ethics has paved the way for ‘an ethical turn’ in Anthropology by focusing mainly on becoming ‘moral subjects and their subjectivities’ (Robbins, 2004; Fassin, 2014, p. 430).

As Didier Fassin (2014) summarises, this phenomenon still continues today: Talal Asad’s formation of the Christian self (2009) is developed upon Foucault’s concepts22 of care, ethics and subjectivity; Veena Das’s ethical self (2007) upon Wittgenstein’s philosophy of language; Michael Lambek’s ordinary ethics (2010b) upon Austin’s ordinary language philosophy; Jason Throop’s moral sentiments (2010) upon Husserl and Csordas’s phenomenology; Jarett Zigon’s moral breakdown (2010a) upon

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22 Faubion (2001) and Laidlaw (2014) also adopt Foucault’s distinction between morals as norms, values and regulations and ethics as practices, discourses and body techniques that a subject applies and utilises in order to become an ethical being in the process of social formation. In more detail, Foucault notes in his *Technologies of the Self* that ethics is understood as ‘technologies of the self, which permits individuals to effect by their own means or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality’ (1988: 18). Accordingly, ethical subjects are formed in the practicing of the self.
Heidegger’s ontology of being-in-the-world; and Karen Sykes’s moral reasoning (2009) upon Hume’s moral sentiments. Ironically, although there has been an excessive increase in the study of ethics and morality, these concepts have become more ambiguous and often confused. In fact, many anthropologists tend to use them either interchangeably or selectively by taking an established philosophical horizon that has been historically transformed and diversified (MacIntyre, 1998). This results in a more complex and confused theorisation of an anthropology of morality and ethics (Al-Mohammad, 2010).

Jarret Zigon defines ‘morality as the unreflective mode of being-in-the world’ and ethics as a tactic performed in the moment of the breakdown of the ethical dilemma’ (2007, p. 137). In addition, he notes that in contrast to ‘morality’ the ‘ethical moment’ is:

[a] moment of conscious reflection and dialogue with one’s moral dispositions, as well as with the other two moralities; it is also a moment of freedom, creativity, and emergence. It is because of this moment, and the way it feeds back into the social world, that not only one’s own embodied moral dispositions change throughout a lifetime, but so too does the possibility arise for shifts, alterations, and changes in the spheres of institutional morality and the public discourses of morality (Zigon, 2009, p. 83).

Despite such insights, it is dangerous to apply his concepts to a dementia context because, like other perspectives based on becoming ethical subjects, his distinction cannot embrace those who lose the capacity of cognition, language and memory. Likewise, Benson and O’Neil’s thoughts on ‘ethics’ as ‘one of ethnography’s “first” moments, just as Levinas says ethics is ‘first philosophy’ (2007, p. 31), does not provide any categorical clarification and motivation to explore the formation of becoming ethical because ethics is already there as an absolute responsibility to care for the Other.

At this point, it is worth mentioning the works of Hayder Al-Mohammad and Gilles Deleuze. While both try to understand becoming ethical subjects outside the concept of conscious and autonomous selves, their trajectories are completely different. Drawing upon Wittgenstein’s idea of ‘friction’ in the philosophy of language, Al-Mohammad insists that rather than approaching ethics through philosophical thought or conceptual experiments we need to feel, touch, smell, hear and taste the ‘rough ground’ where an ethics exists in the form of ‘living-in-action’ (Al-Mohammad and Peluso, 2012, p. 44). Beyond abstract, metaphysical and normative paradigms of ethics where ethical beings only exist without friction, he understands ethics in the process of
ordinary interaction and encounter. In this sense, while he rejects current dominant anthropological paradigms of an ethics based on ‘an ethics of the self’ or normative ethics and morality, he emphasises everyday life as ethics ‘as itself’ in which entangled lives reside with others (ibid, p. 45). Likewise, he criticises recent anthropological trends based on virtue ethics in terms of the self-centred approach (e.g. Cook, 2014) and ethical-terms-centred interpretation rather than reflecting an ‘ethics of the “ordinary”’ itself (e.g. Lambek, 2010b). In doing so, he opens his own way of understanding ethics as ‘the line, the relationships, the with of being as ethical itself’ (italics in original) (Al-Mohammad, 2010, p. 426) and ethics as the entangled lives of others in the ‘rough ground’ itself (Al-Mohammad and Peluso, 2012, p. 44).

Deleuze understands morality as ‘any set of “constraining” rules, such as a moral code, that consists in judging actions and intentions by relating them to transcendent or universal values’; while ethics is regarded as ‘a set of “facilitative” rules that evaluates what we do, say and think according to the immanent mode of existence’ (Smith, 2007, pp. 66-67). To put it simply, any transcendent or universal morality should be displaced by what Deleuze and Guattari call an immanent ethics (Lorraine, 2011), not by asking what we should (ought to) do but by asking what we can (may) do. In order to criticise the transcendence of morality, such as the Categorical Imperative in Kant and that of absolute responsibility for the Other in Levinas, he develops an immanent ethics through his critical reading of Spinoza’s Ethics (Deleuze, 1988b; 1992) and Nietzsche’s Genealogy of Morals (Deleuze, 1983; 2001). It is an immanent capability that rather than ‘judging’ modes of existence based on transcendental morality; he ‘evaluates’ them in terms of immanent differential capacity, namely ‘an immanent ethical difference’ (Smith, 2007, p. 67), as Deleuze and Guattari term ‘possibilities of movements and intensities’ (Deleuze and Guattari, 2014, p. 74). Taking one step further, Deleuze and Guattari go beyond Kantian conscious will and the Freudian unconscious or preconscious libido by adopting Nietzsche’s notion of ‘drive’ and impulse that differentiate our actions, feelings and thinking in the sense that:

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23 For more detail of Deleuze’s distinction between ethics and morality, see Deleuze 1995: 100-114.
24 They mention immanence in What is Philosophy, saying that: ‘There is not the slightest reason for thinking that modes of existence need transcendent values by which they could be compared, selected, and judged relative to one another. There are only immanent criteria. A possibility of life is evaluated through itself in the movements it lays out and the intensities it creates on a plane of immanence: what is not laid out or created is rejected. A mode of existence is good or bad, noble or vulgar, complete or empty, independently of Good or Evil or any transcendent value: there are never any criteria other than the tenor of existence, the intensification of life’ (2014, p. 74).
The drives and impulses are always assembled or arranged, from the start, in different ways, in different individuals, in different cultures, in different eras (italics in original) (Smith, 2011, p. 130).

As the etymological origin of ‘drive’ illustrates, Nietzsche originally uses the French word *ressentiment*, in order to highlight the nature of its power in verb form, which is not ‘to resent’ but to ‘feel the effects of, to suffer from’ (ibid., p. 130). In other words, his understanding of the Moral is based on a kind of passive activity, reaction in response to the influence, stimulation and effects of others. In addition, his concept of desire allows us to encounter the bodily expressive performance of people with dementia without losing their remaining embodied capacities and at the same time revealing the immanent capacity of future-oriented bodily movement and affect. Deleuze and Guattari note that ‘drive’ is never a solid entity, nor does it exist alone by itself; rather it plays a role in the process of social formation in the forms of a ‘desiring-machine’ in *Anti-Oedipus* (Deleuze and Guattari, 2004a) and a ‘nomadic war machine’ in *A Thousand Plateaus* (Deleuze and Guattari, 2004b).

In relation to the study of dementia, a Foucauldian approach to ethics offers a new perspective and approach to exploring the process of becoming an ethical subject not by following normative rules and injunctions, but by guidance and socialisation through a set of practices, techniques and discourse. However, I doubt these are systemically and strictly operated, so there is less room to see the way in which people living with dementia translate and appropriate ethics in the formation of the self. Likewise, phenomenological approaches provide ontological conditions of being-in-the-world that allow us to understand them in relational, embodied and situational terms, yet as Kontos’s studies (Kontos, 2005; 2006a; Kontos and Naglie, 2009; Kontos and Martin, 2013) show, they are limited in terms of their past and present-centred interpretation. Meanwhile, in dialogue with Heidegger’s ontology and phenomenology and Wittgenstein’s everydayness, Al-Mohammad offers a unique opportunity to explore ordinairiness itself as the way in which ethics are practised and experienced as a mode of co-dwelling whilst not making any distinction between ethics and morality. Deleuzian immanent ethics sheds new light on the potential of approaching the formation of ethical becoming through bodily expressive performance and desire with people with dementia. Yet, because of its philosophical orientation, it does not illustrate any practical ways of encountering reality. Synthesising Al-Mohammad’s approach and Deleuzian theoretical orientations and distinctions between ethics and morality, I attempt to unpack Ayla’s sleep disturbance.
(2) An Entanglement of the Ethical and the Moral in Everyday Life

While the previous section highlights the possibilities of new perspectives and approaches towards the study of dementia in ethics and morality, I now reconfigure and revalue an individual’s minute, yet dynamic ethical engagement with others in everyday practice from a becoming-centred approach.

First of all, although sleep is the most private activity which takes place in the most personal space, it is often interrupted in the Home by regular check-ups overnight, unacceptable noise (an alarm or the plumbing system) or staff’s routinised morning work, such as cleaning the beds, getting up and dressing for the day. Sleep also has to be monitored and observed as part of routine care practice in the care home. Accordingly, residents’ preferences and privacy are often restricted by staff time and institutional time management (Martin and Bartlett, 2007). Sleep is never ‘morally neutral’ (Kontos and Martin, 2013, p. 6) in that sleep is regulated, monitored and institutionalised by the subculture, orientation and care practice of the institution (Martin and Bartlett, 2007). Needless to say, sleep disturbance with dementia is regarded as a problematic behavioural sign and symptom and a person who shows such behaviour is usually transferred to a more advanced Unit or becomes the object of intensive care. In response to this, the Home has a long history of implementing Orthodox Jewish methods of care (charity) in collaboration with PCC. While charity and other national, local and institutional regulations and codes of practice provide normative morality, PCC provides the practical guidelines and a philosophical orientation.

The ‘audit culture’ (Shore, 2008; Strathern, 2003) of research is also made up of the ethical entanglements of Ayla’s lived experience of sleep disturbance. On the one hand, the process of obtaining ethical approval offers me the chance to reconsider the transparency, accountability and ethics of the research in demonstrating how I should carry out field work in a mutually beneficial and empowering way at the ethics committee. On the other hand, the fieldwork is incredibly complex, ambiguous and contingent in terms of ethics-in-practice. It calls for a new perspective and approach in exploring this everyday entangled engagement, synthesising theory and practice.

Above all, rather than perceiving her lived experience as characterised by pathological symptoms, Ayla’s own experience is understood as one defined by ongoing existential tension and endeavours in relation to her personal life history, sleep pattern and other worldly surroundings. As Graham Stokes illustrates with Janet, who has dementia and sleep disorder, in his And Still the Music Plays (2010), sleep is never personal but biographical and relational. Janet would never get used to living and sleeping
peacefully in the new environment of a care home where she has no attachments, belongings or memories. Consequently, care workers do not know how to deal with her until they understand her preferences and life story. In this sense, Janet’s anxiety and sleeplessness cannot be diagnosed as a pathological sign or symptom without considering the vulnerability caused by her dramatic social and environmental changes. In the same manner, Bianca Brijnath (2011) shows how Tandon interacts with Sheila, his wife, who has an advanced stage of dementia. If he did not know his wife likes ice cream and never tried to offer her ice cream at 3am, he would not be able to communicate with her and would instead lose the feeling of still being in love. Feeding his wife her favourite food becomes not only an essential method of care, but also a way of loving. In her short autobiographical essay, Gloria Donnelly also demonstrates how she lives together with her father who has sleep disturbance (Donnelly, 2010). Her father, now 100 years old and living with dementia, wakes up at 2:30am, knocking on the door, fully dressed in his work clothes, reminding her of his first job putting out the gaslights 90 years ago. On another day, he is off to work early in the morning, reminding her of his 40-year career as a bus driver. For her father, this recurring waking-up is caused by a digital clock on his bedside table. Donnelly’s discovery is purely accidental. Without her endless trials, she would not know how to get along with her father’s behaviour, even if she understands why he behaves like that. What Stokes, Brijnath and Donnelly’s stories highlight is not only the ordinariness and pervasiveness of ethical practices, but also the infinite endeavour of striving to live together and care for each other.

At this point, it is worth mentioning Allen Power who criticises the PCC approach, insisting that it is based on the perspective of caregivers about what is best practice for the person with dementia, suggesting instead an alternative ‘Person-directed’ Care approach (Power, 2014). More importantly, Power notes that because of the ‘outside-in’ approach, PCC is inherently situated in ‘constant adjustment of values and goals’ depending on how people who care for those with dementia define person or personhood (Graham, 2015b, p. 2). Meanwhile, person-directed care is practice based on direct bodily expressive performance with biographical information and minute observation, without including the outsider’s interpretation or perspective on personhood. Drawing upon Merleau-Ponty’s concept of the body-subject, meaning that the body is neither fully an object nor fully a subject, Graham demonstrates that the body as a mediator of being-in-the-world is continuously perceived, circulated and understood in the process of interaction and encounter. Likewise, illness experiences are not only personal, but also socially constructed, situated and embodied in-the-world (ibid., 2015b). Accordingly, ethics in a life with dementia should be understood
as becoming ethical in the context of the biographical, relational, situational and embodied.

5. Towards Ethics as a Way of Co-dwelling in Everyday Care Practice

This case study does not aim to generalise ethics-in-practice but rather provides insights that allow us to explore the complexity, ordinariness and relationality of ethical dimensions of daily life in the process of engaging with the lives of others, things and the environment. Beyond the narratives of how we should live, work and research, there are stories of individuals striving to make relations, connections and networks with one another in the name of family, carer and friends and in the form of love, care and charity. Accordingly, the outcome is not shackles of knowledge, but rather speculative insights on micro-bodily practices between Ayla, Tracy, care home staff, the researcher and the institution. By carrying out a microanalysis I demonstrated the entwined ethical practices in Ayla’s case, in dialogue with the Deleuzian concept of becoming and Al-Mohammad’s thoughts on everyday life itself as ethics.

First of all, in Ayla’s disturbed sleep and related care practice, moral and ethical stakes are profoundly embedded in their ordinary interactions and communications. Their embodied ethics are performed and revealed in the process of continuous bodily resonance not only with the subculture of care in the Home and PCC training, but also with the ethical disposition and working relationships of individual staff with other colleagues. In other words, charity and PCC do not offer an answer to the question about what is best practice, it is rather an on-going collaborative process through sharing and exchanging bodily practices. As Annemarie Mol and her colleagues insist, ethical care does not demand a literal meaning of ‘negotiation’ between different values and moral judgements; rather it refers to ‘a matter of practical tinkering of attentive experimentation,’ noting that:

"Unlike medical ethics, the ethics of care never sought to answer what is good, let alone to do so from the outside. Instead, it suggested that “caring practices” entail a specific modality of handling questions to do with the good... In the ethics of care it was stressed that in practice, principles are rarely productive... For rather than insisting on cognitive operations, they involve embodied practices. Rather than requiring impartial judgements and firm decisions, they demand attuned attentiveness and adaptive tinkering (Mol et al., 2015, pp. 13, 15)."

From the acknowledgement of Ayla’s biography and medical condition, her challenging behaviours are understood as her striving to cope with her existential concerns caused
by the unfamiliar surroundings and her dissatisfaction of living in an institutional setting. In this sense, I shed new light on her different bodily ethical attitudes and expressive performances toward Sonnet, Silvia and Robert as idiosyncratic ways of communicating with others whilst trying to maintain her feelings of security, familiarity and connectivity within her illness abilities. Drawing upon Kontos’s notion of the embodied self and Goffman’s notion of body technique, I analysed her fluctuating bodily movements in light of the intensities of rhythms, tempos and tones within her bodily expressive performance and continuous attunement of her body whilst engaging with others, things, and the environment. In doing so, I demonstrated that Ayla uses the intercorporeal, intersubjective and interrelational body techniques that have been embedded throughout the course of her life and which emerge in the process of making and unmaking an ethical self, namely her moral and ethical-embedded striving. More importantly, her bodily movements are not limited to immediate actions based in her present remaining capacities, but actually imply her forward-looking orientation with the desire to make her world sensible and meaningful through making connections. Accordingly, her embedded ethics is performed through her tacit body techniques which embrace her immanent bodily desire, her biographical way of life and her ethical disposition.

Using the ethnographic self as a resource (Collins and Gallinat, 2010), I illustrated an example of researching and dwelling with residents with dementia. This experience helps bridge the unnecessary gap between ethics in fieldwork, analysis and writing at University. Anthropological practice proceeds in the process of immediate engagement with an ethnographic event in a wide range of forms including thought, imagination, writing and so forth.

All in all, the ethical is neither a separate dimension of social life, nor is it practically isolated; rather it reveals itself as life unfolds ‘through, against, and with others’ in the process of continuous ‘weaving and reweaving of the lines of life through the lines of others’ (Al-Mohammad and Peluso, 2012, p. 54). In other words, the relations between the care staff, Ayla, Tracy, the researcher and the institution cannot be isolated in action; they are, rather co-constructed and co-constructing in that they are continuously engaging with the lives of others through ordinary interaction and communication, regardless of a person’s mental capacity and bodily deterioration. In fact, ethical dilemmas are immersive in multiple dimensions of daily life and at the same time reveal the ontological existence of diverse ethical practices, dispositions and attitudes. In this sense, ethics is an entanglement of those driven by institutional subcultures, staff cultural attitude and disposition, residents and family members’ own ethical orientation and embodied body techniques and general moral reasoning.
Finally, a new perspective toward becoming ethical opens up an unknown area of bodily practice with dementia. Here, I use the term *immanence* in two ways in order to reveal the formation of becoming ethical. The ethical is neither transcendent nor isolable, but is immersive and indissoluble in everyday practice. As Gilbert Ryle demonstrates the ontological error of distinguishing mind from body in *The Concept of Mind* (1949), it is a categorical mistake to distinguish ethics from daily life. However, it is also true that because of these ‘imbrications’ and the ‘openness’ of daily life in-the-world (Al-Mohammad and Peluso, 2012, p. 46), the ethics of change or transformation always and already exist in the making of everyday life and in the form of the virtual. The question is how to approach, perceive and reveal this immanent feature of ethics in practice without disregarding the capacity of becoming ethical with dementia and without misrepresenting it in the process of conceptualisation. Rather than relying on individual capacity with cognition, language and memory I propose a new potential area of an ethical-subject-making in terms of bodily expressive performance, focusing particularly on the immanent capacity of affect, sense and bodily movement.
1. Are Repetitive Sayings and Actions Meaningful?

*I don’t know why it happens to me. I don’t know what to do. I don’t know what to do. I have a terrible fear. I am worried they will desert me. Don’t desert me. Help me. Help me* (Ayla).

*I may have already told you. It is a pleasure talking with you but I don’t quite understand what you are saying. You murmur. You don’t move your mouth when you speak. If you want to communicate with English people well, you need to know how to speak English clearly* (Daniel).

I do not remember when I gave up counting the amount of times I heard the above from Ayla and Daniel. Once again, Ayla’s talk about the strange neighbouring residents on the Abraham Unit ends in a desperate appeal, revealing her confusion and anxiety while she firmly grabs my hands. Her voice trembles and she is on the verge of tears. She asks again whether I can take her out of the Home. Holding her faltering hands and looking at her tearful face, I listen to her for a while. Likewise, Daniel advises me once more that although I am an intelligent student, if I want to communicate with others in English, I need to improve my pronunciation, emphasising how exhausted he is with figuring out my words. Although I have heard this countless times, I never get used to it when we converse. Yet this time I tell him in a humorous manner that there is no such thing as a free conversation with a foreigner and he needs to pay for it (by correcting my English). We both laugh and the conversation continues. Again, when Yedida sees that someone has left crumbs on their plate from the afternoon tea, she wraps them into a serviette and puts it in her bag, softly saying she will give them to the rabbits on the pet farm.

Throughout my fieldwork I have encountered these kinds of repetitive questions, sayings and doings over and over again, including ‘Why does she/he ask the same question again and again?’ ‘She says she wants to go home all day long and is always calling for her daughter.’ ‘Again, she hides scraps of food in her drawer.’ This repetition is one of the most common illness experiences with dementia and at the same time the main source of frustration and stress for those who care for them (Alzheimer’s Society, 2015). In this chapter, I take these repetitive behaviours and speech as the starting point for exploring subjectivity through repetition and difference over time and space. Problematising two prevailing cognitive and therapeutic approaches towards repetition in a dementia context, this chapter argues that these repetitive actions and verbalisations form the actual worlds of dementia that those affected experience. Indeed, they emerge in the process of acting and corresponding to their
immediate surroundings. In doing so, I attempt to explore relational, adaptive and experiential selves with dementia in the making of a new subjectivity in dialogue with Deligny’s *cartography* (2015) and Deleuze’s *repetition* and *difference* (2004). This involves paradigmatic epistemological and methodological changes in terms of approaching, perceiving and understanding repetition in the dementia context by recognising and revaluing the bodily movement, affect and sensory perception of those affected.

First and foremost, according to the predominant biomedical and therapeutic points of view, repetition in the dementia context refers to a constellation of repetitive behavioural and psychological signs and symptoms. This occurs experientially, frequently for ambiguous reasons, yet manifests a strong neuropathological correlation with certain degrees of functional and cognitive deterioration in the brain (Ballard, 2001; Cullen et al., 2005). Concomitantly, the deterioration of bodily abilities and functions accompanied by the subsequent loss in memorising, storing and retrieving new lived experience results in an individual being stuck in one activity and/or saying, and thus continuously repeating it. Obsession, repetition and routinisation are typical characteristics of these challenging behaviours and verbalisations that encompass repetitive sayings, repetitive walking and moving about26 and a strong attachment to particular objects, such as a seat, a magazine, leftover food, people and particular environments. The Alzheimer’s Society in the UK, which is one of the leading charities for dementia in the world, defines them as below:

People with dementia often carry out the same activity, make the same gesture, say the same thing or ask the same question repeatedly. This may be because they feel anxious and frightened, and want comfort, security and reassurance. The person’s natural interaction with their surroundings may have been disrupted by memory problems, confusion, disorientation or boredom, so they may be trying to make sense of their situation by asking about and exploring it. Repetition may also be a result of memory loss, and the person not being able to remember what they have done or said, or the answer they received to a question (Alzheimer’s Society, 2015, pp. 9-10).

Accordingly, from the biomedical and therapeutic perspectives, we often ask what causes repetitive actions and sayings. Why does repetition take place in certain people, times, places or situations rather than others? Is this repetitive bodily movement a mode of expression through which the person with dementia tries to communicate?

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26 These days, the term ‘wandering’ - meaning an aimless moving and walking - is avoided because of its unhelpfulness in understanding the nature and characteristics of this repetitive behaviour; instead the terms ‘walking/moving around’ are favoured due to their implication of purposeful and intentional action.
Needless to say, this approach is deeply embedded in our social lives, influencing our values and concerns around these experiences. Unfortunately, although interest in these issues has significantly increased over the past three decades, little attention has been paid to them in day-to-day practice outside of medical and therapeutic interventions. Precisely speaking, current normative perception and understanding of these phenomena are limited to the ‘cognitive paradigm’ (Hughes, 2011, p. 226) and ‘therapeutic imperative’ (Wright, 2015). As a matter of course, obsessive, repetitive and routinised actions and verbalisations have been recognised and even stigmatised as loss of control and self, resulting in the self being disregarded and neglected in the course of everyday life. In other words, the existential ground of a connected being (Kitwood, 1997) has gradually become cut off from society, becoming ‘an inauthentic self’ who is no longer ontologically related to and thus is alienated from the world (Heidegger, 2010, p. 317) or an ‘unbecoming’ (Fontana and Smith, 1989, p. 36). Based on the first-person perspective with acknowledgement from those affected as living and experiential beings, I claim that we need to build better bridges between care practice and the world of dementia. To this end, rather than attempting to manage, control or treat these conditions as evidence of neuropathology, this chapter tries to reflect on what Julian Hughes suggests as that ‘challenging behaviour... [which] must be taken as a sign of something else: something yet to be interpreted, but reflective of the strength of persisting selfhood’ (2011, p. 225). This not only calls for an epistemological but also a methodological shift that can shed new light on otherness within the repetitive world of dementia as lived experience in time and space.

Accordingly, I draw upon Deligny’s cartographic approach (2015) and its developmental version of cartographic microanalysis by Deleuze and Guattari (2004b). While the former opens a new way of studying children with autism by living and working with the subjects and tracing their bodily expressive performance, the latter allows us to conduct a ‘microanalysis’ of bodily practices in the Deleuzian sense, exploring the ‘trajectories of individuals through milieus of affect and intensities’ (Biehl and Locke, 2010, p. 337). Synthesising these in a cartographic microanalysis, this chapter attempts to shed new light on the otherness of repetition, particularly with regard to bodily movement, sensation and affect. It focuses on the processes and relations of minute bodily interactions, responses and encounters with others, things and the surroundings during the time that obsessive, repetitive and routinized behaviours and sayings are enacted. At the same time, I critically reconsider current prevailing methods for studying repetition in the dementia context based predominantly on surveys, observation and interviews, by developing my argument on representation and by applying a cartographic microanalysis to subjectivity. In doing so,
I suggest an alternative way of understanding the challenging behaviours and sayings, what I call a *cartographic ethnography of subjectivity*. Consequently, I claim there are many potential possibilities that allow us to dwell with people living with dementia, yet which have been given less attention. Lastly, I attempt to conceptualise this repetition as the formation of subjectivity of those affected by drawing upon Deleuze and Guattari’s concepts of difference and repetition, and Ingold’s concept of correspondence.

In order to make these challenging experiences visible and recognisable, in the following section I give a brief description of breakfast on the Abraham Unit in the context of co-dwelling. In the third subsection, I demonstrate an ethnography of repetitive bodily movement, affect and sensation in response to the existential concerns and desires of three residents with dementia (Dorona, Daniella and Ayla) which take place en route from their rooms to their designated seats in the dining room. In the fourth subsection, based on the ethnographic findings, I establish a new way of understanding the formation of subjectivity by developing an alternative epistemology and method to subjectivity, providing not only a practical way of exploring these phenomena but also an alternative way of understanding. In conclusion, I summarise how subjectivity emerges through recurrent bodily practices, suggesting that the subject is not a static and fixed being, but a being-in-becoming: being emerges in the process of dynamic, complex and recurrent interactions, responses and encounters within the world of dementia.

2. A Brief Description of Breakfast

It is a quarter to eight on an early autumn morning. Most of the windows are still closed. It is too cold for residents in the mornings. The movements of care staff and residents disturb the landscape, their movements gradually spreading across the whole Unit, awakening it alongside the quiet dawn. Although it is almost imperceptible, the fresh air slowly permeates the communal area through the lifts and windows, and with staff members taking over their morning shift. It is not long before two residents with wheelchairs come into the area with the aid of staff at around 7.30am. Sitting by the windows with the warmth of the morning sun on their back, the early arrivals smell freshly-baked bread and fresh fruit from the kitchen. The smell soon overwhelms the sensory environment, tickling my taste buds. Yet the light in the dining room remains partially switched off, making residents aware that the time for breakfast has not yet come.

There are now three residents in the communal area. Today, breakfast is simple: a range of juice, soup, cereal, bread, jam, fruit and tea or coffee. Individual care workers
do their assigned work, including assisting late starters, administering medication and informing residents of their daily schedules. In the dining room there is only one care worker, Maria, a care worker in her late forties, who is preparing for the morning meal. At 8am, she handles the residents tactfully, greeting them and asking them to sit in their designated seats while they wait to be served. The dining room is soon filled with eight residents either being transferred or arriving by themselves, waiting to be served at their tables. Although it is only about five minutes before help from other staff members arrives, Maria, an experienced care worker, struggles to manage these multiple needs and demands alone.

In more detail, as Figure 3-1 shows, Dorona sits in her seat and looks vacantly into the distance. She looks sleepy. Although she has already been served, she is not interested in eating. Like the other wheelchair users, she is usually transferred to the dining room with the aid of staff after finishing her morning personal care at around 7.30am. However, coming early to the dining room does not mean she has a good appetite. It is not until she is encouraged that she begins to eat. Maria puts some butter on her bread and offers it to her. She nibbles on a piece for a while but stops chewing when Maria is called to assist others. She yawns again and again.

After a little while, the couple Jacob and Rachel come in. Jacob quietly follows his wife’s slow steps, often, if necessary, moving Zimmer frames aside as she makes her way to her seat. While waiting to be served, Jacob reads the newspaper and Rachel alternates between looking at the menu and out of the window. There is no conversation. Compared with the previous year, Rachel’s decision-making and eating have become much slower and distracted. Jacob reads the menu to his wife and recommends some choices. Unlike Rachel, it does not take long for him to order and have his meal. He reads the paper again whilst he waits for his wife to finish.

Daniella stands at the dining room entrance looking at the other residents for a while. Unlike her usual behaviour, she does not go to her seat directly but moves around looking at the residents and their food. Maria asks her to sit down. Daniella mumbles and moves around the tables in a zigzag.

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27 When Person-Centred Care was first implemented in Florence House in 2011, its facilitators and other specialists from the Bradford Dementia Group tried to put the dementia-friendly-atmosphere into effect in the dining room as well. One of the key strategies was to provide a self-sufficient and dignified way of dining: residents were encouraged to choose their preferred table partners, the time and place of eating along with a wider range of dietary choices, regardless of their medical conditions. However, this proved difficult in that the fluctuating and changing seating arrangements caused residents more confusion, distress and anxiety than it helped. Today, residents choose their own seats after consultation with staff and their significant others, reflecting their own interests and preferences at the beginning of their residency. Through repetitive practice, this then becomes routinised.
Chemda puts her spoon down and grabs pieces of fruit and cereal with her hands. Emmanuel and Ephraim have already finished their meal and are waiting for their dessert. They are sitting next to each other but do not talk. When they see me, both show a bit of surprise at my presence at this time. Emmanuel thanks me for helping out with the meal and Ephraim asks whether I work for the Home. I tell them I have stayed overnight to observe the nighttime routines of residents and care practices. Ephraim expresses some curiosity and doubts; he believes that there is nothing to see but people sleeping. They both wish me luck with my study.

Figure 3-1 Seating Arrangement on the Abraham Unit

Once other care workers arrive to help Maria, I approach Dorona and ask whether I can sit next to her. She rubs her sleepy eyes and greets me with a smile. I ask her whether she has lost her appetite because she has not eaten very much. She breaks off the slightly burnt parts of her toast, puts some marmalade on the rest, sips a bit of juice and starts to nibble at her bread. I ask her what kind of food she usually eats in the morning. It is the same as her breakfast here, ‘an ordinary English breakfast,’ she
says. I also eat some toast at the same pace as her. I offer her one more slice of bread, but she says she has more than enough.

Ayla arrives late at about a quarter to nine. Like Daniella, she pauses at the dining room entrance for a moment to have a look at the whole restaurant, and then slowly pushes her Zimmer frame towards her seat. She is expressionless and her eyes are swollen and red. Her sweater is unbuttoned. She walks slowly, dragging her walking frame with her.

3. An Ethnography of Repetition

While the previous section shows a brief observation of breakfast, in this subsection I challenge the knowledge, perception and understanding of the repetitive and routinised bodily movements and sayings of those living with dementia, particularly focusing on the affective and sensory dimensions of their experience through their bodily expressive performance. Beyond biomedical and therapeutic paradigms I query the ways in which three residents with dementia (Dorona, Daniella and Ayla) sense and interact with their surroundings while affecting and being affected. I explore the function and role of repetitive bodily actions in their social lives. By reading individual residents’ lines of movement, I also attempt to reveal their singular mode, which is closely related to particular sensory and affective dimensions of experience in the formation of subjectivity. In detail, this is concretised in terms of awakening, glance, rhythm, and facial expression.

(1) Dorona: Awakening

As usual, Dorona is transferred to the communal area as soon as her morning care is finished, which is at about 7.30am. She is well-dressed in a floral purple blouse. Her white hair shines in the early morning sun. However, it does not take long for her to get bored. In fact, she has been alone for about fifteen minutes with no music, the light off in the dining room and more importantly, without any meaningful social contact. Morning shift workers are too busy to talk to her and the other residents are not near enough to talk to. Shortly after being transferred to the communal area, Dorona starts to doze. The partially dark environment and warm sunlight on her back must make her sleepy. The sporadic sounds of cutlery from the kitchen, footsteps of passers-by and the smell of prepared meals do not seem to affect her. Reclining against the wheelchair with her arms on the armrest, she falls asleep. Her movements in response to the surroundings are slow, dull and almost motionless. Her clothes become creased and wrinkled.
At 8am, gentle classical music begins to play and all the lights in the dining room are turned on. Maria gently taps the back of Dorona’s hands and takes her to her designated seat. She gently rubs her sleepy eyes. The bright light, ambient sounds and smell of toast seem to invigorate her, but she still seems less responsive. She barely moves her body, just looks vacantly at what Maria is doing. In the ordinary course of events, she would have a care worker who encourages her to eat, but today Maria is short-handed. After making her toast and buttering it, Maria leaves the scene in order to help other residents. Passing Dorona, Maria sees she is dozing again. Maria tries to wake her by asking whether she is alright and encouraging her to eat her meal. I also cannot be with Dorona because I am helping with the morning meals of others. It is only after other staff help out that I can join Dorona. She welcomes me to her table. We soon start having meals together, intermittently conversing about her breakfast and life these days in comparison to those of her past when she lived in her own house. She often smiles at me and continues to eat her food. Although it is a very small portion she finishes her meal and waits for her dessert.

**Awakening**

Unlike the daily routines of other residents, Dorona’s path to the dining room raises the issue of passivity in her movements and her agential abilities. As her Parkinson’s disease and dementia progress, her personal care and daily routines require more assistance from care staff, including taking showers, having meals and walking. Her gestures and movement are also physically limited to the boundaries of her wheelchair. This raises the question of her agency to act, express and talk in her own way. What stimulates her actions and responses? More precisely, can we say her slight and silent movements, such as yawning and dozing, are actually her way of engaging with her surroundings? If so, what do such bodily movements mean? In the following, I attempt to reconceptualise her unique response to her surroundings in dialogue with the theory of lines (Deleuze, 2004; Deleuze and Guattari, 2004b; Ingold, 2011; Deligny, 2015). At the beginning of Dorona’s transference, she is not only awoken but also responds to the staff touching her shoulders and hands and their amiable voices. However, once she moves to the communal area, where there is less audio-visual and sensory stimulation and social interaction, her lines of movement vary less. Consequently, this analysis calls for the re-evaluation of her ontological expressions of decreased sensitivity and drowsiness, asking what this silent and almost absent movement indicates, what its function is and the role it plays in her life.

Regrettably, in everyday public discourse, her minute bodily movements quickly disappear or are ignored because that they are treated as pathological symptoms or as nonsensical and invaluable actions and sayings. Rather than the kinds of biomedical
and therapeutic approaches which operate within the logic of finding a pathological cause, diagnosis, prevention and care, I do not ask any for the cause and effect of Dorona’s movements but trace them as they form the lines of her everyday life. As a practical way of approaching and perceiving her lines of movement, ‘Tracing in the place of naming and interpreting’ (Deligny, 2015, p. 13) works here because I do not know what Dorona feels or thinks about her setting or what she would prefer to do. Just as Fernand Deligny uses the term autism to characterise those who do not speak in a neutrally descriptive way and does not ask or search for casual explanations of erratic movements, I reject asking for the cause or reason of these movements and gestures. Instead, I dwell with Dorona and trace her bodily expressive performance, consisting of the lines of her bodily movement. The lines therefore represent not only ‘geometric lines’ (Loovers, 2015, p. 115) of transformative and performative movement but also ‘a living person’ (Ingold, 2017, p. 22): Dorona, who has feelings, affect and emotion whilst experiencing the world of her dementia through affect and sensory perception. From this perspective, her silent and minute movements are valued on the grounds of their expressivity and performativity whilst facing unexpected, indeterminate and open reality in the process of constant interaction and encounter with her surroundings. Above all, asking her about her motivation or purpose would be practically and ethically inappropriate. Language, cognition and memory all work behind the world of her immediate affective sensory experience and bodily gestures. I follow the trail of her expressive performance. Then I realise that her body moves and, at the same time, her movement reveals performances which are common as immanent human features of co-dwelling in Deligny’s sense (2015), reflecting her ways of communicating and of networking with her surroundings. Her movement takes place within her abilities and in response to a given milieu linked to her social, affective, sensory and environmental surroundings. It is worth looking here at Alphonso Lingis’ study on ‘awakening,’ which is another form of being out of the momentum of continuity and recurrence:

You shake your head and peer about to find where you are. Awakening is a bound, not weighted down with the past that inculpates the present and demands compensation from the future, a bound out of the drunkenness of remorse and resentment. Awakening is a commencement… a point of departure… a birth… joyous. The innocence of awakening, the active disconnection of the past, makes possible this joy (Lingis, 1999, p. 203).

It is certain that her life is not constituted by successive awakening or consciousness but is rather made up of continuous disjunctive and conjunctive processes of becoming in the Deleuzian sense. What is important to know is that as the Deleuzian notions of
‘active’ and ‘reactive’ forces show, her passive and disjunctive enactment is a different mode of action:

A reactive force can certainly be considered from different points of view. Illness, for example, separates me from what I can do, as a reactive force it makes me reactive; it narrows my possibilities and condemns me to a diminished milieu to which I can do no more than adapt myself. But in another way, it reveals to me a new capacity, if endows me with a new will that I can make my own, going to the limit of a strange power (Kaufman, 1999, p. 155).

When all the lights are on, music is playing in the dining room and Maria gently taps her hands, Dorona awakens. What draws my attention is not simply the cause of her reaction but the intensity of exterior stimuli and the way she responds throughout the course of the interaction and encounter. When Maria moves to another table and when Ayla keeps disrupting her meal (described in detail in Ayla’s vignette), her lines of movement intersect with other lines but no longer follow or trace them; they move parallel to each other. Namely, her feeling of indifference, tiredness and boredom toward her surroundings are constantly affecting and affected in the form of her bodily expressive performance. Her bodily practice is not just a personal action, nor is it limited to human relations; it reflects her embodiment in the dining room in an ‘intercorporeal’ and ‘intersubjective’ way (Csordas, 2008). Thus, as a range of her transformative and expressive performances illustrate, her lines of movement travel with different tendencies, directions and intensities. Accordingly, it calls for acknowledging not only the singularity of her bodily expressive performance in response to the social, sensory, biographical and medical situation outside of language, memory and cognition, but also its attributes of the relational, contingent and indeterminate.

Her slightest gesture, scarce movements and near silence do not offer a kind of knowledge we can pathologically name, but more fundamentally gives us an understanding of her way of life which takes place in response to the ever-changing environment whilst she copes and lives with Parkinson’s disease and dementia. In this process, her performance becomes otherwise, fresh. Her passivity in her lines of movement reflects the ways in which she interacts and communicates in becoming, no matter how small.

(2) Daniella: Glance and Rhythm

Daniella walks with long steps toward the dining room. She is greeted by the morning sun, gentle classical music and delicate smells. Standing at the dining room entrance, she enjoys the morning sensory-scape for a short period of time. With a contented
smile, she looks at the dining room. She shakes her head as if disappointed and moves around the room. It is unusual for her not to go to her seat directly. In fact, she zigzags through the tables, knocking them all on her way to her seat. She looks at what the other residents are having for breakfast whilst walking as slowly as she can to her table. When she arrives, she still hesitates to sit. Her obsession with her seat has been a well-known fact since she first came to the Home in 2011, not only among staff but also among the residents. In a word, she has never yielded her seat to another person. It is always for others to give away theirs to her if she insists she wants to take it. Maria asks Daniella if there is a problem. She says something but it sounds as though she is mumbling to herself. However, it is clear that she has changed her mind and decides not sit down after all. She goes to the neighbouring table where Maria is assisting Hyden in having her meal. She tries to take a seat next to Hyden, but soon stands up again. She repeatedly gets up and down and walks around the table. Hyden keeps being distracted and her meal drips from the side of her mouth. Maria asks Daniella to sit down in her seat to stop interrupting Hyden. After a while, Daniella leaves and walks to the bar for breakfast. She picks up a bowl by herself and puts some cereal in it. Then Chaya, her table partner, enters the dining room. She smiles brightly and her eyes are wide open. Daniella greets her and stands aside for her friend to pass. Chaya puts her belongings on her seat, comes back and looks over the two types of cereal. Daniella stops talking and follows Chaya with her cereal. Daniella looks cheerful and happy, as though nothing had happened.

**The Glance**

I trace and follow Daniella’s lines of movements and gestures in terms of the glance and modes of communication. Firstly, in his essay ‘The Time of the Glance,’ Edward Casey (1999, p. 80) argues that the ‘glance’ has been paid little attention in academia considering it is ‘the very medium of human transaction,’ or the making of human perception and knowledge due to its familiarity and ubiquity. With its most varied forms ranging from the mere blink to the penetrating look, the glance has been little focused upon in the study of dementia too. However, like Daniella’s glance (as well as Ayla’s) at the threshold of the dining room reflects, her relations with others, things and the environment are distanced by a momentary cut, which is revealed through her frowning or shaking her head. It is in this glance that the immediate and unmediated awakening of the ‘now’ is actualised. It also implies a duration of movement in the opening and closing of her eyes. Furthermore, although it is of a momentary duration, it contains a reciprocal movement, in Casey’s terms, a ‘folding-back or self-return’ that allows her to respond to her surroundings:
The glance […] folds back on the subject, coils over onto this subject, falling back onto it… No sooner does this happen, however, than my glanced-at glance returns to me and is absorbed by the very face that sent it out in the first place: it folds back over this face, re-joining it at its own surface, as if to acknowledge this face as its own progenitor. Yet, the glance returns to me not simply as to the same self but to a self-augmented by its own looking (Casey, 1999, p. 86).

The return journey of the glance is not always travelled or distributed equally. Daniella is initially satisfied with her surroundings, the classical music, the smells of bread and soup, and the warm morning sunshine. But this is quickly transformed into disappointment over the absence of Chaya, reflected in her glance. In addition, glancing is relational and interdependent not only upon people but also on non-human entities, including the surrounding atmosphere. As Merleau-Ponty points out (1964), trees do not see us in the same way as the seer; our glance is not merely mechanical, nor metaphysical, but is expected. To paraphrase, unlike Husserl’s one-way intentional journey, Merleau-Ponty acknowledges that our glance is always intersubjective and we do not know exactly ‘who sees and who is seen’ (Merleau-Ponty, 1964, p. 167). Because of this asymmetrical relation between seeing and being seen, the glance is always undetermined and indefinite as life unfolds. Needless to say, the glance returned from the journey is always and inherently different to the original one. The intensity of the glance either progresses or degenerates in response to the reactions of others. In this sense, the terms of reciprocity, intersubjectivity and intercorporeality do not mean a state of glancing but rather a way of becoming. It is a corollary that the individual glance is constantly transformed and never fully integrated into the one before, whilst synthesising an unforeseen future as expectation, hope or desire (Casey, 1999). Throughout the process of glancing, it is transforming and transformed into ‘the absolutely new’ and in this regard, the glance is ‘the sentinel of the sentient being’ in that:

Beyond the active reaching out of its initial action, the glance engages in a receptive moment of attending to what is beginning to happen, taking in the new surface of its emergence… The attentiveness of the glance ushers the oncoming future into the present. The imminent event is accepted, carried, supported into the present, allowed to become part of the duration scene, permitted to become at once actual and virtual and no longer only possible (Casey, 1999, pp. 91-92).

Similarly, Daniella’s glance infinitely bifurcates and diffuses in the process of interaction and encounter. Needless to say, every single momentary cut within the glance becomes ‘a source of the differentiation of duration and the absolute newness of each becoming,’ ‘becoming otherwise’ (ibid., p. 97).
In this sense, her repetitive behaviour of knocking into tables, looking over the meals of others and moving around the dining room can be described as lines of bodily expressive performance linking her actions (walking and her gestures) and her mumbling speech with the material and immaterial surroundings and with other residents. If we say communication is in order to connect or mediate with others, establishing a certain relation or network by using verbal or nonverbal language, her repetitive actions are a form of communication. In other words, her repetitive movements and gestures are alternative means to speech. In particular, in this case, her speech is performed in a form of soliloquy, yet her affect is expressed outwardly. Likewise, here the terms of language need to be carefully applied because her lines of movement, gestures and mumblings do not mean she directly wants to communicate anything, but rather her communication emerges in the process of repetition, as a mode of connection and of being.

**Rhythm**

Depending on the intensity of interactions and encounters with people, things and her surroundings, Daniella’s lines of walking become entangled with different tempos, durations and rhythms. For example, when Daniella sees Chaya it is different to when she moves around Hyden. Her lines of walking before and after encountering Chaya are quite different in terms of the intensity of her step; she does not waver or hesitate, nor is she slow-footed any longer; instead she steps lightly and quickly. Namely, her lines of moving around refer to the *unfillable*: the absence of Chaya. It is worth noting here Tim Ingold’s study of sawing and basket making (2011, p. 59) in understanding differentiation through repetitive work. These crafts are based upon repetition. However, just as every craftsman tries to reduce risk and make their work efficient through repetitive practices without losing professional skill or the beauty of the artwork, some levels of embodied skill with reference to attention and revision are continuously operating for the carpenter. For example, when the saw journeys the same groove back and forth following the predestined line, and the hands move through bodily memory unconsciously, the body (the gut) and its senses feel before perceiving when something is wrong. Drawing upon Leroi-Gourhan’s thought of ‘rhythmic quality’ (1993, pp. 309-310), Ingold extends it to ‘rhythmic repetition,’ claiming that repetition is not mechanical and automatic, but rather each movement is ‘felt’ and recognised through the body in the process of continuous bodily ‘attunement’ to the ever-changing surroundings (Ingold, 1999, p. 437; 2011, p. 60).

In brief, glancing is never the only way of perceiving and experiencing the world surrounding us. As Ingold notes, ‘Lives are bound up in the tangle’ (2010c, p. 302), in a ‘vaguely defined zone of admixture and intermingling’ (2011, p. 119), suggesting that
our ways of perceiving and knowing the world are the entangled ‘meshwork’ of the senses, affect and bodily movement (ibid., p. 83). To put it plainly, Daniella is glancing at people, things and the surroundings while listening to music, smelling the morning soup and toasted bread and feeling the atmosphere at the same time through ongoing bodily action and response. For this reason, her bodily movement can be characterised as ‘resonance,’ in Ingold’s term (2017, p. 19), in that her world of dementia is experienced not by a single action, sense or affect, but by more or less a combination of all based on her ‘attentive engagement,’ which is her ‘very foundation of sociality’ (1993, p. 160).

In addition, her lines of movement illustrate her entangled lifework, reflecting the social, affective and sensory dimensions of experience in response to her surroundings. At a distance her trails of movement proceed toward a designated point, but in detail her lines are varied by tempo, duration, and rhythm. Starting with a circumferential zigzag line she ‘drifts,’ in Deligny’s sense, around the dining room. Then her lines repetitively intersect, curve, pause and in turn respond to the lines of others. When Chaya enters the dining room, her line echoes and follows that of Chaya. In this sense, as Felix Guattari mentions in his schizoanalytic cartography (1996, p. 197; O’Sullivan, 2012), Daniella’s repetitive hesitant movements reflect her place-making in the absence of Chaya and emerge in process. In other words, her hesitant and recurrent behaviour is actually an affective and sensory way of making herself familiar through continuous contact, interaction and encounter. It is the most fundamental terrorization in Deleuzian’s sense (Deleuze and Guattari, 2004b) in terms of securing herself by making herself at home.

(3) Ayla: The Face
Just like Daniella, Ayla stops at the dining room entrance, glancing over the people and the surroundings. For a while, she is expressionless. Then she starts walking toward her seat. Whenever she takes a step, she stops for a moment to look at her surroundings. Although it is only a short distance to her seat, considering her way of walking it usually takes her a substantial amount of time to get there. Yet, as soon as she recognises me at Dorona’s table, she stops walking. Her pupils dilate and her previously inexpressive face breaks into a bright expression, holding a mixture of surprise and delight. She stretches out her arms and holds my hands, saying she has missed me so much, followed by questions of where and what I have been up to over the last few days. I tell her I went trekking over the weekend with my housemates and ask her about her weekend. She says, disappointed, that nothing happened and it was quite tedious. She does not mention her daughter’s visit last Saturday. We are quiet
for a moment when she finishes telling me about her weekend, and I suggest she sits down. However, she does not want to move; instead, she turns to Dorona’s table and continues to talk.

Sipping her tea, Dorona looks at Ayla and listens to our conversation. Ayla asks about my family and my studies. She does not wait for me to finish before asking what I will be doing today and so on. Shortly after, her voice trembles when she starts to talk about her daily life at the Home. As her story progresses, her face, complexion and emotions are dramatically transformed. Her voice falters and I can see she is about to burst into tears. She seems to no longer be consciously aware of her surroundings; the sensory assemblage of classical music, the smell of food and the presence of other residents are suddenly diminished behind the scenes. She does not move, standing in the way of other residents and staff, and keeps speaking to me about her insecure and anxious situation. Although Dorona looks uncomfortable, Ayla does not seem to be paying her any attention. In fact, Dorona stops drinking her tea to look up at us, but does not join the conversation. Even though she does not look outwardly displeased, I am sure Ayla’s abrupt intervention has interrupted her morning meal. After a while, she stops paying attention to our conversation and looks out of the window. Taking this into account, I tell Ayla I am in the middle of having a meal with Dorona and ask her if she would like to move back to her seat. Taking a step aside, Ayla looks around the table and searches for an empty seat. She tries to sit on the other side of Dorona, where she has never sat before, but I expect Frederik will soon come to move her, so I tell her that she had better sit in her designated seat by the window. I guide her there, telling her that I will be back after breakfast with Dorona. She simply cannot sit and wait to be served by staff. She does not even look at the menu. She repeatedly gets up and down with a slightly annoyed expression on her face, as if she feels nothing is of interest to her here. She then turns towards Dorona’s table, looking at us with a miserable face, as if she is yearning for me to come as soon as I can. Her helpless and hopeless expression reflects how she feels.

Once Dorona finishes her dessert, I move over to Ayla. She grabs my hands and looks at me with a desperate face again. Gayora, her table partner, has not arrived yet. I take a chair from the next table and sit on her right-hand side, leaving Gayora’s seat free. I ask her what she wants to eat. She waves at the menu and says nothing is suitable for her because everything is dull and dry. For her, the meals in the Home are not good enough to eat. Instead of having breakfast she proposes going out to have a cup of tea and cake in the cafe. Her voice still falters slightly. It is too early for the cafe to open so I suggest she has a light meal now and we go for a walk another day. I explain I feel very tired because of the fieldwork I carried out overnight. She listens to my story and
starts to eat. Her brow becomes less furrowed and the deep wrinkles around her eyes smooth out and straighten. Her face becomes calm and her immediate disposition is gradually transformed until she becomes gentle and at peace.

**The Face**

As Ayla’s dementia and chronic depression evolve, she becomes restless and anxious more often these days, withdrawing within herself and away from her unfamiliar surroundings. I imagine the only thing she is able to do is look for a familiar face and build a relation. Her lines of movement reveal the way she interacts and responds through the face. It starts with a glance at the dining room. Unlike Daniella’s glance, Ayla has to continuously retune her sight because of the deterioration in her vision caused by macular degeneration and cataracts. With every step she takes, she stops and searches for a person who is close to her, whom she can rely on, before she takes another step. What is important to recognise here is that her lines of movement embrace not only her stop-and-go movement but also the different rhythm and duration of her glance, and more importantly her fluctuating feelings depending on whom she sees and talks with.

Once she recognises me, her way of engaging with the world and particularly with me, transforms dramatically. Her face quickly responds, showing a mixture of gladness and surprise. This contingent encounter awakens her body, providing her with the fundamental force to connect with me. Her pulse quickens, her complexion gains colour, and her eyes become watery and red. In other words, this encounter makes her body resonate with her surroundings, not only ‘through her various bodily rhythms and modalities’ but also ‘through the troughs and sieves of [her] sensation and sensibility’ (Seigworth and Gregg, 2009, p. 2). Simultaneously, her expressive bodily performance echoes my response and becomes integrated into her feeling, emotion and desire. Yet, it does not take long before the expression on her face transforms into a miserable one, accompanied by a thin and faltering voice. She desperately and stubbornly tries to take a seat next to me. It takes time to disentangle these knots she makes. It is no surprise however that her line of movement does not separate from mine even when we are at different tables. Although her line seems to stay at one place (at her table), it continuously heads towards mine. She keeps sending me her message of longing and yearning through her posture and desperate gaze. Needless to say, her line does not just represent her bodily movements and gestures, but also encompasses the affective and sensory dimensions of her lived experience, longing for attachment to a familiar face.
What is interesting to me is that, as her gestures, attitude and bodily movements in relation to Dorona (and myself and the other residents) show, her encounters with the faces of others are not the same. Neither do her facial expressions always reflect the same intensity of feeling or merely represent or mirror her static inner voices: the signifiers do not always match with the signifieds, there are always slippages, excessiveness. Unlike Darwin’s generalised and categorised facial expressions in *The Expression of the Emotions* (1965), her face is constantly transformed, manipulated and concealed in the process of interaction and encounter with the faces of others in order to obtain the best (potential) result she wishes to obtain. In this sense, from her point of view, the way in which she approaches a face is quite different from the Lévinasian face in terms of her singular and irreducible experience. Emmanuel Lévinas’s model of the face-to-face relation reveals a fundamental vulnerability when one encounters the face of the Other.28 For this reason, just standing in front of the Other demands a social and ethical responsibility. Although a person is expressive and exposed to the Other in the diverse forms of gesture and other performative expressions, ‘the face as a living presence’ (Levinas, 2012, p. 66) is at its utmost vulnerability in the presence of the Other. This human condition of vulnerability and the impossibility of reducing the Other to Sameness brings persons to a particular relation that demands an ethical obligation of caring for the Other (ibid., p. 294). In contrast to Lévinasian ethical and unreflective encounters with the face, Ayla perceives and understands the face through its enactment of ‘socialising,’ of ‘communicating’ and of ‘individuating’ in Deleuzian’s sense:

It is individuating (it distinguishes or characterises each person); it is socialising (it manifests a social role); it is relational or communicating (it ensures not only communication between two people, but also in a single person, the internal agreement between his character and his role) (Deleuze, 1986, p. 99; cited in Rushton, 2002, p. 221).

The roles of the face thus suggest that what she expresses on her face does not directly reflect her thoughts and feelings but rather the face emerges in the formation of communication, socialisation and individualisation. Accordingly, a face is never fixed but made up of potential, existing in the form of the virtual. It is non-identical in Deleuzian’s sense, implying that a face as an established entity is unavoidably flawed (Deleuze, 2004). Therefore, in order to explore the ways in which she perceives and relates to the faces of others we need to ask not ‘what is a face?’ or ‘what does a face

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28 Emmanuel Lévinas uses the term ‘Other’ translated from the French word *autrui* which refers to ‘the other person’ or ‘someone else.’ He normally uses it as a singular form in order to emphasise face-to-face relations that happen one at a time.
represent?’, but ‘what can a face do in social life?’ (italics mine) (Rushton, 2002). In more detail, we need to follow and trace:

The tendencies and trajectories of the face, the direction of the thoughts, feelings and affects that energise the face rather than the thoughts, feelings and affects that the face expresses (Rushton, 2002, pp. 228-229).

Furthermore, her face shows a varied mode of repetitive expressive performance in the process of interaction and encounter. This repetition then invites reflective and intensive methods of response and resonance. From a Deleuzian perspective, a reflective face is one that is ‘fixed and immutable and without becoming’ and that is ‘collapsing inward, toward the inside, toward the interior of the body, and as a mutual unfolding outward of the inside’ (Rushton, 2002, p. 230). Paradoxically, because of this unknowability of the reflective and thoughtful face, the face in turn calls for an eternal return to capture this mystery. In contrast to the reflective face, the intensive face is characterised as transformative, transitory and dynamic. Ayla moves and feels at the same time, resonating with the faces of others and her surroundings with diverse and ever-changing facial expressions and voices which differ in tone, speed and volume. Affective and sensitive experiences are particularly important at this moment. As we have seen, Ayla’s affective and sensory dimensions of experience expressed and exposed through bodily performative actions and enactments in the process of dramatisation are embedded in her movements, sayings and gestures (Deleuze and Guattari, 2004b). When her body moves, it feels; in fact, it happens simultaneously, so ‘it moves as it feels, and it feels itself moving’ and here we realise that there is ‘an intrinsic connection between movement and sensation’ in a way that:

the slightest, most literal displacement convokes a qualitative difference, because as directly as it conducts itself it beckons a feeling, and feelings have a way of folding into each other, resonating together, interfering with each other, mutually intensifying, all in unquantifiable ways apt to unfold again in action, often unpredictably... Felt and unforeseen (Massumi, 2002, p. 1).

Ayla’s subjective experience of interaction and encounter is dramatised as being affected and affecting, namely, ‘the feel on the skin’ and ‘to feel on the inside’ (Cassaniti, 2015, p. 136). In particular, I pay attention to her anxiety accompanied with hopelessness and helplessness as evidence of her existential crisis. Ayla feels insecure and unfamiliar with the dining room, even though she repeats this routine daily. In Heidegger’s terms, she finds her own existential experience of ‘not-being-at-home’ (Heidegger, 2010, p. 328). However, it does not mean that her ontological being is nullified or has become an ‘inauthentic being’ in Heidegger’s sense (ibid., p. 328);
instead she responds and resonates with the world in the most dramatic and singular way, on her own terms and within her capability:

Anxiety brings one back to thrownness as something to be possibly repeated... it also reveals the possibility of an authentic potentiality-of-being that must, as something futural in repetition, come back to the thrown There. Bringing before the possibility of repetition is the specific ecstatic mode of the attunement of the having-been that constitutes anxiety (italics in original) (Heidegger, 2010, p. 328).

Her anxiety is embedded in the individual parts of her organs, sinews and muscles and at the same time her organic body reflects such feelings, affects and emotions by transforming, relating, adding, relieving and nullifying. These individual becomings of bodily expressive performance on her face reveal a kind of momentary awakening, constructing her ever-changing subjectivity in repetition. In a word, her face provides a platform for us to witness the formation of subjectivity.

4. Repetition, Dementia and Anthropology

With critiques of cognitive- and therapeutic-oriented approaches, I have reconfigured one of the most critical issues of dementia, which is repetition, in the event of a morning meal. Based on the ethnographic findings I now shift the intellectual interest of searching for cause or meaning in these repetitive experiences to questioning its value and function by problematising this repetition. What do these repetitive behaviours and sayings do? Why are mundane obsessive, repetitive and routinised bodily practices so important in the formation of subjectivity? This problematisation firstly demands a new practical approach to identify the processes of individual events and relations between repetitive behaviours and verbalisation, and other constitutive components of social life, rather than just representing the phenomena. I proceed by exploring how we alternatively perceive and understand the repetition. In doing so, I show the agential ability of a map by illustrating generative and emerging relations between subjects and their surroundings and by reflecting transformative lived experiences in the making of subjectivity. Moreover, I attempt to reveal that subject (the self) is not a conferred or given being; it is rather constituted in time, emerging through a tenuous yet continuous repetition and differentiation in the process of engaging with people, things, and the surroundings.

(1) Repetition and Performative Cartography

Fernand Deligny (2015), a French educator and alternative psychiatrist, who maps the movement of children with autism, conceptualises their mode of living as a network, rather than as reason or language, beyond predominantly medical categories, models and research methods. From the 1960s onward Deligny, in association with a militant
filmmaker, Jacques Lin, operated a series of residential programs for children and adolescents with autism and other mental disorders in the Cévennes region of France. They strongly reject any established linguistic and symbolic order whilst writing, drawing and filming the lives and walks of the autistic across the forest area of Cévennes. For example, he uses his neologism of ‘camering’ rather than filming because while the latter means a ‘narrative and pre-existing project’, the former implies the ‘unfiltered recoding of images as traces of what is in the making’ (Wiame, 2016, p. 43). Likewise, the word ‘image’ in his maps and writings does not mean anything, but rather suggests lines of movement, not pathological symptoms and signs (ibid., p. 42). Here, the line thus refers not only to people with autism per se, but also to their bodily experience, such as affect, sense and movement. In other words, these lines extend to and encompass more detailed information showing entangled relations, encounters and responses between the natural environment, individual biography, other people, things and animals throughout their journey. As a result, although lots of lines of movement on the maps seem to be inexplicable because individual lines move in unpredictable directions and ways, he begins to realise that there are some patterns, knots and nodes on the maps where individual paths meet, intersect and become entangled. The lines of movement thus demand new interpretations outside of linguistic or rational spheres regarding the singularity of individual children with autism, as well as their interactions with their surroundings. Through his life work mapping and camering the movements of children with autism, Deligny discovers an entirely different way of being autistic and a way of co-dwelling with others, suggesting the singularity of children with autism, particularly with regard to their imminent desires, sensations and affect without necessarily referring to their cognition, language and consciousness. He also defines co-presence and networks as ‘something that forces them to weave or to spin - as a spider spins a web’ (Miguel, 2015, p. 188) which is a fundamental and preconscious way of life. This method of networking is based on the ‘common’ in Deligny’s terms, that is the shared and immanent nature of human beings, what he calls ‘the Arachnean,’ implying ‘a network is a mode of being’ (Deligny, 2015, p. 33). Concomitantly, his cartographic practices contribute to building an alternative connection and relation between the space and the subjects, highlighting in particular sensory and affective experiences. In doing so, the theory of lines emerges to interpret these unexpected transformative movements and dramatic changes - such as curving,

29 Deligny’s French term Lignes d’erre is translated as ‘lines of drift’ in A Thousand Plateaus (2004) by Brian Massumi and ‘lines of wandering’ in Dialogues II (2007) by Hugh Tomlinson and Barbara Habberjam. This chapter uses ‘drift lines’ in order to reflect the tendencies and orientations of lines that are neither predetermined nor preconditioned, but rather contingent and complex. For a counter-argument to this, see Aline Wiame’s Notes in Reading Deleuze and Guattari through Deligny’s Theatres of Subjectivity (2016).
pausing, crossing, entangling and traversing on the maps – which show idiosyncratic ways of subject-making.

In relation to the study of dementia, Deligny’s cartographic approach offers very useful paths for reshaping anthropological accounts of subjectivity for the following two epistemological and methodological reasons. First, Deligny strongly rejects pre-existing formulas, categories and concepts in the practice of his project; he does not categorically differentiate children with autism based upon their mental capacities or abilities to speak, and neither does he normatively separate the normal and the pathological (e.g. Canguilhem, 1998). Therefore, if a child with autism does not speak or behaves ‘erratically,’ it does not mean that he/she possesses pathological signs or symptoms, but rather suggests they have a different way of living. He perceives such erratic behaviour or movement not as pathological effects, but as raw experiences that should be transcribed into new lines of movement on the map. He then defines the difference between children with autism and those without as the ‘crevice’ (fêlure), emphasising that it is ‘not a difference of level, degree or quality, but just a “mark of acceptance” in which nothing is presupposed’ (Miguel, 2015, p. 188). Nor does he accept intention, consciousness and ability to speak as the given. Instead, he acknowledges the way of life for children with autism itself as a singular mode of being autistic. It is self-evident for him that while those who can speak are regarded as ‘the-human-that-we-are’ living in the ‘reign of the symbolical,’ those who do not live in the ‘reign of silence’ (ibid., p. 188). It goes without saying that for him, mapping is not the representation of what it is and of people, but ‘tracks and traces’ of their movement (Wiame, 2016, p. 44).

Second, his practices based on living and working together with the autistic offer alternative methods to more conventional approaches. Unlike established clinical experiments or institutionalised and therapeutic interventions, Deligny creates a residential space (territory) in the Cévennes where he co-dwells and works collaboratively with those living outside of the linguistic world. For him, children with autism are not merely the objects of research, but co-dwellers: both subjects and collaborators regardless of their abilities in cognition, language and memory. In this sense, individual bodies are perceived not only as the site of ‘knowledge production’ (Milton, 2014b), but also as the situated and embodied ‘becoming of autism’ (Milton, 2014a). His practices, which are not caring or curing but which rather trace the ‘common’ in the sense of the imminent, pre-personal human features of co-dwelling, offer a new potential space where becoming-autism can be validated with its own singularity and its commonality with others as networking beings in the world.
Accordingly, his re-evaluation of the ‘common’ provides both ethical and political grounds which extend dichotomous thoughts, such as those of subject-object, the normal-abnormal or human-non-human (Milton, 2016). His concept of ‘common body’—more directly, the ‘bodies without a language’—is therefore a manifestation of their singularity, ‘the promotion of forms of space-making’ (Wiame, 2016, p. 48).

Deligny’s thinking and practices shed new light on a rhizomatic way of approaching lived experience by refusing descriptive representations and by considering the expressive and performative dimensions of being autistic. His practices reflect upon the creative, generative and repetitive formation of subjectivity, which is outside of language but which has something in common with people without autism. These maps do not mirror pathological symptoms, but keep traces of movements, reflecting a range of embodied experiences which are illustrated as a series of lines, ones which are curved, straight and entangled. In Deligny’s words, the act of tracing maps is ‘the act of developing a pre-individual and pre-historical mode of knowing and thinking,’ drawing along with the evolution of a gesture, and not drawing across a surface’ (italics in original) (Wiame, 2016, p. 45). Consequently, Deligny’s alternative thinking and practice have the potential to contribute to building a new cartographic paradigm of subjectivity in the dementia context based on bodily performance, which does not necessarily rely upon language, reason and cognition.

(2) Repetition, Difference and Subjectivity

While Deligny offers a possible new way of understanding repetition in the dementia context by shifting epistemological and methodological paradigms, in this part I demonstrate Deleuze’s cartographic microanalysis and its potential for exploring the expressive and performative qualities of repetition by those affected. This involves the following questions: how are lines of movement identified from others without recourse to established concepts or individualized entities? How can the cartographic paradigm of subjectivity provide ontological ground for the singularity of Being with dementia? In doing so, I explore the ways in which the subject emerges through repetitive dramatization of the affective, the sensory and the gestural as life moves forward through continuous differentiation.

Indeed, the main reason Deligny uses maps is because lines better reflect the immanent possibilities and potentialities for concretising the very nature of human expressiveness, performance and mobility and more importantly, for revealing the immaterial and invisible relations between people, things and their surroundings (Miguel, 2015). In other words, the questions call for creative and generative ways to
differentiate individual movements. It is the ‘other thought’ in the Deligny sense that is a ‘thought without a subject, a thought that thinks on its own, without being thought, without reflexively thinking itself... this other thought is made up of acts... such as gestures, images, moves, and spatial organisations’ (Wiame, 2016, p. 48). From the Deleuzian understanding of subjectivity, that is a process of ‘dramatization’ (2004, p. 216-221).

Similar to Deligny, Guattari in collaboration with Deleuze\(^\text{30}\) regards psychiatric patients as equal members of society, looking at their positive attributes by working in a ‘more open, more processual, more deterritorialised way and working ‘toward the consistency of [the] virtual lines of bifurcation and differentiation, in short towards its ontological heterogeneity’ (Guattari, 1995, p. 61). They describe appreciatively Deligny’s thought and practices in \textit{A Thousand Plateaus} (Deleuze and Guattari, 2004b, p. 290): like rhizomes, Deligny’s maps have no predefined start or end points, no predetermined centres, no pre-structured structures or systems – they are new ‘potentialities of becoming.’ Rather than considering the subject as a pre-established entity, they encompass all performative lived experiences in the making of a cartographic formation of subjectivity - such as milieu, movements, affect and the senses. Accordingly, diverse modalities of line are used for conceptualising complex, dramatic and entangled ways of engaging with the world, involving structuring, organising and disorganising relations with it. Rather than relying on individual residents’ symptomatic illness experience, the lines follow and trace the daily trajectories of those affected and at the same time, they reveal and emerge in the process of interaction, response and encounter with people, things and the surroundings in a wide range of different modes; some are expressed as thick, straight or zigzag lines in-between two designated points (places, persons, things or environments), others are recurrent, meandering, curved, spiralled or intermingled depending on individual bodily performance while engaging and responding with the given situation. Other recurrent encounters with objects, place, mood, people, and the environments are described as knots, plane figures and other types of diagrams depending on the intensity of experience quantitatively and qualitatively. Through this line drawing, enmeshed and entangled lines of encounter emerge in the human-geographic map. Therefore the tracings are, as Deligny asserts, ways of co-dwelling and of learning through not talking about loss, but following and tracing the creation of bodily movements (2015).

\(^{30}\) Guattari has practised the theory of schizoanalysis at a psychiatric clinic called \textit{La Borde} since the mid-1950s, including collaborating with Deleuze in 1972, producing \textit{Anti-Oedipus} (1972) and \textit{A Thousand Plateaus} (1980).
As a result, as Deleuze and Guattari insist, these cartographic lines not only reveal diverse lines of movement but also traces of lines of becoming. This cartographic approach to subjectivity is not self-reflexive or a ‘mathematical representation’ but rather the gestural resonance through lines of movement and thus tracing does not merely reflect on movement from one pre-determined point to another but rather like ‘wayfaring’ that is ‘neither placeless nor place-bound but place-making’ (Ingold, 2007, pp. 84, 101). Therefore, the cartographic paradigm of subjectivity emerges in the process of act and enactment in a horizontal direction (Wiame, 2016). Guattari names this way of exploring the formation of subjectivity as ‘schizoanalytic cartography’ (2013) by de-individualising and re-constructing subjectivity. The following key questions help to specify this approach and method: how can individual action and response be differentiated from mundane repetition? How can a difference which has emerged in the process of social interaction and encounter be identified? How can an existing Being integrate with an emerging being-in-the-becoming? In this sense, the act of cartographic tracing is ‘a geo-analysis, an analysis of lines,’ lines that resonate with the world as a way of life (Deleuze and Parnet, 2007, p. 128). Unlike points and networks which represent stable and fixed locations or positions on the map, lines can reflect performative and transformative movements with different rhythms, forms and intensities. As such, the lines of traces become lines of becomings, demonstrating the contingent, indeterminate and open-ended process of becoming-subject.

5. **Toward a Cartographic Ethnography of Subjectivity**

Developing upon a cartographic ethnography of subjectivity I now attempt to expand our understanding of the singularity of becoming-dementia in repetition and build a potential space of co-dwelling focusing on movement, sensation and affect. Individual residents’ lines of movement, verbalisation and gestures invite us to an alternative sphere away from conventional cure and care-centred approaches (i.e. bio-medical and therapeutic approaches) and analytical tools (i.e. survey, observation and interpretation). These lines themselves are the revelation of individual residents’ singular ways of becoming-subjects in sometimes uncomfortable and unfamiliar circumstances by repetitively attempting to make relations with (or distancing themselves from) others, things and their surroundings. In this process, subjectivity is expressed and exposed in a range of different modalities, such as awakening, glancing, rhythmic movement and facial expression with different intensities of feeling, affect and emotion in response to ever-changing circumstances.

First of all, Dorona’s lines of movement in having breakfast reveal seemingly passive actions and sayings. The trajectories of the staff coexist with those of Dorona, yet the
tendencies, directions and orientations are quite different. The intention of staff movement is relatively clear and straight in that the staff transfer Dorona to the communal area and then to the dining room. Meanwhile Dorona’s movements and gestures oscillate slightly, following and distancing in relation to the lines of staff movement and the surrounding milieu. It is in awakening that she resonates with her world of dementia in two different ways - no matter how slight her actions, sayings and gestures - by connecting and disconnecting (distancing) herself from her surroundings. What is important to remember is that here connection and disconnection do not mean a dualistic network linking two different points, but embrace entangled ‘lines of affect or sentiment’ (Ingold, 2017, p. 22) that are constantly expressed and transformed as the intensity of the social and sensory surrounding enfolds.

For Daniella, without her partner, the morning meal is hardly pleasurable. Her glancing and ensuing feelings lead her to idiosyncratic bodily movements consisting of various modes of repetition in actions, gestures and sayings. This forms a rhythmic transformation that ‘relates, as well as separates, the cyclical and linear processes, continuation and discontinuation, repetition, and difference’ (Bon and Repič, 2016, p. 76). At the same time, as Henri Lefebvre infers in his posthumously published book *Rhythmanalysis* (2004, pp. 6-7), this implies that every rhythmic repetition inherently involves differentiation in the process of engagement with the surroundings as life enfolds. In a word, this rhythmicity involves ‘differences within repetition’ (Ingold, 2011, p. 60). It is a corollary that Daniella’s steps and murmurings echo not only her changed situation but also her attentive attunement by way of differentiating her steps.

Ayla’s lines of movement keep stopping and starting whilst she looks for a person she is familiar with or she can rely upon. Whenever she takes a step, her minute changing facial expressions and minute bodily gestures reflect her complex lived experiences not only of her physical difficulties in walking but also her inner voices, such as those of frustration, disappointment and expectation. It is her way of resonating with her world of dementia. Likewise, her zigzag, slightly faltering and slow lines of movement reflect her current entangled relations and situation. Therefore, without interaction and encounter, the face of the other is neither subject nor object but exists as a possible relation, a virtuality that has not yet come into being. Through asking the same questions and performing the same bodily gestures and movements repetitively, Ayla continuously reshapes the precarious and vulnerable world around her through repetition and differentiation.
In conclusion, the daily breakfast schedule consists of the same routine repeated over and over again and thus residents with dementia become routinised. Are they all on the same journey with these repetitive itineraries? Of course they are not. When Dorona, Daniella and Ayla look at the details of light, smell, people, atmosphere and weather, they resonate with their surroundings in astonishingly varied ways over time. In this sense, the social life of those affected is a kind of ‘correspondence’ with its constituents, in that people, things, and environments literally resonate with one another over time to affect and be affected within the capabilities of individuals by attending to and undergoing something over and over again, in Ingold’s sense (2017, p. 14). Accordingly, here repetition does not mean the exact same actions that one experienced before, nor does it refer to a completely different form of transformation which has no relation to past experience and memory. Rather past events and memories exist as ‘virtual’ in the present and thus people keep selectively resonating (in their ways of calling, retrieving or forgetting) with them as potentially ‘real’ in Deleuzian’s sense (Deleuze, 1988a). The future instead is pulled into the ‘actual present’ in the form of ‘passive expectation’ through ‘contraction’ and ‘synthesis’ (Deleuze, 2004, pp. 94-96). Furthermore, each interaction and encounter brings up complex bodily affective and sensitive responses through ‘the facial muscles, the viscera, the respiratory system, the skeleton, autonomic blood flow changes, and vocalisations that act together to produce an analogue of the particular gradient or intensity of stimulation impinging on the organism’ (Demos, 1995, p. 19). In doing so, the power of affect attests to the fact that it is ‘unformed and unstructured’ feeling which is ‘transmittable’ and thus plays a role as a ‘powerful social force’ (Shouse, 2005). In other words, affect is becoming a vital force to affecting and being affected.

In this sense, the lines of movement are the entangled ‘meshwork’ of those affected where their relations and their lives unpack as a mode of co-dwelling ‘in an open world’ (Ingold, 2008, p. 1809) that has ‘neither beginning nor end,’ and thus ‘a line of becoming is always in the middle’ (2011, p. 83). Those affected dwell in the world as wayfarers who continuously engage with people, things, and their surroundings within their capabilities. Subjectivity is therefore ‘the verb in the infinitive as pure becoming’ which is continuously generated through repetition and difference (Deleuze and Parnet, 2007, p. ix). As a result, it is a corollary that repetition in the dementia context has to be reconsidered as ‘a situated phenomenon’ that is ‘embedded’ in social life and at the same time we (as connected beings) are already ‘embedded’ in the same world, as it were, in ‘dementia-in-the-world’ (Hughes, 2011, p. 226). Namely, repetition takes place in the context of the relational and situational in-the-world and in the process of becoming otherwise. Last but not least, the cartographic map should
not be seen as finished work because the lines of movement and gesture of those affected will continuously accumulate as they constantly respond to and resonate with their surroundings. The subject is an entanglement of the new creation of singularity generated by the logic of difference and repetition: ‘Being is both being and becoming, where becoming is the condition for being’ (Williams, 2013, p. 64). It is no surprise that the act of mapping concretises ‘a theatre of subjectivity’ from Deligny, Deleuze and Guattari’s point of view (Wiame, 2016, p. 38), emphasising the expressive and performative aspects of subjectivity and at the same time the process of the formation of subjectivity.
CHAPTER 4 - WAITING AS ENTANGLED MOVEMENT

1. Where are the fish and chips?

There’s no one there! No fish and chips! (Daniella)

It is about 9.40 on a Thursday morning. Looking around the kitchen on the Abraham Unit, Daniella complains there are no fish and chips and no staff. The residents in the common area become lively with conversation. ‘It is Thursday’ and fish and chips are normally only served at Wednesday lunchtime. Bracha tells her ‘It is too early for fish and chips’, shaking her head in disbelief, as she had her breakfast only an hour ago. At the same time, Bracha also confuses what day of the week it is. Low and continuous murmurs of ‘Mashugana!’ are mixed in with the conversation.

This chapter asks the simple question of how people living with dementia in the Home experience time, with a particular focus on waiting. More specifically, it will look into the processes and relations which shape time and waiting and suggest a new understanding of waiting as entangled movement, in dialogue with Ingold’s concept of dwelling. The purpose of this chapter is to problematise the prevailing understanding of waiting and to explore its formation, shedding new light on otherness in the taken-for-granted temporality of dementia. This implies significant reflections on temporality within the dementia context from three closely interwoven perspectives: the epistemological, theoretical and practical.

My aim is to challenge prevailing perceptions and the social valuation of temporality in dementia. We often take for granted that we share the same time experience, but as the above ethnographic vignette illustrates, people living with dementia frequently forget or confuse time, especially in relation to social structures as well as familiar environments, directions and people. Unfortunately, like Daniella, the time they perceive and experience is often ignored or deemed abnormal by not being synchronised with the existing reality for a group of people, being characterised as imagined or confused illness experience. Here we witness a significant epistemological gap between the lived experience of those affected and the experience of others. Indeed, less value is placed on the way those living with dementia experience and practice time, and it is instead often labelled as incoherent, irrational, inarticulate and fragmented.

Problematising prevalent cognitive, medical and institution-centred approaches, this chapter attempts to reveal the experience of time from the perspective of those

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31 A Yiddish term which means a person is nonsensical, crazy or silly.
affected as ‘other,’ calling for an alternative theory and practical methods to explore this social phenomenon. I claim that existing research methods based predominantly on interview, observation and surveys are insufficient in embracing the enmeshed social processes and relations of temporality. In existing studies, those affected are often treated as mere sources of information, rather than as subjects who feel, listen, smell, taste and see the world around them. However, as a substantial body of autobiographical work shows (e.g. Bryden, 2005; Taylor, 2007), the chaotic, fluctuating and confused reality is the lived world of dementia that those affected feel, experience and live through in day-to-day life. Likewise, I insist that the predominant understanding of time is a reflection of our culturally, historically and medically embedded perceptions and social valuation, one mainly based on cognition, rationality and consciousness. Moreover, the temporal dimension of everyday life cannot be isolated from the institutional care practice and physical environment, nor do they remain a mere backdrop, regardless of mental capacity. Living with dementia involves not only living with other non-human entities, such as food, the weather, music, atmosphere and so forth, but also with institutional care practice and more importantly with social relations. The temporality of the illness experience calls for a co-dwelling perspective, emphasising that ‘human life is a process that involves the passage of time’ (Ingold, 1993, p. 152) and this process inherently involves the formation of co-dwelling.

To explore this, I understand those living with dementia as ‘living, experiencing beings’ who are ‘perceptually attuned to picking up information’ in their immediate surroundings (Ingold, 1993, p. 153). I specifically focus on minute bodily affective, sensory and expressive movement in response to the ever-changing surroundings from the perspective of co-dwelling. Here, bodily movement includes a myriad of social experiences in relation to everyday care practice, including institutional management, the physical environment and social relationships with others. Time is then considered as entangled movement or flux, qualitatively experienced through individual bodies, and more precisely, through intersubjective bodily interaction and response in the making of co-dwelling. In this way, the dwelling perspective allows me to explore an untapped and incomplete yet generative social life that not only unveils multiple dimensions of waiting in co-dwelling, but also unravels dynamic interaction and communication among those engaged in waiting. By rethinking the ways in which residents with dementia and staff experience time in care home settings, I attempt to uncover the characteristics of waiting in institutional settings. I do not merely look at how residents and staff pass through it or its outcome, but take note of the ways in
which they engage with it, and how they interact with one another while waiting in a co-dwelling condition.

Following this problematisation, I shall now proceed with my argument on temporality from the perspective of co-dwelling by drawing upon a participatory ethnography of waiting that takes place during the period after breakfast and before daily activities begin, which is approximately 9am to 10am. This consists of four sections. In the first, I illustrate the moment of waiting in the communal area based on a brief observation. In the second, I attempt to specify the limits and implications of previous approaches toward waiting within the dementia context. It criticises the ways in which residents with dementia have been perceived and understood, which then affects the appreciation and valuation of their actions, and the ways in which their behaviours and relationships are experienced. Drawing upon Ingold’s dwelling perspective, I argue that temporality is inherently embedded in the spatial, and more importantly this entangled spatio-temporality is directly experienced and incorporated into the individual kinaesthetic, sensory and affective experience. In the third section, I remap the waiting based on a co-dwelling and becoming perspective, focusing on four components of what the Home, residents, staff and the researcher experience as co-dwellers while waiting. In doing so, this study demonstrates the ways in which the singularity of an individual mode of waiting and a unique illness experience are intermingled with multiple dimensions of social practice in terms of affect, sensation and movement. In the conclusion, I argue that waiting is not idling or doing nothing, just a ‘hanging around’, but instead it is a dynamic and rhizomatic response to illness, biography and enmeshed relationships with others, things and environments.

2. The Moment of Waiting in the Communal Area
It is about 9am. When a small lift – in the middle of the left wall (Figure 4-1) – opens, the sound of life spreads through the communal area of the Abraham Unit. A familiar, recursive scene with the sounds of calm classical music guides me into the world of dementia. As usual, I face two different groups of residents sitting in the small communal area situated between the dining room (behind the glass wall) and the care worker desk (behind the pillar on the right-hand side of the image). They are divided by two red sofas which sit back-to-back so residents are not facing each other (although they no doubt hear one another).

By the entrance of another lift for wheelchair-users (behind the pillar on the left-hand side), Basha is waiting for a porter to take her down to the Physiotherapy Department on the Ground Floor. When she hears the bell of the small lift I am in, she turns her head toward it and opens her eyes wide. As soon as she recognises me, she lowers her
head in disappointment and closes her eyes again. Over the past half-decade, Basha has experienced deterioration not only in physical strength - including in mobility and other medical complications such as diabetes, hearing loss and rheumatism - but also in cognitive decline. In order to meet her medical needs and provide her with sufficient quality of care, including the appropriate medical appliances, she has to transfer from the Joel Unit to the Abraham Unit and then again to the wider room in which she currently resides. Recently her prolonged inactivity has caused another issue in a pressure ulcer. More seriously, her recent weight loss indirectly reflects a warning sign that her immune system is deteriorating and subsequently she has been prescribed a low potassium diet together with regular exercise with the help of physiotherapists at least once a week.

Figure 4-1 Communal Area of the Abraham Unit

Raphael is still sitting at the dining table, gazing vacantly through the window into the distance. An unshaven face with tangled hair shows he has risen late. Although he likes walking and doing other activities, he cannot do them without an assistant for his wheelchair due to the progressive deterioration of his physical strength. He has had to rely on others for transportation for a long time and his illness gradually makes him more inactive and reclusive, resulting in his spending most of his time in his room watching TV. Getting up early has become a thing of the past. His mornings start around 8am, when he has a morning shower before he eats breakfast around 8.30am with the help of the care staff. Today he seems to have gotten out of bed without having a shower. Although he has already finished his dessert and has been waiting for
assistance with his morning care, there are no care workers to attend to him at the moment. Raphael remains in the dining room until a care worker transfers him somewhere else. An administrative staff member passes by, greeting all residents sitting in the dining room and in the communal area. Raphael can neither see what is happening behind him, nor know who is talking. In fact, he seems indifferent to what is going on around him. He is expressionless and his eyes behind his thick glasses are unfocused and vague. He continues looking absent-mindedly into the distance until he gets the attention of an Activity Leader.

My gaze moves from the dining room to the window across the corridor. Mild sunlight streams into the communal area. As I expect, Ariela is dozing in the same chair, near the boundary between the small communal area and the dining room. Although her personal preference to stay relaxed and enjoy a solitary life often causes serious medical concerns over her lack of activity and weight, her determination to live an independent life has not been easily swayed. Except from when she smokes in her room, she spends most of her time in the same seat, listening to music or looking at passers-by. Since she came to the Home in 2008, she has remained independent as long as she is able to control her bodily pain and personal hygiene. Taking painkillers has worked well so far, but these days she seems to be approaching the edge of her secure independent zone. Her lack of movement affects her metabolism, resulting in increased body weight, and recently, she has been heard protesting in a furious voice whenever a carer checks her weight and personal hygiene.

Passing by the dining room, I look at the small communal area. Ayla and Gayora are on my right, sitting side-by-side and drifting off. Bracha, Yedida, Gevira, Chaya and Emmanuel are on the other side. Two care workers are at the desk, answering phone calls and looking through the day schedules and medical files. Yedida is sitting in the middle of the seating area by the wall, cracking pistachios and looking around. Some cracked shells are piled up on the table and others are scattered on her jumper. As always, her thick handbag - full of outdated newspapers, weekly schedules, other notes and leftover food - is on the sofa beside her, covered by her heavy sweater. As soon as she recognises me, she winks and smiles at me, shaking off pieces of pistachio and gesturing me to come and sit. I wave my hand, meaning ‘in a minute’.

On the window side of the communal area, Chaya is reading a book. Emmanuel, holding a detective novel, sporadically turns to look at her. Chaya is completely absorbed in reading, enjoying her favourite time - the calm and silent morning - to the full and without interruption. As Emmanuel cannot talk to Chaya, he turns his head to look elsewhere, playing around with his walking stick and tightening his belt. These
days he no longer wears a trouser suit and belt, but instead wears a tracksuit with an elastic waist. I assume this is recommended by care staff to manage his Alzheimer’s disease and Irritable Bowel Syndrome. Yet, his behaviour of checking his belt and adjusting his clothes still express his embodied social manners.

Bracha puts her newspaper on her right-hand side and reclines against the sofa, closing her eyes gently. She adjusts her glasses and hunkers down into her body. Gevira, who sits between me and Bracha, mainly listens to others and intermittently nods her head, holding her Zimmer frame with two hands. Gevira greets me with a smile. Despite her knee replacement, her longstanding morning walk has not been compromised so far. Although her recent loss of short-term memory and language makes it difficult for her to join a conversation directly, her socialising persists regardless of her inarticulate and fragmented way of speaking.

Ayla and Gayora are dozing. When the lift door makes the announcement ‘the door is open’ and ‘the door is closed,’ this seems to wake Ayla up. She rubs her eyes and tries to recognise the person who has just entered her world. She turns her head towards the lift and opens her eyes wider to adjust her vision. Although she does not appear to recognise me due to her loss of vision, she does not give up trying to identify me. With her limited vision, she may have memories of individuals who would come at this time. She might narrow down her guesses based on the vague human form but her attempts seem in vain. She lowers her head and reclines on the sofa again. Meanwhile, Gayora does not move at all, closing her eyes.

3. Waiting, Anthropology and Dementia

(1) Temporality in Institutional Dementia Care

Although we may all agree that people living with dementia are coevally dwelling with us, the ways in which they undergo time are often perceived and described as though they live ‘in a timeless world’ (italics in original) (Edwards, 2002, p. 184) or out-of-time and space, namely ‘displaced’ (Reed-Danahay, 2001, p. 48). It is as if time is suspended or of no use at all. Those affected are understood in contemporary society through metaphors of disorientation and dislocation (Milligan, 2003). Under the circumstance of lost cognitive abilities, time is no longer invariable but becomes variable in everyday care practice. Several clinical studies have documented the presence of disorientation and confusion as criteria of dementia (O’Keeffe et al., 2011; Yew et al., 2013; Dumurgier et al., 2016). It seems an inevitable conclusion that this approach no longer clinically supports the consistency of personal memory, identity and narrative (Orona, 1990). Accordingly, seemingly disoriented and confusing illness experiences are
regarded and diagnosed as typical Behavioural and Psychological Symptoms of Dementia which require monitoring, management and care via medical and therapeutic intervention.

In particular, timeless worlds (Edwards, 2002) and total institutions (Goffman, 1961; Paterniti, 2000) are well-known descriptions of long-term care facilities which criticise the culture of institutionalised care - such as ‘bed-and-body work’ (Gubrium, 1975, p. 123; Diamond, 1992) or ‘time and task’ (Henderson, 1995, p. 46). They all insist that not only the structure of the building, but also the training of individual staff members, their personality, life experience and organisational policies influence their attitude, perception and care practice in terms of temporality. Subsequently, unequal power relations between carer givers and care receivers are made, circulated and embedded in personal bodies and subjectivity through time discipline, medicalisation and the building structure, such as Foucault’s Panopticon (Henderson, 1995; Waterworth, 2003). Individual residents with dementia are dehumanised as immobilised ‘points of [medical and therapeutic] application’ rather than as ‘vehicles of power’ (Foucault, 1994, p. 36). Needless to say, the subjective experience of time governed by an institutional time framework has hardly been valued as a meaningful social experience (Zerubavel, 1979; Waterworth, 2003; Wiersma and Dupuis, 2010), disregarding diverse understanding of time-perception, practice and appropriation from the first-person perspective. What is worse, this medical and institution-centred approach often brings about unexpected results in that the staff in these settings become less interested in residents’ personality, preferences, life-history and their relationships (Reed-Danahay, 2001). They are apt to ignore what those affected express and even lie to them in order to control and manage them. The feelings of anxiety and insecurity in such a chaotic world, a common experience among those affected, become a part of the social, cultural and medical understanding of dementia and again make people fear this social phenomenon. Their social life in terms of time has either been ignored as trivial or regarded as a pathological symptom. Even when time is applied in dementia care settings, it is either oversimplified or linearly described, focusing mainly on the perception, practice and management of time from the institutional or staff perspective. People in care homes may continuously encounter one another, but they remain relatively anonymous and their relationships are task-oriented and there to be ‘passed through’ (Augé, 1995, p. 104). The relationships between people, the institution and environments are mainly constructed by assigned duties or predetermined daily schedules and thus remain transient, ahistorical and less identifiable. Care homes become ‘placeless spaces’ (Twigg, 2000, p. 78) in a sense that care practices as well as architectural structures become uniform and standardised,
resulting in loss of personal and meaningful attachment and belonging. Christine Milligan describes such places as ‘non-places’ a term coined by Marc Augé (1995), where social relations and interactions are superficial and transient (for more detail, see Chapter 6).

The prevailing ways of understanding temporality within the institutional dementia context are mainly based on neurological, physical and psychological damage, causes of suffering and therapeutic intervention. Loss in the sense of time reflects a malfunction of human biology, yet at the same time and more importantly, it becomes a ground of marginalisation and discrimination within the illness experience. It is regrettable that although the above existing research illustrates the failure of institutional care and its negative effect on everyday life in terms of institutionalised temporality, it has been less applied to the experience of people with dementia per se. More directly, temporality has barely been questioned as a valuable aspect of social life in the study of dementia. This implies that not only theoretically, but also practically and methodologically, we have not given much attention to the temporality of dementia. The experience of time for people with dementia is rather perceived and understood as a disoriented and confused illness experience which requires medical, therapeutic and other types of social intervention in order to improve, maintain or control pathological signs and symptoms (Nygard and Johansson, 2001). The way we perceive temporality in dementia becomes stigmatised and epistemologically as well as existentially violent. Giorgio Agamben (1998) describes a form of deprived life as ‘bare life’; people exist in a state of exception and with less social value. In this sense, people with dementia literally live in a timeless world (Edwards, 2002) and time exists only as ‘a point of reference according to which lives are set and adjusted like a clock’ (Schweizer, 2008, p. 3) for the benefit of others, such as care staff, in order to measure and organise their daily work. In turn, these institutional temporalities affect the ways individual subjectivity and power relations between care givers and care receivers are shaped (Goffman, 1961; Foucault, 1977; Auyero, 2011; 2012).

(2) Waiting as a Mode of Co-dwelling
Whereas medical and institutional perspectives fail to tackle the ontological question of otherness in the experience of time within the dementia context, they open up a new debate about ‘social time,’ A time that is ‘fundamentally qualitative, something to which we can affix moral judgements such as good or bad’ (Ingold, 1993, p. 158) beyond purely mechanical, quantitative and homogenous clock time. This dichotomous understanding of time is concretised in more detail in Gell’s dynamic and immanent A-series time (social time) versus objective and measureable B-series time
A-series time synthesises the past and future by retrieving historical experiences and memories and anticipation and desire in the formation of social life, in B-series time, social events are understood as ‘isolated happenings, succeeding one another’ (Ingold, 1993, p. 157). According to the A-series perspective, time is never ‘the neutral “medium” in which matter and life are framed’; it is rather a ‘dynamic force in their framing’ (Grosz, 1999, p. 3). Nancy D. Munn notes in The Cultural Anthropology of Time (1992) that time is therefore irreducible, intangible, pervasive and inescapable in the lived world, so this inescapable pervasiveness should be embedded and incorporated into all aspects of our social and cultural experience where life is physically bounded, situated and occurring within space. Thus, it disappears in order to come into being:

It disappears into events, processes, movements, things, as the mode of becoming. And it disappears in our representations, whether scientific or artistic, historical or contemporary, where it is tied to, bound up in, and represented by means of space and spatiality (Grosz, 1999, pp. 1-2).

Accordingly, individuals experience time differently in diverse situations. As Johannes Fabian (2014, p. 21) pointed out in his book Time and the Other, the ways of perceiving, understanding and practising time are to some extent ‘schizogenic’ in terms of its remarkable ethnographic divergence and its fleeting absent-presence. Namely, time is singular in terms of personalised experience and at the same time multiple, involving different namings, tempo, duration and social implications depending on the way its relation and connectivity to space, action, people and the future is conceptualised (Munn, 1992).

Meanwhile, the perception of existing time can be distorted, manipulated and transformed in practice in correspondence to the ever-changing socio-cultural, historical and political context. Wendy James and David Mills criticise dichotomous understandings of time in The Qualities of Time: Anthropological Approach (2005). Analysing ethnographic evidence, they reveal dynamic relations between the representation of time in social life and the ways in which people actually experience and practice it from the processual perspective. In particular, they focus more on how people, as situational agents, interpret their temporal system and redefine and remake it in the face of immediate situations. Some reference can be made to existing anthropological literature on practices of temporalisation concerning how people appropriating time are already situated within societal and ideological time, and how they simultaneously have their own ways of utilising time (Fabian, 2014; Gerke, 2011).

In this sense, I agree with Ingold’s (1993, p. 159) critique of Durkheim’s understanding of time as ‘an illusion of disembodiment,’ that it ‘is at once chronological and social,
for society itself is a kind of clock, whose moving parts are individual human beings’ (italics in original). Durkheim claims that the social ordering of time is understood through divisions of chronological or calendrical events or dates on one side and the lived experience on the other side. The latter is therefore enculturated, practised and contributes to social integration in the process of experiencing the ‘periodical recurrence of rites, feasts, and public ceremonies’ (Durkheim, 2008, p. 10) and in turn individuals receive the social meaning of the passage of time. People are not just onlookers but ‘participants’ in the making of social life, undergoing moments of time through their bodies, in Ingold’s term through ‘taskscape’ (1993, p. 159).

Here, Ingold’s dwelling perspective offers a useful theoretical and methodological tool for exploring complex relations and friction in the formation of the lived experience of time. Based on his conception of dwelling - developed upon a phenomenological understanding of dwelling that is later characterised in terms of continuous making and growth (Ingold, 2013b) - he criticises Durkheim’s disembodiment of social life. He insists that time is not objective, chronological or neutral but rather subjectively experienced in the process of bodily engagement with the personal, social, and environmental surroundings. Developing upon his dwelling perspective, I argue that even people living with dementia attune to, incorporate and respond to the ever-changing environment at every moment, regardless of their mental and physical capacities, although there can be different intensities and modes of participation. Just as other people, the lived experiences of those affected are inherently situated and embodied in time, and embedded in place. Considering the loss of bodily abilities and functions, this dwelling perspective offers a significant theoretical ground in terms of bodily activity and experience that are not necessarily limited to cognitive abilities and bodily functions. For example, those affected may experience some difficulties or disability in fluency or in expressing their feelings in a clear, rational and articulate way, but this does not mean they cannot watch, smell, feel, taste and listen. Although there may be different degrees of perception and response depending on the progress of dementia, they continuously engage with the world around them. As wayfarers, in Ingold’s sense, who live with dementia-in-the-world, they continuously interact and engage with the world of dementia through their limited abilities for sensory, affective, and bodily movement in any given time and space.

Likewise, waiting in dementia care settings is equivalent to the embodied experience of time from a co-dwelling perspective in a way which means that:

Time no longer seems to serve as transparent medium or instrument. It is no longer something external to which the waiter could refer, from which
he would be separate, of which he [or she] could avail himself [or herself], through which he [or she] could pass to accomplish something... the waiter must live the hour, feel it, embody it, perform it willy-nilly, in his [or her] characteristic vacillation which manifests itself... in his [or her] agitation, his [or her] pacing, his [or her] glances at his [or her] watch, his [or her] fixation on objects (italics in original) (Schweizer, 2008, pp. 16-17).

From this understanding, I am particularly interested in time as ‘motion or flux’ (Munn, 1992, p. 94) from the perspective of duration, which is influenced by Henri Bergson’s experience of time: ‘a qualitatively differentiated but unsegmented, temporal movement’ (ibid., p. 95). In order to revalue individual residents’ distinctive ways of waiting, which appear to be unproductive, meaningless and distracted without purpose or orientation, I take note of the concept of duration because time must be undergone and endured (Schweizer, 2008, p. 24), as ‘it is we who are passing when we say time passes’ (Bergson, 2002, p. 216). While waiting, expectation of the event that has not yet arrived is fuelled. But undergoing the time of waiting is not always smooth and the modality of waiting differs depending on individual history, personality, and illness and in relation to one’s surroundings. Duration does not consist of continuous movement and growth but rather of unexpected, sudden ruptures and discontinuity (Hodges, 2008). Waiting is, as it were, ‘a dizzying movement of duration’ because the time of waiting is not only ‘partially conscious, partially fragmented,’ but also ‘vexingly uncomfortable’ due to ‘the strange phenomenon of our own existential enduring’ (Schweizer, 2008, pp. 18, 35). In brief, waiting is no longer a simple passage of time to move through mechanically, but must be experienced bodily because the time of waiting is felt and must be endured for ‘something, anything to happen’ (Crapanzano, 1985, p. 43), regardless of cognitive capacity.

In this sense, waiting can be defined in the Deleuzian sense as the event that is ‘an instantaneous coexistence of two heterogeneous dimensions in an empty time in which the future and the past perpetually coincide and encroach on one another, distinct yet indiscernible’ (Zourabichvili et al., 2012, p. 127). In The Fold, in the chapter “What is Event?” Deleuze (2006) emphasises the four important qualities in the event, distinguishing from Whitehead’s definition in terms of extension, intensity, the individual/prehension and eternal objects/ingressions. For him, the extensiveness of events demonstrates their indeterminate relationships with time and space between events, emphasising an open-ended and unpredictable differentiation and transformation in its qualities. This does not mean, however, that there is an ‘absence of a cause’ but it is rather ‘the excess, superfluous, of causes, the profusion of causes, which no longer produces singular or even complex effects but generates events, which have a temporal continuity quite separate from that of their “causes”’ (Grosz,
The second character of intensity shows different degrees of the intrinsic properties of events such as speed, tempo, colour, sound, height, texture or value. The third intensifies Whitehead’s concept of the individual and the relationships between individual entities in modes of being affected and affecting in Deleuzian terms, or experience or feeling in Whitehead’s words, insisting that ‘the event is inseparably the objectification of one prehension and the subjectification of another; it is at once public and private, potential and real, participating in the becoming of another event and the subject of its own becoming’ (Deleuze, 2006, p. 78). The last provides a condition as the permanent object that can be felt (sensed), perceived and scientifically proved.

Waiting as event is thus neither built nor predesigned, but is rather an on-going construction emerging through perpetual engagement with worldly surroundings. This means that, as Ingold claims, in ‘dwelling in the world’:

> We do not act upon it, or do things to it; rather we move along with it. Our actions do not transform the world, they are part and parcel of the world’s transforming itself. That is just another way of saying that they belong to time (italics in original) (Ingold, 1993, p. 164).

Here, engagement implies relation, process and friction through interaction and encounter, suggesting that it is not necessarily limited to human activity and involvement, nor does it refer to a separate and isolated activity; it is rather ‘interactivity’ in the context of co-dwelling (italics in original) (ibid., p. 163). In this regard, this engagement could be understood as a ‘resonance’ that is the ‘rhythmic harmonization of mutual attention’ through actual movement and contact (ibid., p. 162) in that all senses, including feelings, are fundamentally and practically experienced through the felt body by affecting and being affected in the making of social life. In particular, affect has a significant role in the formation of social life among those affected because as their dementia evolves, their sensory perception deteriorates while their affect still remains relatively intact even at the advanced stage of dementia. Just like those without dementia, they do not perceive the world of dementia through one sense. While watching, listening or tasting, they continuously feel people, things and environments through ‘mutually attentive engagement’ (ibid., p. 160). Their felt experience becomes a prevailing way of engaging with worldly surroundings as their perception is deteriorated. They may see the surroundings in vague forms, yet these would already be overwhelmingly felt whilst affecting and being affected through their bodies.
We experience chronological or mechanical time of waiting differently because of the different speeds, tempos and intensities that are felt, endured and experienced through our bodies (Bergson, 1919). To explore this, I approach waiting as a mode of co-dwelling in dialogue with the concept of the event. The event is ‘revolutionary becoming’ which is ‘beyond the dichotomies of historical determination or human freedom and physical determination... distinguished in terms of the intensity of this revolution’ (Williams, 2013, p. xi). Deleuzian insight into the event offers not only an epistemological tool to analyse such embodied and lived experience but also to the ontological ground of waiting that is elusive and may otherwise never be clarified. From this understanding, waiting as an event in the context of co-dwelling can be understood as difference, something that is ‘the endless unfolding of the new, restless transformation, upheaval, redirection and digression, which ensures the impossibility of the same event through the modes of repetition’ (Grosz, 1999, p. 5). In Maurice Blanchot’s (1995, p. 273) view, ‘whatever the importance of the object of waiting, it is always infinitely surpassed by the movement of waiting’ because of its nature of being anticipatory. Consequently, waiting as an event in everyday life can be revalued as a dynamic and potential force of becoming, although it often generates immeasurable suffering or boredom. The narratives of waiting become an assemblage of individuals’ singular experience of events always over and above the present and which have not yet arrived, but which exist as a virtual force to come into being.

Edwards, Reed-Danahay, Goffman, Ingold, Bergson and Deleuze form, or at least suggest, a theoretical and methodical horizon for socio-cultural concepts of time and waiting in terms of transformation, emergence and differentiation. In what follows, drawing upon the concept of event in the context of co-dwelling, I will revalue the ways in which residents with dementia and staff experience waiting in the common area, focusing on four elements of the waiting: institutional temporality, the physical environment, staff and residents.

4. Ethnography of an Entangled Waiting

(1) Institutional Temporality

From the institutional level, time deeply involves a structuring with regard to a ‘temporal reference framework’ (Zerubavel, 1979). This means temporal patterns are to some extent regulated by certain tasks which are expected to be completed within a limited amount of time, for example, administering medication, assisting residents’ washing and cleaning up, providing meals and doing paperwork. Therefore, the ways in which individual staff organise their daily work is often contested and negotiated with these ‘background expectations’ that require staff to perform ‘the act of time
management’ (Adam, 1995, p. 42). In this sense, for staff, time is often perceived as a measurement of ‘getting through the work’ in reference to the time framework. Likewise, people dwelling in the Home are also influenced and to some extent required to adopt the new way of institutionalised life. This includes not only social activities and hospital visits but also everyday routines, such as sleeping, eating and washing, which are mostly provided within scheduled and allotted time. Of course, the Home always emphasises person-first care service, insisting that depending on personal necessity and preference there are many things which are negotiable within the availability of time, resources and staff, for example, eating, bathing, dressing and exercising. Yet, institutionalisation is to some extent true in that residents hardly ever ask for a cup of tea or coffee outside of the scheduled time, and they rush to the dining room or wait for the service in their rooms at 10.30am and 3.30pm.

Whereas this kind of institutional time framework cannot be ignored, the way the Home provides medical and therapeutic care has dramatically changed since the introduction of Person-Centred Care (PCC) in 2011. PCC involves diverse basic and compulsory training for all staff, such as Jewish Cultural Awareness, Jewish End of Life and Customs, Protection From Falling Down, Infection Control, Moving & Handling, Food Hygiene, Fire Training, Safeguarding of Vulnerable Adults, Palliative Care and Other Dementia Related Ethics, End of Life Care & Understanding and Managing Pain, Person-Centred Care and Namaste (spiritual care). This training extends to individual career development plans to qualify as a ‘dementia champion’ as well as a senior member of the care staff. PCC has transformed in terms of care practice, staff training, alongside interior design and organisational policies and commitments that combined to change the ways in which staff work with residents. Unlike top-down or task oriented care practice, PCC involves three different parties in implementing the practice between staff, the institution and residents (including family members) in partnership with the Bradford Dementia Group. It is continuously developed on a day-to-day basis.

In short, institutional temporality is closely related to how much time (duration) staff can (should) spend with residents, how quickly (tempo) they need to complete their assigned work and the ways in which they work with others including residents and related staff (synchronization) (c.f. Fine, 1996). In fact, staff experience time differently in that they are required, implicitly or often explicitly, to adopt institutional temporality which demands they complete a certain task at a certain rhythm, speed and tempo and within a particular duration in order to meet predetermined expectations and consequences. In practice, different dimensions of temporality and attitude toward dementia care co-exist, are contested and negotiated between
individual staff, the team and the overall institution. The following provides some complex and multiple temporalisations in terms of place-making and viewing the organisational temporality from the staff and residents’ subjective perspectives. I shall demonstrate the ways staff embody institutional time frameworks as well as PCC training depending on their cultural, religious, educational and biographical backgrounds. Accordingly, staff practice time differently in different situations and that affects the ways in which they work with residents, followed by residents’ temporalising the waiting.

(2) Temporalising the Waiting
As illustrated in the image of the layout of the Abraham Unit in Chapter 1, the communal area is located in the middle of three different wings. The area is regularly redecorated, not only with infographics and images of dementia awareness training, but also for constructing a dementia-friendly environment in collaboration with residents. The area around the desk is regularly transformed in harmony with seasonal changes, for example, with autumn-themed sculptures – such as mobiles made of dried leaves and fruits – hanging from the ceiling and hand-crafted pumpkins placed on shelves previously filled with medical files and charts. The walls which used to be empty or utilised for advertising organisational rules and regulations are regularly renewed with quotes and illustrations of the activities of individual residents, such as Monthly Photogenic Images, I AM ME (introductory paragraphs with photographs of residents), or SHARE A SMILE WITH US (individual residents’ best moments). In addition, celebratory decorations for seasonal Jewish Holidays and Festivals and personal occasions, such as anniversaries, birthday or weddings again shape experiences of waiting. This regularly altered physical environment provides a key resource for staff and residents to share their stories as well as to facilitate conversations among staff, family members, visitors and volunteers. In other words, ever-changing physical surroundings are not just standing there as backdrops, but emerging in the process of temporalising waiting through engagement with personal biographies, cultural traditions, institutional policies and seasonal changes.

Alongside seasonal, personal, institutional and cultural transformations in the physical environment, the soundscape cannot be ignored. Diverse comfortable, lively or relaxed music (either jazz or classical music) is almost always provided depending on time, climate, mood and ensuing social events. Of course, there are always unexpected sounds, such as the dragging of chairs, telephones ringing, the rain, wind, car horns, building work, bird song, lift announcements, human voices and so forth. These sounds are not just things that exist alone but affect individuals in diverse ways which irritate,
relax, stimulate and provoke certain emotions, feelings or bodily movement. Depending on individual residents’ tolerance, preference and interests, their response and engagement varies. For example, Gayora cannot bear the telephone ringing consecutively, so she answers the phone in person if nobody picks it up. Ayla keeps her eyes on the lift when she hears it opening to identify who enters her world of dementia. These days her hearing is more sensitive than any of her other senses due to her deteriorated vision and sense of taste and smell. And Chaya looks for the quietest place so she can read her book without interruption.

In particular, I pay attention to human voices in this waiting because unlike their remarkable tolerance or indifference to the noise of building work, which only stops at the weekend, voices quickly affect and are affected. Indeed, it is not difficult to imagine that in care home settings, life is full of voices ranging from whispering, crying, shouting, screaming, laughter, humming, songs and so forth that are expressive of different subjective feelings. The sounds of voices flow, stop, whirl, curve, emerge, block, and disappear in the engagement of residents and staff with one another. Chaya may first come to the desk and ask for help from those who scream or cry. Ayla may say in disbelief that those who repetitively ask questions or make ‘noises’ should be in hospital rather than in the Home. Yedida may express sympathy for them and keep her eyes on what is happening. In this regard, the human voice is not just taken as a given, but is rather a production of bodily movement and gesture that reflects situational meaning, feelings and emotions embedded in the rhythm, stress and intonation of voices as well as in non-verbal modes of expression.

All senses are invaluable in forming the experience of waiting, although there are different degrees of intensity and sensory perception depending on individual deterioration in neurological and physical bodily functions and abilities. The feeling on the skin, as a result of ‘sudden’ unexpected and incomprehensible bodily deterioration, intensifies and accentuates affect in making individuals depressive, insecure, lonely, sympathetic and empathetic. This affective force or energy drives those affected to express their desire through their bodily practice. It reminds me of Donna Haraway’s rhetorical question, ‘Why should our bodies end at the skin?’ (2013, p. 220). While answering this question, Elspeth Probyn offers immaterial and invisible dimensions of bodily differentiation, demonstrating that the boundary of the body does not stop where the skin ends, in its physicality, but actually extends further by projecting its ‘desire’ and ‘yearning’ which are registered in our bodies as a sense of ‘belonging’ (1996, p. 6), affecting and being affected. In this sense, the body in waiting is not just a collection of flesh and bone, but rather a self-organising intermediary that exerts its sensory, affective and embodied properties. In other words, it is “not just be-ing, but
[be]longing” to the world (Bell, 1999, p. 2). Consequently, waiting is not an experience that is given or ready-made. It is rather continuously produced, circulated and reproduced, emerging in the process of people’s engagement with their personal, social and material surroundings. It not only includes people, their activities and their affect, but also non-human entities including sound, smell, weather, things, images, atmosphere, and their continuous movement. And as time goes by, the waiting has its own social life as a living process which affects those who dwell within it, and is also partially made by them.

(3) Staff

At the desk, two staff members are engaged in their own tasks. Middleton, a care worker, is checking the daily schedules, organising medical check-ups and handing over medical files to a visiting GP. Helena, another care worker, is answering Basha’s request of whether a porter is coming soon or not. Other staff members are delivering morning care in their designated wings, and the phone rings intermittently. Gayora eventually opens her eyes, asking the staff to take the call as she can no longer endure the noise. When she tries to pick up the phone, Helena thanks her and answers it.

This waiting looks like an ordinary busy morning. However, because of the diverse understandings of institutional care practice, personal biographies and cultural background of individual staff, the ways in which they experience waiting are heterogeneous and differentiated in the process of interaction and encounter with residents and other colleagues. For staff, waiting is first perceived and practised as a continuous process of attentive engagement by negotiating with the institutional time framework, person-centred care and their own ways of caring. Once entering the world of dementia care, person-centred care becomes a normative practice that individual care workers are required to perform within institutional temporality, whilst recognising the rich and diverse life stories, personalities, preferences and careers of individual residents. They are also expected to be aware of how residents with dementia experience time not only in their old age, but also after institutionalisation. Mace and Rabins illustrate in The 36-Hour Day (2011) that caring for people with dementia feels like looking after them for 36 hours a day as they continuously demand attentive care. Likewise, in this waiting, Middleton and Helena’s attentive vigilance responds to the here-and-now situation, particularly the symptoms and immediate reactions of the residents. Although the brief has informed them about any sudden behavioural changes, unexpected medical episodes and events can happen anytime and anywhere due to the uncertainty of the residents’ medical conditions:
We put everything in her care plan, but one day she entered the kitchen trying to find something. No matter how much we tried to distract her, it didn’t work. All of sudden she got out of the kitchen and complained there was no food, even though she had just finished her meal (Interview with Lisa, a Care Worker).

Meanwhile, staff members are assigned their duties by task and by wing and also have a designated resident whom they specifically pay more attention to within the institutional timeframe. While there are visiting nurses and doctors, their approaches are limited to the biomedical context; care workers document the detailed progress of illness and disease, including bodily changes and the effects of medication, alongside residents’ personal backgrounds. Therefore, for staff, time is often considered as a measurement of productivity (Adam, 1995): work assigned to them individually needs to be done not only because it is an individually assigned task, but also because it is a sharing of the responsibility as a co-worker. The following interview highlights some of the difficulties they face when they are expected to finish on schedule while working as a team:

It depends on who you work with. I sometimes feel that some people don’t work as a team. Some people don’t care what they are assigned. But I have never told anybody about that. I do not like solving the problem in that way. I just go and help them and that is my way. But the other day, you know, a team leader came to me and asked why I did not finish the work. What could I say? I just do what I have to do (Interview with Alice, a Care Worker).

For staff, time is not only shared with residents but also with other staff, meaning that if a colleague on the previous shift does not finish their work, the burden is passed on to other colleagues. Feeling ‘behind time’ puts pressure on a carer to ‘rush’ so as to catch up on delayed work within the time (Adam, 1995, p. 46) and this is at the same time seen by other colleagues as incompetence or the sign of a novice.

Back to the waiting. A senior worker is administering medication and other care workers are cleaning residents’ rooms and preparing them for the day in terms of organising daily schedules and dressing them. Middleton and Helena are handling GP and specialist appointments. However, this collaborative work does not always go smoothly and often involves tension and friction among those involved. Like Basha’s waiting, unexpected (medical) events, calls or visits can happen:

We keep looking after them and putting any challenging behaviour on their Behavioural Chart and try to monitor them and refer them to doctors and specialists. They then review residents’ medications in reference to their Behavioural Chart and then either increase or decrease medications or prescribe new medication. But, there are a lot of risks and side effects. They
could have a heart attack from medication. So we continue to monitor (Interview with Lisa, a Senior Care Worker).

It is no surprise that staff often experience what Hochschild calls ‘time-debt’ (1997), in that they do not always feel they have sufficient time to engage with residents:

_We cannot pay attention to only one thing. Somebody who is sitting in the corner quietly putting their feet up to rest, your mind is still on keeping your eyes on them so as to check their safety_ (Interview with Ghassan, a Care Worker).

Furthermore, the action or response of staff is relational in any given situation, suggesting that time is experienced, consumed and reproduced in the formation of social life where different individual interests and demands come together. This can be exemplified by the experience of Harold, a care worker. He is in charge of the desk whilst other care workers are working in different wings. Gayora keeps complaining, saying he needs to leave and is not the right person for the desk. Harold’s ten years of experience in the hospitality industry does not seem relevant to her. Lisa quickly involves herself in the situation, finding out that Gayora does not like him not because he is male, but because of the way he carries out his morning care with her. It takes a while for Harold to figure out the friendly and amiable way in which to assist her without hurting her feelings or dignity. In contrast, it takes no time at all for him to assist Yedida’s morning care and the cleaning of her room. As a consequence of her strong self-defensiveness, which is closely related to her obsessive compulsion about her belongings, her room is always closed and her private life is extremely limited to specific care workers. Yet for the health and safety of all residents, her room should be regularly monitored and cleaned. Interestingly, thanks to his multilingual competence - particularly in French – Harold quickly becomes one of the closest care workers to Yedida.

Moreover, the ways in which residents sit on the sofa in the communal area is delicately guided and arranged by care staff. For example, all staff are briefed that Gayora and Yedida are not on good terms with each other, so they often recommend they sit separately or at a distance, whereas Gayora and Ayla’s seats are arranged side-by-side, even though they rarely engage in conversation with each other. In other words, individual residents have their own ways of structuring time in relation to their surroundings, so staff are required to respect and negotiate their preferences, tastes and more importantly, their medical needs:

_For example, he [Raphael] likes to stay alone quietly at a table. He does not want to move and seems to be more comfortable being there. We know that this is his habit after a meal, so I would say it might be intentional, or_
something he just feels like doing. But, we also know that he is diabetic. His blood sugar level is high, so what we do is keep an eye on him and give him more fruit instead of sweet pudding which makes him very unhappy and sometimes he raises his voice in a nasty way to the person serving him (Interview with Elizabeth, a Care Worker).

In short, from the point of view of the staff, because they are asked to provide attentive care for a whole day within limited budgets and resources, they often feel rushed or behind schedule when required to manage time as a capable and efficient worker. For staff, waiting is not just waiting for something to happen, but being constantly alert and ready for action, looking towards what will or may happen in the near feature. This suggests that waiting is never idling or simply a ‘passing through’ (Schweizer, 2008, p. 2), but rather calls for a more attentive and relational care that is embodied and at the same time contested and negotiated as residents living with dementia move along with the activities. This idiosyncratic mode of practice in waiting is therefore differentiated as time goes by in terms of rhythm, speed, tempo and relations of bodily engagement.

(4) Residents

After looking around the communal area, I walk towards the desk to register myself in a logbook and check the activity scheduled. Helena tells me that Ayla has asked several times about where the care boy (myself) is and when he is coming back. It is at this moment that Ayla hears her name and the familiar voice of ‘the boy’. She perks up and her eyes follow my steps. For her, waiting seems to be a pure effort of attention (Weil, 1951, p. 34). This time she inclines her head slightly and listens attentively so as not to miss any words from the unknown person. She tries to confirm my presence, asking ‘Boy, oh boy? Oh! Boy!’ She is on the verge of tears. She stretches out her arms to hold my hands. I kneel down and maintain eye contact. She holds my hands and strokes them again and again. ‘Hello! I’ve missed you. I’m pleased to see you,’ she says. But the joy of the encounter does not last long. She makes a long and hopeless face overwhelmed with despair, telling me her feelings of insecurity and helplessness:

\[
\text{I do not know what to do. I do not know what to do. Do not desert me! Do not desert me!}
\]

She is desperately looking for someone to rescue her from ‘this prison’ and ‘this hell,’ in her words. I hold her hands firmly and ask her what has happened. Then I listen to her stories of this morning, her daily life and her prosperous past life, again and again. Whenever she talks, she sighs deeply. Her eyes become red; she is already on the verge of crying. At this point Gayora opens her eyes and jumps into our conversation, asking who I am and what I am doing. Ayla is surprised she does not know about me,
reminding her that we have met each other before and that ‘he is a very nice student with two degrees.’ Gayora responds nonchalantly, bends her head down and asks me not to come any closer, complaining of a horrible smell. She waves her hands and pinches her right thumb and index finger to her nose. Ayla is astonished by her reaction: ‘Oh! Do not do that. He is nice. You are so rude. You lie! You are a liar!’ This is not the first time and is Gayora’s way of avoiding people when she wants to be alone. I say I’m sorry I have interrupted her rest. She sits back on the sofa and closes her eyes again. I move away from Gayora and lower my voice in order not to interrupt her dozing. Yet, her rest is soon interrupted by the insistent ringing of the phone on the desk. Gayora points at it and asks the staff to pick it up, but the two care workers are too busy. She stands up, walks toward the desk and tries to answer the phone. Stopping her work, Helena quickly thanks Gayora for her concern, saying she will do it. As soon as Gayora goes back to her seat, she begins to doze again.

Gevira looks over and gives me a smile, gesturing at me to sit between her and Ayla, making space by moving her Zimmer frame to the other side. Our conversation moves from Ayla’s home in Stanmore in North London to Gevira’s relative, who visited her the day before. Ayla holds my hands and listens to Gevira’s story of lunch with the relative for a while, but she soon turns her body away as though she has no interest in her neighbour’s story. I can feel she also begins to loosen her grip. I tell Ayla to come back after conversing with other residents. The relationship between her and Gevira is not particularly close, although they always sit next to each other. Indeed, they do not talk and are not really interested in each other. More precisely, Ayla likes those who speak articulately and clearly, not with Gevira’s fragmented way of speaking. On the contrary, Gevira does not like Ayla’s drawing attention to herself by crying and telling her sad stories over and over. Nevertheless, the two do not mind being together as long as they do not necessarily have to converse with each other, and so long as one of them does not cross the line.

Gevira’s story about the lunch does not flow smoothly. She mumbles a little, often misses verbs and does not finish her sentences. She quickly changes topic and asks whether I passed a test, referring to my ethical approval for this study from the National Research Ethics Service. As if I am asked for the first time, I reassure her that I finally obtained it. She congratulates me on my progress and wishes me success with the project. I briefly ask about her daughter who lives in Israel, particularly because of the recent escalating Israel-Palestine conflict. Gevira says she talked with her on the phone the day before, and her daughter and family are okay, although there is an increasing sense of crisis. After a short spell, she tells me that she had better go for a walk and wishes me a nice day, checking she has all of her belongings, including tissues,
her mobile phone and room key. Although the morning path is a bit slippery, this seems to be no problem for her. She takes this walk every morning before her prearranged activities start and proudly says she has barely missed a morning since entering Florence House. After making sure everything is ready, she pushes her Zimmer frame over to the small lift.

At the desk, Middleton tells Basha that she needs to wait a minute longer for a porter to come. She has already been waiting for ten minutes. Although she has booked in advance, this happens frequently. She finally gives up looking at the lift and passers-by and lowers her head, closing her eyes.

I take Gevira’s seat and give all the residents a nod. In the corner, Chaya and Emmanuel are still doing the same thing, reading and looking around respectively. I ask what book Emmanuel is reading. All gazes turn to him. He shows us the book, telling us the name of the author. Chaya and Yedida say that the author is very well-known in the UK, publishing a lot of detective novels. Unfortunately, Emmanuel says that he has not finished reading it yet, so once he has read it, he will tell us the story. Bracha opens her eyes once but closes them again when she sees there is nothing of interest going on. Conversation stops and is followed by a short silence.

Then Yedida gestures for me to come closer to her, as though there are far more interesting things happening there. She describes the residents sitting around the communal area. Bracha and Emmanuel prick up their ears, seeming to find some interest in this conversation, particularly when Yedida tells us about Daniella’s argument over a seat the other day. In fact, everyone in the communal area adds some words to the conversation. I can hear all their opinions, except for Chaya, Daniella’s best friend, who shows her indifference to the gossip. Some wave their hands, saying that she is strange. Others show their sympathy, saying she is the kind of a person who often behaves strangely because of her illness. The waiting place becomes vibrant. Yedida enthusiastically agrees with other people’s thoughts and dramatises the event.

The following is a summary of Yedida’s narrative:

‘Bonjour Madam!’ Ingunn welcomed Daniella and asked her to take a seat. Daniella fluently responded to his greeting in French, yet she did not sit in the empty seat and instead wandered left and right restlessly. Suddenly, she insisted that Bracha’s seat was hers. Bracha was surprised and argued that she had sat in the seat all morning and Daniella had just arrived. Emmanuel stopped their conversation and suggested that Daniella sit in the empty seat next to him. Daniella folded her arms and refused his offer. I also stood up to offer my seat, which was between Bracha and Yedida. Daniella reluctantly accepted it, but kept insisting that she wanted Bracha’s seat. Suddenly she stood up and left. Bracha sighed and said Daniella
always wanted everything her way, exclaiming ‘What a rotten day!’ At this point, Ayla sat on the other side of the sofa, rebutted: ‘Look outside. It is a beautiful day now’. Bracha sighed again and said: ‘It was a good, sunny day this morning but now it is cloudy’. And she became lost in thought, saying ‘Maybe we will forget the rotten day and see a good day tomorrow’. After a short spell, Bracha asked me which day of the week it was. When she realised it was Thursday, she said in a subdued voice: ‘Shabbat is coming’. She asked me what programmes were scheduled that day. There was a reminiscence session and a pottery class in the morning, then a game of Bridge and a talk in the afternoon. I showed her the weekly programme. After looking at it for a moment, she tells me that she hates Florence House because residents like Daniella often make problems. But now in the restored quiet she says: ‘Thank God. They all are gone.’ The waiting place becomes quiet again.

When Yedida’s narrative reaches its climax, Suzanna, a volunteer, comes and calls residents to the pottery session. Catherine, Activity Coordinator of the Abraham Unit, also encourages residents to engage in activities. Their suddenly passionate and energetic voices change the atmosphere again. Simultaneously, a staff member who is passing by reminds Bracha that she has promised to make a vase for her birthday gift. Abruptly, most of the residents head for the centre.

I also stand up and when Ayla sees me leaving, she grabs my hands and asks repeatedly ‘Where are you going?’ I tell her that I am going to interview a resident in the Joel Unit. She continues with her questions and asks whether or not she could come with me. She is very disappointed when I tell her that the interview is private and confidential. She asks me again what time it will be finished and whether or not I could go for a walk with her or have tea and cake in the cafe after the interview. I am not sure what time I can come back but promise her I will come back after lunch and walk with her in the garden. Eagerly, she asks again what time I can come. I assure her that it will be two o’clock. ‘What time is it now?’ she asks. When she realises it is ten to ten, she sighs again. For her, time does not flow; instead, it ‘must suddenly be endured rather than traversed, felt rather than thought’ (Schweizer, 2008, p. 2). ‘Waiting has to do with lived experiences’ (Sutton et al., 2011, p. 32). In the end, I change my afternoon schedule of helping with the Bridge Club to go out with her into the garden. She gets up and follows the other residents to the ground floor.

5. Revaluing the Temporality of Waiting

To describe the Home as an ahistorical, timeless or displaced place may be persuasive on the grounds that the institution does not provide a feeling of ‘being-at-home-in-the-world’ (Jackson, 2000, p. 154). Yet, as I showed earlier, although this could be argued in terms of intensity and the quality of interaction and response, the way
individual residents and staff experience time and place is intricately enmeshed in their entangled relations with illness, biography, personality and the here-and-now situation. In other words, time is passed through by residents with dementia who experience and perceive time passing through their body, although the sensitivity toward duration may be progressively and irreducibly limited as dementia worsens. From this understanding, waiting as event is revalued in a mode of co-dwelling in the context of situated and embodied persons enmeshed within social, physical, historical, medical and environmental relations in a particular time and space. In essence, residents’ experience of time is characterised as biographical (time), embedded (place), embodied (body) and interpersonal (relation) in response to age and chronological time. This understanding is equivalent to Ingold’s co-dwelling perspective in terms of the phenomenological understanding of perceiving, living and making. Time perception is continuously renewed through the process of dialectic interaction with lived experience in that the perception of biographical age is continuously redefined through the person’s felt experience (embodied time) of fragility and vulnerability. Biographical time is perpetually revisited and redefined in the form of memory, enabling the elderly not only to retrieve past life stories but also to re-emplace and re-experience past events (e.g. Chaudhury, 2008). Embedded time reflects their ongoing adjustments to new places and institutionalised environments.

For Ayla, although the loss of her vision makes it difficult for her to identify a person entering her world, her sensitive hearing and tearful appeals keep her engaged in the recursive event of waiting. Her responses have given her the negative reputation amongst residents of being ‘a clever girl,’ but it is also true that on the other hand, her vulnerability invites others to become involved in her situation. For example, Yedida always makes sure that I see and talk with Ayla first. As we have seen in Chapter 2, Ayla still denies her biographical time and physical vulnerability. From her perspective, and from having dementia with chronic depression, the here-and-now is unknowable, uncertain and insecure. Her vulnerability forces her to some extent to get used to institutional time, such as having a shower, her meals and tea at set times. However, the time in which she and I meet is quite different, and her continuous questions reflect her strong desires, expectations and purposes in waiting. Her waiting is no longer a passing through or waiting without meaning. It is meaningful in contrast to quantitatively equally divided clock time, so she may feel the duration as an hour or a minute depending on the way she undergoes it. Her decision to join an activity needs to be understood in this context of waiting.

Gayora’s whimsical reactions and barging into the conversation between myself and Ayla is caused by us having interrupted her rest. Interestingly, her use of the word
‘smell’ is complex, generating several unexpected encounters; for Gayora, I may be seen as an interrupter or someone without interest, yet it still remains ambiguous why she uses the word because these days, she has lost much of her appetite accompanied by her sense of smell and taste. Either way, thereafter I stop eating food that possibly emits a strong smell, looking forward to exploring how she will then perceive me.

Basha looks tired, having to wait for a porter before even starting her therapeutic exercise session. She asks the care workers several times, in a feeble undertone, when the porter is coming, but the only thing she hears is that she has to wait a few more minutes. Her prolonged wait and enquiries become an issue because staff also cannot do anything but wait for the porter to come. While Middleton and Helena check and organise individual residents’ daily activities, they liaise with persons for help. However, these condensed and overlapping tasks call for staff to perform their multitasking and management skills. The rhythm of Basha’s life becomes extremely slow and makes her lethargic, whilst the care workers rush to call for a porter as quickly as they can.

For Gevira, time used to be manageable and something she could anticipate. It was she who persuaded her adult children and made the decision to come to the Home in 2011. Before completely losing her competence, she voluntarily wanted more time to get used to living in her ‘second’ home, in her words, and to make friends. Over the past half-decade she has developed good relationships with some of the residents and although she becomes taciturn due to the deterioration in her language, cognition and memory, she is still welcomed by her companions in the synagogue, in talks and other activities. Recently, she is evasive in that she tries to avoid confusing situations where she finds it difficult to express what she wants to say or does not understand what is being asked. Nevertheless, before going for a walk, waiting is enjoyable for her as long as she can be with her friends and participate in that situation without feeling embarrassed. However, in terms of intensity, this is different from her waiting for the call from her grown daughters around 9pm almost every night. At this time, it is necessary for her to wait in her room with her mobile phone.

Sitting between Yedida and Chaya, Emmanuel ends up listening to Yedida’s story. Although he often forgets to bring his walking stick, he hardly ever forgets to bring a book, regardless of whether or not he reads it. His calm and gentle etiquette is embedded in his bodily expression as if he is still working as a lawyer in court. Instead of a thick, hard law book he chooses a novel his wife recommends. In fact, there is not a single law book on the shelves in his room. As his wife says, he has worked with law cases over the past five decades and now it is time for him to relax and enjoy his life. At the same time, waiting for his wife’s visit becomes a moral requirement he has to
endure. He used to work as a lawyer all day long, so previously it was his wife who waited for him at home. Now, his wife is working as a nurse consultant on the outskirts of London and it is difficult for her to visit him every day. Therefore, it is he who needs to wait for his wife patiently. As ‘a moral man’ in his words, he is willing to endure. Although these days he often listens to others more than talking to them, and although his shoes and trousers have been changed to the dementia-friendly ones, his attentive attitude emerges in the process of his social interaction (Kontos, 2003; Kontos and Naglie, 2009; Kontos, 2014). Meanwhile, Chaya enjoys her favourite time reading a book in the communal area. She does not mind the place as long as she can focus on reading.

For Yedida, it is a bit early to come to the communal area. Nevertheless, she spends her time cracking pistachios. Of course, my presence offers her the chance to speak up. She not only invites me but other residents into her storytelling. It starts with describing passers-by in the communal area. She describes their characteristic impressions and particular ways of moving, such as habituated gestures or steps. Her imitation of her neighbour’s voices and the behaviours of residents and staff quickly draw the attention of other residents in the communal area, particularly when she dramatizes Daniella’s story. In fact, her attention and attachment to things and people is closely related to her illness, biography and career as an antiques dealer. For her, anyone and anything becomes of interest, if not at present, in the future; ‘all have unique ways of living’ with idiosyncratic characteristics, in her words. For example, she characterises her neighbouring residents as walking unsteadily, seeing vacantly, acting strangely, speaking awkwardly, dancing sexily, asking feebly, wearing oddly, eating greedily and so forth. Her skilful storytelling shifts the atmosphere, although not for Gayora. They barely get along, do not sit on the same sofa and do not cross over to the other side of the room where one of the two usually sits and takes a rest. Although her hoarding of food in her room may be problematic, it is self-evident that she is a good storyteller as well as an icebreaker during waiting.

In conclusion, waiting is an immanent human condition of co-dwelling that occurs in the process of contingent, undetermined, uncertain and incessant interactions, encounters and communications (Schweizer, 2008; Hage and Hage, 2009; Sabo, 2014; Sheets, 2015). As we have seen, residents with dementia wait for something or someone, not with the same aims or motivations, nor with the same tempo or intensity, but with idiosyncratic affect, perception and bodily movement in the communal area. Waiting is an ordinary experience. However, its subjective meaning differs as its intensities, ways, attitudes and perceptions are continuously differentiated in response to illness and the here-and-now temporal and spatial
context. Its contours are neither predetermined, nor clearly outlined but rather emerge in the process of ceaseless encounters and responses in social life. Waiting is not inactive or dead time but is characterised as bodies-in-waiting with bodily anticipations, demands and attentiveness and thus is demonstrated as an enmeshed assemblage of experiential, historical, cultural, neurological and psychological dimensions. It is actualised in a rhizomatic world, in Deleuzian’s sense, through the felt body that ‘has no beginning or end’ (Deleuze and Guattari, 2004b, p. 27).

Waiting-as-event provides us with a flow, a procedural and dynamic perspective at a particular given time and space. Idiosyncratic illness, life story and the contingent co-dwelling of individual residents become enmeshed with one another and such encounters become more complex through continuous interactions, responsiveness and communications. In this regard, I argue that the concepts of intersubjectivity and intercorporeality which imply reciprocal interaction in the Csordas sense (2008) need to be carefully applied because they are neither complete nor certain due to generative entangled relations and movements. But this does not mean that these relations are mutually reciprocal. Due to the different levels of dementia, complex and enmeshed relations and personal biographies, individual experience of waiting is continuously differentiated, bringing out new ways of communal life that move beyond individual vulnerability and limited capacity. Accordingly waiting is not purely creative, nor purely imaginative or transcendent. Even the most unexpected bodily movement or gesture is situated and embedded within time and space, reflecting socio-culturally habituated and pre-reflexive modes of practice (Bourdieu, 1984; Merleau-Ponty, 2002; Kontos, 2005). The diverse ways of waiting do not need to be thoroughly rational, nor are they necessarily purpose-oriented. Although the modalities of waiting are expected to follow or harmonise with socially expected modes, they cannot simply be reduced to the same patterns of social behaviour; rather individualised ways of waiting reveal idiosyncratic life experiences, their creative interactions and responses to the lived reality of dementia. In other words, waiting is not just a passing through, but is experienced: ‘endured rather than mastered, felt rather than thought’ (Schweizer, 2008, p. 2). In recognition of such intricate and enmeshed relationality and diverse ways of undergoing time, waiting is a generative social event that creates a potential condition of co-dwelling. The experience of waiting is neither transparent nor transient, but rather is always intermingled with other dimensions of social life, such as memory, aesthetics, sense, affect and narrative, generating complex and multifaceted social events in the process of social life. Yet, because of the illness condition of individual residents, their lived experience of
waiting is also fragile and precarious. This essay is a testimony to waiting-as-social-becoming, oscillating between attentiveness and inattentiveness in day-to-day life.
CHAPTER 5 - AGENCY IN WORKS OF DEMENTIA AS CREATIVE ENTANGLEMENT

1. Rethinking Agency and Art in Dementia

If someone can only say ‘Bah,’ ‘Sharh,’ ‘Brrrr!’ and ‘Bupahupah’ (Kontos, 2006a, p. 207), how can we understand their storytelling as aesthetic or even comprehensible? What if a mother with dementia does not recognise her own daughter? How can we say that they communicate with each other (Taylor, 2008)? If we do not know that leading abstract expressionist Willem de Kooning has Alzheimer’s disease, how can we understand his emotions and the new art forms based on abstract figures, lines and diverse colours in his later artworks, such as Saturday Night (1956) (Espinel, 1996)?

The prevailing perception of dementia assumes that people living with it have less or even no agency because of a progressive loss of cognition, memory, language, and bodily functions and the accompanying deterioration of the self (Kontos, 2003; Boyle, 2014). Based on an ethnography of practice-based arts activities in Florence House this chapter aims to contribute to the critical development of a concept of agency in the context of co-dwelling. It wishes to explore how agency is generated and practised, and also how it constitutes the elements of everyday life. To explore this, I conceptualise practice-based arts activities in the Home as works of dementia which refer to a range of social, therapeutic and cultural engagements, such as painting, crafting, drawing, singing, talking, dancing, writing poems, knitting, cooking and so forth.

Drawing upon Ingold’s concepts of making (Hallam and Ingold, 2007; Ingold, 2013b; 2014) and line (2007; 2015) in this chapter I attempt to not only critically develop existing theories of agency by demonstrating the complex process of works of dementia, but also to provide conceptual and analytical tools for the context of co-dwelling. In doing so, I shed new light on the limits and implications of existing phenomenological theories of agency and argue that agency is not limited by ‘individual entities and singular forces,’ but is rather understood as ‘assemblages of agency’ (Bennett, 2005, p. 447) that are characterised as heterogeneous, decentred and contingent and nonetheless co-exist in an embedded co-dwelling milieu (Marcus and Saka, 2006). That is to say, works of dementia in the Home are kinds of ‘creative entanglements’ (Ingold, 2010b) that encompass not only organising and facilitating works of dementia from the perspective of the organisation and staff, but that also encompass complex negotiations, encounters and communications with those affected in response to their ever-changing personal, social and material surroundings. These creative entanglements emerge in the process of complex and enmeshed
engagement with worldly surroundings through ongoing relation, interaction and encounter. Consequently, I argue that the problem involved in agency is not loss itself, but the ways in which people perceive, understand and work with loss. In the following, an ethnography of five residents making of works of dementia, demonstrates that agency is not limited to individual art practice but is neither mere collective phenomena. Rather, agency emerges in the process of experiencing and engaging with the human condition: co-dwelling.

2. Ethnography of Works of Dementia
The purpose of the first subsection is to explore the complexity in preparing for works of dementia in the Home, unravelling four characteristics: ambiguous, improvisational, relational and collaborative. The initial focus will be on the ambiguity of participants within collaborative activities and I will then demonstrate the improvisational and relational qualities of facilitating and setting up works of dementia. In the second subsection, I explore the ways in which individual residents with dementia experience and practise works of dementia, focusing in particular on their processes and relations.

(1) Complexity as Ambiguous, Improvisational, Relational and Collaborative
As Emily Hall, an Activity Leader at the Home writes in Caring UK, the ways in which staff organise and facilitate works of dementia vary depending on the different necessities, medical conditions and preferences of individual residents, and upon available resources at any particular time and place:

The class can mean so many different things to each person. Some want to really get stuck in, some don’t like clay work but like to paint, others like to watch, some sit and chat; the atmosphere has to be right. The music is always on, tea and cake at the ready, books and inspiration strewn round the table and an enthusiasm for what and who you are teaching. When you are working with such varied abilities and disabilities, such as those with dementia or who have had a stroke, the whole process of working with clay becomes very personal and has to adapt to suit their needs... noticing the little things about someone, analysing their moods, their behaviour and trying out different things with them. It’s a conversation starter and a way of socialising, reminiscing about things they have done (Hall, 2013).

As such, works of dementia are ambiguous in that individual participants have different interests and tastes, and therefore tailored initiatives are preferable when it comes to facilitating these activities. More fundamentally, due to the different levels and forms of dementia, potential participants for works of dementia are always indeterminate not only in terms of the number of participants, but also in terms of their particular characteristics, as they all have different requirements and react
differently toward here-and-now social and material circumstances. For example, in her interview, Claudia, an Activity Leader, described the contingent, indeterminate and impromptu group organising when she initially planned two different painting groups according to residents’ capacity and medical necessities. However, not long after she had to adjust her plan based on individual medical conditions, available materials, aid from staff and volunteers and above all, individual preferences. She could not control the criteria for participants, nor could she anticipate exactly who would join the activity, or predetermine which materials she would be able to use.

Works of dementia are improvisational not because residents with dementia are ‘living in the past’ (Hulko et al., 2014, P. 139), but because there are no predetermined forms, destinations or directions they should follow. Here is a letter and an interview:

*My plan had originally been to paint several watercolours of singular objects belonging to the residents, items that reflected their personality in some way and could pose as a form of portrait. After my first meeting with Elaine I realised that the residents not only did not have many belongings but did not need or react to objects in the same way that they used to, other than the odd teddy and bundle of knitting. My plan evolved to more of an imaginative realm whereby the residents considered images, places, colours, animals and objects that they wanted to see in the painting and I took notes (A farewell letter to the staff from Vickie, Activity Leader).*

*For example, today we tried to draw a flower. When we did crawly things it was about the colour, it wasn’t about the drawing. Ayla didn’t respond to the drawing, but picked up a few colours, doing something nice with them. Even Gevira! I would say Gevira was the same as well. But she was the most difficult for me because it was very difficult to explain something in a way she could understand. Again with Rachel, it was not about the drawing but about the colour. That gave her something, although not confidence. But at least she could do something. They could do something which didn’t have to be exact but they could focus on it (Interview with Claudia, Activity Leader).*

Activity Leaders are not just contributing their skills and ideas to works of dementia with residents, but they also support, stimulate and motivate residents’ creative powers by acting as facilitators and building a stimulating atmosphere. To know the background of individual residents, such as their life history, career, personality, preferences and medical history, is extremely helpful in improving and strengthening friendly interaction and communication. For example, Daniel, a retired headmaster, prefers me to bring some intellectual questions for us to discuss together. Unexpectedly, my Korean-English is always a good talking point; it is unfamiliar to him and as an English and Drama teacher, he always points out ‘strange’ things about my accent, intonation or pronunciation. For Ayla, a retired teacher, a sociable and
empathetic approach to her ‘miserable’ situation, along with open ears to listen to her ‘terrible’ life story are always best. Facilitators should not forget that they also need patience in order to endure Ayla’s repetitive asking for help, and they need to be able to allocate time to devote only to her, otherwise she may get upset. Daniella, a retired teacher and artist, prefers you to give her the confidence in her remaining skills and abilities, and guarantee her private space with well-equipped materials to inspire her works of dementia, such as still flowers in a vase, art magazines or fruits and vegetables. Above all, her seat should be arranged near or next to her best friend, Chaya. For Gevira, a retired secretary with cognitive deterioration, it is helpful to demonstrate things for her step-by-step rather than explaining everything in one fell swoop. Staff should remember that although her speaking is fragmented and she often mumbles, rarely expressing her feelings outwardly, she quickly recognises more than anyone else when she is treated as someone who is disabled. Yedida, a retired art dealer, would love it if staff enjoyed talking and had multilingual competencies. Rachel, a retired housewife, needs the room to adjust to her illness on her own terms. This is in contrast to her husband’s early interventions to assist and help her by explaining, representing and exemplifying what she wants to do and say, as this gave her no room to adjust to her fluctuating Alzheimer’s world. Chemda, a retired volunteer, would have more confidence in what she was doing if she was given more appreciation and acknowledgement with wit and jokes. Clearly, these requirements do not have universal and unique solutions. Solutions need to be responsive and attuned to specific situations.

Works of dementia are relational, considering that every resident is already situated in their immediate biosocial surroundings. Individual experiences are not just obtained by ‘being enfolded into the body’ but they rather require us to acknowledge the enmeshed relations and interactions between people, things and environments. For example, at the beginning of a crafting session, calm and classical music might be playing, although pop or jazz music from the 1930s and 40s could be used. As time goes on, increasingly rhythmic and livelier music is played, while the smells from the kitchen and the flowers, the circulation of fresh air, the adjustment of sunlight and room temperature are also attuned to contribute towards a dementia-friendly atmosphere. At the same time, it is essential for staff to arrange the seating and work-partners of those affected as, depending on whom they work with, they will respond and act in significantly different ways to the session. Indeed, residents do not only practice their artistic skills in the Centre, but they navigate, constitute and experience these kinds of affective and sensory ‘atmospheres’ (Ingold, 2012a; 2012b).
Works of dementia are collaborative. First of all, the provision of a wide range of activities requires not only the ‘emotional labour’ of the staff (Adams, 2007, p. 191) but has the effect of diversifying their skills, experiences and human relations in a collaborative way. For example, Lynne used to be a hotel manager in the Philippines and her wages and quality of life were far better than they are now, working as an Activity Leader in the UK. After her marriage, she settled down in London and started a completely different career. Yet, as she says, the fundamental ‘spirit’ which is required for both jobs is the same: attentiveness, empathy and love from her heart. It is fitting that when she was asked in her job interview what the best care for elderly people with dementia is, her answer was ‘to treat residents like my family’; regardless of skin-colour, medical condition or personality, residents are all her co-dwellers who need attention, acknowledgement, encouragement and support:

My principle is wherever you are, guest first, person first. One day, I met a gentleman who didn’t know where he was in a hotel and the reception was busy… Actually, I was working in a souvenir shop in a hotel as a salesperson when he came in. I approached him with a smile… that’s my character… just made him comfortable. Then he liked to talk to me. This is beyond my job description, but I entertained him and then he came back to me with his wife and children later. In this way, I don’t directly sell to people but make them close and comfortable first and then the sale always follows… Just as my customer service in the Hotel, here, some people can only say ‘mm-hm’, ‘voour’ when I talk, and then I start listening to them. I say: ‘How are you today?’ They say ‘A-ba-ba-ba...’ My spirit is that we are connecting... I do not see them word-by-word but I know that if I work slowly, there is no problem at all. It is a kind of magic... even in my unit, there are no words at all. It is not about you but the feeling you get with the person you talk to. What is lacking is listening to them (Interview with Lynne, Activity Leader).

Fiona is a retired teacher as well as an active dementia ambassador, not only in the Home but also with the Alzheimer’s Society, UK. Over the past decade her new career as an Activity Leader has extended into knitting, storytelling, singing, befriending and almost everything and everywhere that people with dementia reside. She does not need special tools or particular mediums in order to facilitate an activity. All ordinary things, stories, encounters and lives are indefinite resources for her, a reservoir of improvised creativity:

My husband had dementia for 7 to 8 years. I always engaged with him in terms of his capacity and preferences. We peeled carrots endlessly because he wanted to do something... What he used to like to do was mending things, but these skills were gone... but he wanted to be with me and cooking with him was quite good, although I had to eat carrots for a while. Similarly, you have to know a little bit of biography and life history... someone likes doing this, others don’t... interacting and finding out... For
example, this morning, Ayla, she used to knit but her hands are not able to do it now... but her mind in terms of doing something is still there. You have to think about the resident’s capabilities and what they want to get out of it. Caroline may wander around. One day I talked to her, I sang to her, as I did to my husband. She then engaged in the activity, did some cutting and pasting... What a lovely morning it was (Interview with Fiona, Activity Leader).

From her point of view, to provide quality of care and life is not an unreachable goal, but is already and always here around us, we just need to realise it. Interestingly, as seen above, the way she works with people with dementia relies very much on her personality and previous experiences with her husband who went through dementia. In retrospect, she said that the most difficult thing when taking care of and living with him was not the fluctuating cyclical nature of his illness, but her weak physical strength when offering the daily support he needed, as they had no assistive technology at home, such as a hoist. Recently, she has reduced her working hours and increased her voluntary work in the Home and with the Alzheimer’s Society. As she said, it was the experience, know-how and skills gained during these difficult times that meant she was able to give back to society.

Other Activity Leaders are not very different and among all of them, there is no-one who initially specialised in care for the elderly with dementia. For example, Kate used to be a cookery teacher at a college, Claudia a freelance video and film artist, Radley a primary school teacher, Hughes and Hall both artists, Catherine an Activity Leader for children with special needs and Archer a Salvation Army Officer. The period of work experience as an Activity Leader or a Coordinator significantly differs from a few months to over fifteen years. Accordingly, based on such diverse personal historical legacies and relations with others, the ways in which they collaborate with residents are also very varied.

Furthermore, whilst the main purpose of works of dementia is to maintain, stimulate and improve the particular body functions and abilities of those affected from a medical and therapeutic perspective, the ways activity leaders approach these activities differ in terms of focusing more on socialisation and collaboration by stimulating becoming in a co-dwelling condition:

I always have a button box and I ask ‘Can you find all the white ones for me?’ It is a very simple task but for me it is not about the end product, it is more like therapy, it is engaging... I don’t know how to do this other than by doing or finding things. Sharon would do it, then Katy used to sit down next to her and muddle them all up again and Sharon would put them in order
It doesn’t matter how we do it or what the purpose is (Interview with Fiona, Activity Leader).

Fiona is not only concerned with remaining body skills and abilities but also with loss. Whilst kindly asking Sharon to arrange disordered buttons in the sewing box, she suggests to Katy, who sits next to her, to play with them, so two residents who have completely different cycles of dementia are able to join together to order a disorderly encounter. The basic concept of organising such an activity is ‘person first’ in her words, considering ‘what they can do’ and ‘what they want to do’ first. In this regard, because of the conditions of co-dwelling and of the cyclical nature of illness, even vulnerable people who have lost their abilities can participate in works of dementia in a collaborative way. In another example, Josiah’s failing eyesight means he can barely engage in any figurative or expressive artworks except for the crafting of organism-like artefacts made of clay. His works are then handed over to other residents to paint, resulting in some of the most famous collaborative artworks at the Home. Furthermore, Silvia, Josiah and other residents with dementia who are less active and sometimes motionless become the best drawing models. It is here where facilitators (mainly Activity Leaders or volunteers) play an important role in motivating, operating and assembling residents and works of dementia. What strikes me about collaborative artwork is that as Kirsty, a senior care staff member, insists, care is not always about giving more but is sometimes about taking away from residents by way of nudging or stimulating, like in the example of the button box; the possibility is open-ended, depending on the ways in which staff and residents collaborate, and thus people may undergo a completely different trajectory through works of dementia. As Claudia says, it is the ‘communal effort‘ in that the staff do not see individual limits but see the immanent potential of collaborative becoming that emerges through interaction and encounter in the context of co-dwelling.

In brief, works of dementia are experienced and practised in the process of collaborative and participatory engagement with staff, residents, materials and physical environments. From the point of view of the staff, organising and facilitating works of dementia require them to ‘collaborate more productively’ not only with the material, but also with their own and residents’ cultural, historical and medical legacies and the atmospheric environment (Ingold, 2013b, p. 31). Although they work individually by distributed assignment, their participation in works of dementia always makes them collaboratively interwoven by interacting with one another beyond human and nonhuman boundaries ‘in the dynamic potential of an entire field of relationships [...] for the persons situated in it’ (Hallam and Ingold, 2007, pp. 6-7). This open-ended and enmeshed relation embedded in a particular socio-cultural, historical
and environmental context opens the potential possibilities of works of dementia which have been characterised as generative, heterogeneous, improvisatory, and nonetheless singular and collaborative.

(2) **Works of Dementia as Creative Entanglement**

Due to unique trajectories of dementia, some residents experience too much loss of memory, cognition, language and rational thinking, and also of bodily skills to bring something to life, whilst others may unexpectedly generate (untaught) creative abilities in works of dementia, called ‘Acquired Savant Syndrome’ (Corrigan et al., 2012). This subsection explores the ways in which four residents with dementia and a husband without dementia engage in works of dementia and reveal the potential agency of their unvoiced and entangled creativity from the perspective of persons with dementia, not as individuals but as co-creators.

### A. Ayla

Sitting next to me, Yiskah, a retired college and prison teacher, grabs a pencil and her sketchbook. Although she usually prefers to draw still life, such as a flower in a vase, today she chooses to draw one of the potters in the crafting session. She shows some of her previous works to me saying that Josiah, a retired architect is the best model as he hardly moves during the drawing process. Motivated by Yiskah, I recommend drawing to Ayla who is already fed up with crafting pottery and keeps being distracted. She frowns. Yiskah tries to soothe her, which does not work. Hughes, an Activity Leader, also comes to talk to her. In the blink of an eye, Ayla adjusts her posture and grabs Hughes’s hands, pouring out her difficulties and miserable life in the Home, which is the total opposite of her previously affluent life. Hughes is unable to stay and listen to Ayla’s story as there are already other residents calling for her attention and assistance. As soon as she moves onto another resident, Ayla crouches over in her chair, looking miserable. She frightens easily when she hears a loud noise, such as cutlery being dropped in the kitchen, and classical music does not seem to relieve her. She keeps looking around, forlorn.

As soon as I have offered tea, coffee and biscuits to the residents, I return to my seat beside Ayla. She instantly grabs my hands and within a few seconds I have an idea. I suggest to her that she draws me. She waves it off at first, saying that she has never tried it before. Yiskah enthusiastically encourages her and gives her some tips on how to draw. I encourage her again and she finally accepts my invitation. I give her a piece of A4 paper and Ayla fixes her eyes on me. Although Yiskah tells her something, she does not seem to be listening. Instead, Ayla keeps asking me which colours and which tools are best to use. I take a pencil and two yellow and pink pens which are closest to
Her hands are very slow and shaky, yet that does not seem to be a problem in exploring a new experience. Whilst drawing the contour of my face, she keeps telling me that I have very clean-cut features with prominent cheekbones and chin, calling me a handsome boy. I thank her and say that I really look forward to seeing her drawing. She repeatedly says it is not very good, but she seems to enjoy her time drawing and touching my face to figure out its texture and lines. On paper I can see that she has drawn lines crossing and folding over each other with her pencil and two coloured pens.

It takes roughly ten minutes for Ayla to finish my portrait. When I see the completed image, I have mixed feelings: I feel apologetic, sad, yet surprised, and enthusiastic and something which I cannot pin down in words. But the impression of the portrait will remain forever in my heart. It is abstract and ambiguous, and I can hardly recognise where my eyes, nose, mouth and ears are. It consists of a lot of pinkish horizontal curves and some cog-like wheels in the lower-middle part of the paper, with yellowish fragmented curves in the bottom-left. She draws what looks like a daisy in the middle with a pencil. It is as if she has expressed her inner feelings about me rather than what she can see. At the end, I ask her to sign her drawing. She asks me where she is supposed to do it. I guide her hands and follow the movement of the pencil. Her grip is weak and unsteady but she manages to sign her masterpiece.

![Figure 5-1 Ayla's Portrait of the Researcher](image-url)
Ayla’s image triggers a wide range of opinions within the Home, including that of strangeness, surprise, disappointment, mystery and obscurity. Kelly, a volunteer, says that Ayla definitely perceives my face but is unable to reproduce it in the form of an image taken from her brain. Some describe her drawing as nothing but scribbles. Others are curious about what she tries to express through abstract figures and colourful lines of movement, encouraging her to try again. However, Ayla does not seem to like the picture and thus I cannot ask for another. Although I hardly know how Ayla, as a woman with macular degeneration, depression and dementia, perceives, recognises and represents her dementia world, it is clear that her portrait involves entangled interactions and encounters with her surroundings, generating another social happening and thus adding to the flow of this story.

First and foremost, it is worth asking what makes Ayla engage in the activity and why she does not want to sit next to Julie, a resident who hardly acts or reacts to exterior stimulation. Engaging in any work of dementia is the remaining means by which Ayla can escape from the Abraham Unit, which, in her words, she dislikes due to its unfamiliar atmosphere, its ‘strange’ residents and ‘useless’ staff. It goes without saying that it would be much worse if she sat next to someone who had less capacity to communicate with her or who did not pay any attention to her. Of course, her gradual deterioration cannot be ignored either. Ayla gave up knitting a year ago due to her failing eyesight, and since then she has not engaged in any figurative art. She likes listening to music and talking, but inviting her to events is another matter.

It reminds me of Janelle Taylor’s autobiographical study *On Recognition, Caring, and Dementia* (2008). Taylor, while caring for her mother with dementia, repetitively asks her readers ‘Does she recognise you?’ The answer, unfortunately, is ‘No,’ but what she argues is that our perception of a person with dementia is based on the perspective and logic of healthy persons. From Taylor’s own experiences of co-dwelling and caring for her mother, she recognises the importance of acknowledgement; namely, what makes two different worlds of the real (daughter) and the unperceivable (mother) connect is not recognition through cognitive capacity, but appreciation of her mother’s actions, expressions and sayings. From this understanding, in relation to Ayla, I would like to change the question in a rhetorical way to: ‘Does she act and respond?’ There are many *How to* books on improving quality of life through therapeutic, religious, social and art activities but I believe that in practice - at least in Ayla’s case - works of dementia are a ‘knotting’ with other co-dwellers with whom she can share similar feelings, experiences and perspectives. It is perhaps not surprising that the main reason Ayla participates in such activities is to escape her unpredictable and insecure circumstances through social interaction and encounters. Consequently, the most
important motivation for her to join any activity is not just the doing, acting and expressing of something, but more importantly the relating and associating with others who may understand and trust her.

**B. Couple: Rachel and Jacob**

Rachel makes many geometrical and abstract figures using clay laid onto a flat dish. Whenever she carves out an image, she looks at it in detail, inch by inch, over the rim of her glasses. For her, time seems to flow extremely slowly as all her attention is focused on her pottery. However, the style of her artwork is uncanny; parts appear to follow a rule of repetition, yet, seen from a panoramic view, it shows a totally different composition and a dissonant harmony.

These days, Rachel’s crafting, painting and drawing have changed dramatically from the figurative and representational to the abstract. With the recent development of neuroscience, we can, to some extent, define how the brain perceives, interacts, translates and transforms visual-spatial perception, language and aesthetics (Mendez, 2004; Rose, 2004; Zeman, 2008; Sacks, 2010; Zaidel, 2015). Furthermore, this scientific achievement enables us to identify the neurological deterioration of the brain through art, called ‘the neurology of art’ (Mendez, 2004), by tracing the transformation of expression in terms of tone, texture, colour, brightness and abstractness over a substantial period of time (Rustin, 2008). Sadly, Rachel’s dramatic transformation in her modes of expression over the past year reflects a significant deterioration in her dementia.

Yet, what her works of dementia draw more attention to at the Home is not just loss per se but the unexpected effects of loss that generate, stimulate and affect not only her idiosyncratic ways of expressing and representing her dementia world through

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![Figure 5-2 Rachel's Paintings Before / After Dementia](image-url)
diverse colours and repetitive patterns but also subsequent transformation of the couple’s relation and the way they live out such difficult moments. On the one hand, many people in the Home say her skills and dexterity have gradually deteriorated in one way or another, but on the other, her newly emergent modes of expressive performance lead to different aesthetic interpretations amongst the people around her. At this point, we can claim that the neurology of her artworks cannot explain why, for example, she is more interested in red than in black, or in a brush rather than a pen; that is the creative force of bringing things to life by integrating her agentic abilities in response to the here and now situation, which includes her illness condition and the social and material relations of a given time and space. Whilst reading backward from her finished artworks possibly illustrates the state of her brain, it cannot tell us what she and her artworks have undergone in the making of them; nor is the aesthetic dimension of art her only concern. As the staff members claim, her passion for works of dementia is deeply embedded not only in her aesthetic but also in the affective, sensory and expressive dimensions of her social life, particularly with her husband and three adult children. In DeLanda’s words, this idiosyncratic way of art-making is ‘unique, singular, historically contingent, individual’ (DeLanda, 2006, p. 40). The question therefore is not to discover to what extent her participation in works of dementia can improve her health and well-being, but rather to explore the new ways in which she interacts and engages with her dementia world within her limited agentic abilities.

Taking one step further, the role of her husband, who tries hard to maintain ‘couplehood,’ cannot be ignored (Hellström et al., 2007; Hellström and Torres, 2012; Eriksson et al., 2013; Hellström et al., 2015). Jacob always admires Rachel’s delicate and detailed paintings and drawings. Therefore, recent dramatic changes in her art means that he has few days left in which he can communicate with her as, sooner or later, she will no longer have a ‘clear mind’. In this regard, it is worth remembering how we perceive the world, and in particular, how we perceive images. Using John Berger’s *Ways of Seeing* (1972), Irving (2009) discusses how words can transform the impression of an image. He argues that we see Van Gogh’s *Wheatfield with Crows* as completely different before and after the moment we hear it is his last work of art. Likewise, for Jacob, the works of dementia he looks at now are not mere ‘art objects’ that represent Rachel’s ‘aesthetic response’ or symbolic ‘meaning’ (Gell, 1998, p. 5); they rather imply not only her performative, expressive and affective power but also the remaining time the couple have left to talk. In addition, because of their dramatic life stories, her works of dementia are invaluable beyond her illness and her feeling of aesthetics. Here time has multiple dimensions in social life. It is not just our usual
means for counting, calculating and measuring, but embraces the multiple qualities and implications of a couple’s emotional, moral and biographical life. This draws my attention to the couple’s life story.

Jacob was one of the children Kindertransported\textsuperscript{32} at the age of ten and subsequently, in his words, raised in a ‘totally professional’ Quaker family, meaning that he needed to adjust to a strict Christian home discipline. Unfortunately, his entire family ended up at Auschwitz. Long after the War, he visited his home town in Austria a few times and met some surviving relatives, but the relations did not develop further. As a ten-year-old boy, there was nothing he could do at the time except calmly adjust to the unforeseen world and strengthen his internal and physical stability for the future. As soon as he could start work, he tried to stand on his own two feet. He began work in a local shop when he was about fifteen-years-old, and he continued to study at an art school where he met Rachel and they both became architects. Yet, all this came at a price. Unlike other Kindertransported children, such as Yiskah on the Joel Unit, he hardly remembers anything from his childhood, including his mother tongue and specific Jewish ways of life. This difficulty in retrieving memory has continued to the present in one way or another, but is not related to dementia. I assume that his unconscious mind represses, denies or displaces these memories so as to defend him from potentially damaging feelings, emotions or stimuli (Freud, 1992).

In this sense, Rachel and Jacob are the perfect couple in terms of the way they distribute and share their family histories and memories. His wife played a significant role in memorising family anniversaries, such as birthdays and celebratory events, keeping all the information in her memory, while Jacob collected material evidence, such as photographs. However, their married life has not always gone smoothly. They waited almost five years for their first child, trying everything they could, including travelling from Norfolk to London to visit a specialist. They did not have enough money to buy a house, so they bought land on which to build their house, a project on which they worked every weekend, and which took them almost ten years to complete. Retrospectively, Jacob emphasised that in time, there would be a time for everything but, until then, they needed to try their best to not be frustrated or give up.

However, as Rachel’s chronic depression and confusion progressed about half a decade ago, he realised he needed to take it seriously. Before long, Rachel was diagnosed with dementia. He always thought he would be the first person to leave this world after having three heart operations, believing his heart can stop again any day.

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\textsuperscript{32} The \textit{Kindertransport} was a unique British humanitarian rescue mission evacuating 10,000 children from Nazi occupied territory in Europe just before the outbreak of the Second World War.
and any minute. He stopped playing table tennis about two decades ago due to his heart condition. It was not an easy decision because he used to be a local champion and led the Table Tennis Society as a Chairman for a decade. However, once he made the decision, he swiftly put it into action. What would he do next then? He simply says:

*The future... it is what it is now. If we like it, we will stay longer, for one year or maybe five... But I do not have a future. Maybe the children but not us! We are just facing forwards... Look at the pictures on the wall. She did it all but now she does not have it anymore...*

These days, Jacob often witnesses Rachel struggling to converse with their grown children over the phone. There was a time that as an informal carer he tried hard to ‘fill in the gaps’ (Fontana and Smith, 1989, p. 39) in the sense that he normalised his wife by correcting her words, helping to finish her sentences, and suggesting some words for her that she could use. That was his way of practising his care, love and responsibility, which was often described as over-patronising by the staff. This has changed over the past year. The more he tried to give (correct) her something, the more he lost. He has learned through his trial and error and consultations with staff and specialists to stay connected while letting her go (Braff and Olenik, 2005). Rather than correcting (or rejecting) Rachel’s condition and behaviours, he accepts and lives with them, just as they have gone through the past sixty years together. Keeping hope that she might have a better day today, he suggests participating in crafting. In the session, he looks over what she is doing. This is Jacob’s way of going along with the here-and-now situation by acknowledging ‘continuity and loss’ (Gillies, 2012) and supporting and providing the necessary attention for Rachel. He continues, but this time he keeps cool as if he has an ordinary life like anyone who experienced the War as a Jew, and as anyone who has had a lovely married life for a long time:

*Someone has had to cope with their life against an unusual and difficult start at the age of ten, and they are still fighting... But being with Rachel for more than sixty years, I think we cope very well.*

He smiles and asks Rachel ‘Is that right? Say yes or no?’ ‘Absolutely yes!’ Rachel answers. Of course, the couple’s itinerary has not stopped there. It was his son-in-law who recommended the Home where his mother used to live. They moved into the Home in late 2013 at the cost of selling their house, in which all their memories were embedded. Relying much on their adult-children and grandchildren’s ability to travel to see them and Rachel’s quality of care and life, the couple decided to move in even though ‘it was not quite right’ and ‘it was not the best option’ they had, as Jacob says. ‘Should you be reasonably happy?’ their three grown children asked him one day. He answered that ‘there won’t be happiness, but our lives go on.’ He waited a year for his
single room in the Joel Unit, which was an agreement with the Home when they entered. The couple found new ways of living in the unusual environment. It is ‘a miracle’ he still has a scrapbook made of photographs and cuttings published in local newspapers and magazines about his family life, including pictures of him with trophies for table tennis. When he started making the scrapbook, it was just for fun and to support his memories but it has become essential both to his memory, and to stimulating the memory of his wife. Furthermore, living in an Orthodox Jewish Home gives him the opportunity to retrieve and learn about forgotten memories and Jewish history and culture. It is never too late to start to learn new things. For Rachel, she gave up drawing for a while before entering the Home. Through works of dementia she can now explore, express, and communicate her inner world outwardly. At the same time, from Jacob’s point of view, looking at her works of dementia is perhaps one of the remaining ways he is able to show his feelings of love and attention, although it also demands a sense of loss and frustration in the recognition that nothing can be done for his wife, he can only stand by her.

C. Friends: Chaya and Daniella

As usual, Claudia arranges two seats for Chaya, a retired headmistress, and Daniella, a retired artist, which are slightly separate from the main pottery group. It is not only because they always go as a couple of best friends but also because their engagement with works of dementia is maximised when they can support each other by being together. Other residents seated at a neighbouring table have started making pottery, but they are still looking at the art magazines offered by Claudia to give them some ideas for works of dementia. A little while later, Chaya puts down her novel and looks at the magazine carefully. It takes her time to decide what object she wants to draw. Eventually, she begins to draw flowers not from the magazine but from the vase on the table. Once she starts drawing she becomes oblivious to anything else going on around her. She does not touch her tea and biscuits until she finishes, nor does she talk to anyone else, even Daniella.

Meanwhile, Daniella still tries to find the right image. She takes another book from the shelf, and repeats this several times. She looks at the flowers in the vase on the table and back at the magazines. In this sense, Daniella and Chaya share a commonality in that it is difficult for them to be persuaded to come down to the Centre and start engaging with the materials provided. Of course, Daniella’s compulsive obsession with things cannot be ignored, meaning she may feel uncomfortable, out of place and agitated unless she is with a particular object in particular colours with a particular seat and a particular table partner. That is the main reason Chaya and Daniella are almost always invited to works of dementia together, not only for medical reasons, such as
relieving agitation (Kutner et al., 2000) but also to elicit the benefits of the ‘multi-layered and fluid nature of friendship,’ including collective and creative agency and emotional support (Ward et al., 2012, p. 288). Yet, once they are involved, their inherent potential for art-making begins to flow. As soon as Daniella connects with her imaginative and creative realm, she becomes silent and concentrates on her work. This time, she decides to craft clay and starts to hum a tune. Although Chaya’s hands are slightly shaky, she manages to carve a beautiful lady with a thin waist and slim neck, in a long pleated dress and wide hat. Only once does she sip her tea when it is offered. Classical music is always played in the Centre. Sometimes me and the other volunteers ask her whether she would like a cup of tea and cake, but she does not have time for our interruptions. For about half an hour she does not say anything but keeps concentrating on carving detail with a fine engraver.

![Figure 5-3 Chaya's Drawing and Daniella's Crafting](image)

Only after her artwork is done does she put the wooden tool back on the table and enjoy her cold coffee and cake. She gets a lot of praise for her detailed, aesthetic and dexterous depiction and the statue is given the name of ‘a Victorian Lady’ by other residents and staff. She adjusts her dress with pride. Yet, her craftwork does not finish there. After drinking the coffee, she looks around and considers what else she can do. She keeps looking for something and then she takes a book and puts her ‘Victorian Lady’ on it before taking it off again. She places her work here and there. At last, she cleans the crumbs of clay from her table with her hands and takes a cake plate from the tea tray. The plate is colourfully decorated around its edges. She puts her sculpture on the plate and appreciates her work of art. Everyone is surprised and marvels at her improvisatory artistic imagination again.
Chaya and Daniella met each other at the Home for the first time, but their love of art has made them sincere friends, just as described ‘facilitated friendships’ (Ward et al., 2012, pp. 299-300) that have been fostered and supported by staff through engaging in works of dementia together. Their relationship has extended to their adult daughters who are their main informal carers and hold the Power of Attorney for them. Their adult-daughters have become friends, exchanging useful information about caring for their mothers and inviting each other to family days-out in the city or near parks. Chaya and Daniella’s growing intimate relationship stands in contrast to the perception that a community such as this - a care home for people with dementia - has often been described as asocial or as bringing about a ‘social death’ as there is no talk, no movement and no socialisation (Sweeting and Gilhooly, 1997; Brannelly, 2011a).

Indeed, they had been inseparable up until the point Daniella was transferred to the Christie Wing (the Advance Dementia Care Unit) in early 2014. However, as Daniella’s dementia dramatically evolved, Chaya’s family, and the Home had to reconsider her condition seriously. Their relationship has deteriorated and their conversation often stops. However, the decision to transfer Daniella to the Christie Wing is more complicated than the families initially thought. In fact, the transference is delayed and reconsidered for at least six months on the basis that the current provision of dementia care is appropriate for them. More precisely, the Home as well as their family members need to check the balance between losing close relationships with friends and to the physical environment and the undeniable benefit of friendships, not only through mutual emotional and psychological trust and support but also in the way they built relations with others and their surroundings through verbal and non-verbal language in the mode of being together. When the Home considers Daniella’s transfer, the friends’ mutual voluntary and participatory engagement in conversation and daily activities through recognition of otherness and caring for one another within their own capacity is weighed upon much more than just mere medical need. Daniella and her family members are advised to think seriously about her transfer after Daniella enters a couple’s room several times without knocking, and only after staff on the Abraham Unit reason they do not have enough resources to care for her.

Recently, Daniella has been transferred to the Christie Wing. After her transference, Daniella never sits at the table she used to sit at with Chaya. Her paintings, drawings and sculptures are kept aside. During the first month of her transition, Daniella had friendly visits from Chaya, but as time goes by, they both either get used to living separately, or perhaps forget each other. Does this mean the end of the story? It looks as though it does in terms of their friendship, yet their stories keep generating in a different place and in different forms. Although the progression of their dementia
cannot be reversed, their works of dementia keep being reborn in response to the cyclical nature of their illness and their social and physical surroundings. Chaya now spends most of her time sitting on the sofa reading books in the Abraham Unit and Daniella spends most of her time in the new unit keeping herself busy. In doing so, their new relations with people, things, and the physical environment, in particular, friendships and familial relationships, keep generating, being maintained or ending as their dementia progresses.

D. Daniel

Daniel, the retired headmaster, is crafting a man’s head whilst a message, ‘THINK WOMAN’ stares at him. The more he crafts, the more the shape of the man’s head emerges; his hair is shortened, the previously egg-shaped jaw transformed into a square one, the thin eyebrows into thick, straight lines. As usual, after setting up and facilitating the painting and crafting of other residents, Claudia sits next to him and makes conversation. Daniel enjoys talking and their chat continues nearly to the end of the morning activity.

Daniel and Daniella are well known for their artistic talent and obsessive behaviour when it comes to their materials. As a regular potter, Daniel often crafts with clay, making human heads with varying facial expressions, but his work always finishes with the faces of men, regardless of his intention or the intervention of other people or things such as the memo on the table. He is also widely known as a companion to talk to amongst the staff and volunteers, including myself. The ups and downs in his life provide an endless repertoire. Although he often forgets what he has just said due to his short-term memory loss, this does not interfere with him conversing with others as long as the talk focuses more on the here and now situation or on his youth. Love, sex and religion are the most common subjects in conversation with Daniel. Furthermore, because of his eloquent art and way of speaking, he has become an honourable ambassador for fundraising and diplomatic encounters with figures such as Jeremy Hunt, the Secretary of State for Health. As he emphasises, he is too busy to die. More importantly, every Thursday he now has a regular visit from his daughter and often with his granddaughter, making and crafting together. Through crafting, three generations are reunited again. This was not what he expected when he lived in another care home in Eastbourne. Parse (2014, p. 110) defines family as ‘an invisible, unpredictable, ever-changing connectedness with close others,’ and once they loosen, family relations weave together again in light of the participatory engagement through craft-making. Furthermore, making art together provides him and his family not only with a subjective sense of well-being, strengthening resilience for coping with dementia and caring but also provides mutual support for intergenerational relations,
mitigating the sense of loss and offering resources for coping (Pienaar and Reynolds, 2015).

![Figure 5-4 Daniel’s Head Figurines](image-url)

Unlike Rachel, Daniella and Chaya, Daniel has never tried crafting or other types of works of art. His dexterous craftsmanship is a surprising talent not only within the Home but also for himself and his family. His first two months were spent trying to find out which activity he might enjoy. Amongst the activities, he was regularly invited to the Man’s Group, a weekly discussion group for men. However, he often had to face uncomfortable feelings and struggles because of the way in which the activity was organised. To ensure smooth and inclusive engagement in a discussion, Frazer, host volunteer of the meeting, had to point out their turn to speak their opinions individually and repeated what had been said in order to deliver the message clearly and effectively to all discussants. Yet he could not often control who spoke when, and sometimes the discussants would all talk at the same time. Daniel could not bear this ‘patronising’ atmosphere and disorderly discussion, making him feel estranged and keeping his ears constantly buzzing with nonsense. Finally, he found the activity in which he could freely exert his untaught talent and talk in a more comfortable and private environment. Here, there is no talking over and above each other, which often happened at the Man’s Group. He does not need to worry about his hearing aid as long as one-to-one conversations are taking place. After the activity, the soup made by residents in the kitchen is another privilege to try.

Due to his short-term memory loss, Daniel needs to check what he has already done or what he has not yet finished before starting a new craftwork. All finished figurines are
collected and on-going work is kept on the shelf next to the worktable. Over the past few years, the path to his seat in the Centre has been routinised, so there are barely any problems for his short-term memory and he just follows the route his body takes. During the activity, being able to talk to staff, like Claudia or myself, is an extra pleasure he enjoys. For him, life is open-ended and simply requires him to try it. Daniel’s lines of becoming are energetic and they dance despite his dementia, damaged arteries in the heart and prostate cancer. There are too many things left for him to do instead of waiting to die. He approaches the present moment as an adventure, within which he forges his fragmented memories from the past with an expectation of the future.

3. The Limits and Implications of Existing Concepts of Agency and Art

People living with dementia are often perceived as repetitive, incoherent, inconsistent, illogical and even unrecognizable. Accordingly, it is reasonable to question whether or not we can be sure of what Ayla is trying to express in her portrait. What makes Daniel always craft the same male head, and can it be interpreted as talent, even though it is repetitive? Can we say Rachel’s drawings and paintings are inspired by artistic creativity, even though they mainly consist of repetitive and abstract patterns and the same colours? What does the plate mean for Daniella? Can her Victorian Lady be appreciated as an artwork without the plate? Above all, can all works of dementia be appreciated as artworks or merely as complementary therapeutic activities?

(1) Rementia and Embodied Agency

Agency in art for people with dementia has been one of the most contested issues, concerning whether or not people living with dementia have agency and are enabled to exert it, or whether their works are aesthetically valuable in everyday life. Since Kitwood (1997), an exponent of person-centred care, claimed the potential capacity to regain skills and recuperate from dementia, what he calls, *rementia*, many followers have attempted to reveal a potential and vital force which still remains unvoiced; in this context, a kind of agency. In particular, phenomenological approaches which reference pre-reflective and embodied practice have greatly contributed not only to promoting and developing quality of life and care and daily practice, but also to demonstrating the agential self despite the loss of bodily functions and abilities (Phinney and Chesla, 2003; Kontos and Naglie, 2009; Kontos and Martin, 2013; Twigg et al., 2013).

Kontos recognises creative energy as a kind of embodied agency that is not necessarily conscious and reflexive, but is embodied, intentional and deeply sedimented in the
body as ‘body knowledge,’ providing ‘a source of creativity’ and an ‘impulse’ to express and make works of dementia. She suggests that bodily movements, gestures, postures and styles do not entirely belong to pre-reflective bodily practice, but can also reflect sociocultural disposition (Kontos, 2003; 2005; 2006a; Kontos and Martin, 2013). Based on her theoretical understandings of lived experience and the embodied self, she sheds new light on the ways in which dementia is experienced and claims that even a person with dementia is capable of relational, moral, aesthetic and social dimensions of agency (Kontos, 2003; 2005; 2006a; Kontos and Naglie, 2009; Kontos and Martin, 2013).

Despite her theoretical and empirical contributions to the study of dementia, her understanding of embodied agency includes critical epistemological, conceptual and methodological lacunae; first and foremost, she pays less attention to our own culturally value-laden judgements which rely upon everyday thoughts and practices concerning how we define what it is to be human. To put it plainly, in contrast with other ‘works of illness’ (Radley, 2009) and ‘outsider art’ (Cardinal, 1972), works of dementia are rarely considered artworks in their own right; instead, they are considered either as pathological markers, reflective of neurological deterioration in the brain (Espinel, 1996; Crutch and Rossor, 2006) or merely as practice-based art activities for improving and promoting health and well-being (Basting, 2006). For example, as the above studies of Crutch, Rossor and Espinel show, the paintings and drawings of abstract expressionist Willem de Kooning during the last decade of his life focus primarily on his transformative yet deteriorated skills and styles (exceptions include Kontos, 2003). This implies our culturally embedded understanding of personhood is somewhat based on individual, artistic and cognitive capacity. Accordingly, there are doubts and ambiguities over whether those affected have a kind of agency over works of dementia and whether or not these works are valuable aesthetically or in any other way.

Secondly, these doubts and ambiguities are deeply related to our neglect of the social role of the loss of body function in works of dementia, resulting in unintentionally perpetuating negative images, perceptions and understandings of loss for those affected. Although I acknowledge the contribution of previous studies to health, healing and wellbeing within the dementia context, I strongly disagree with many studies that unwittingly share a misconception of loss as an ‘assumed existential outcome’ of the disease in a negative sense (Kontos, 2014, p. 109), namely, the loss of the self (Herskovits, 1995). Thus such negative interpretations and representations of loss need to be avoided within our daily lives as well as in the research field, resulting in loss being excluded and even stigmatised in a social as well as medical context. For
example, as Zeisel asserts in her book *I’m Still Here* (2010), when someone is diagnosed with dementia, they are considered as losing their memory, cognition, language and other social behaviours and attitudes, and thus as also losing their ‘self’ as a consequence. Of course, as she argues, the diagnosed can still dwell together and connect with others using remaining skills and abilities by building new relationships and participating in social and art activities, emphasising metaphorically ‘the half-full rather than the half-empty glass’ (Zeisel, 2010, p. 2). Likewise, Hydén, Lindemann and Brockmeier’s edited book *Beyond Loss* (2014, p. 2) focuses mainly on these ‘remaining abilities’ that allow those affected to interact and communicate with others. It is true that unlike a malignant cancer, which mostly requires us to remove it from the host body in order to survive, loss in the dementia context is inseparable, incurable and irreversible. We even have limited knowledge about the exact cause, process and effect of loss in the brain. What I would like to highlight here is that although Zeisel and Hydén and his co-editors elaborately demonstrate the potential of ‘remaining’ skills and bodily abilities, they fail to embrace the other side of the coin, the half-empty glass, so to speak: that of loss. As Taylor (2007, p. 106) rhetorically emphasises, his Alzheimer’s world described as ‘half empty,’ caused by neurological, physical, psychological and behavioural deterioration is the lived reality he actually feels, understands and lives through. This is what I call the paradox of *rementia*. Despite Kitwood’s contribution to dementia, he and his followers do not pay much attention to the role of the shadow of the illness: that is loss which is inherently part of the lives experienced by those affected in the process of making their bodies become otherwise in order to attune them to the new norm (Canguilhem, 1998). In this regard, it is regrettable that Kitwood and his followers who focus predominantly on revealing a remaining intact ability (or agency) beyond loss, barely embrace the other side of becoming-dementia.

Thirdly and most importantly, existing bodies of thought rely mainly upon human-centred notions of agency which are based on a human/nonhuman hierarchical divide, implying that works of dementia are perceived as less social or as mere actors in the formation of agency. That is to say, less attention has been given to the inherent human condition of co-dwelling as well as to the social life of works of dementia. However, as illustrated in the previous section, there is always some friction in works of dementia. Needless to say, these processes involve non-human entities, such as the atmosphere, temperature, light, sound, smell and so forth. There is no such thing as agency which is self-sufficient: participants engaged in works of dementia are already embedded, situated and related in an entangled web of co-dwelling, practicing culturally acknowledged forms of practice. Works of dementia are always open and in
progress, responding to the ever-changing biosocial surroundings and individual situations. In other words, they can no longer simply be characterised as a social, medical, moral, political or artistic category alone, nor can they be predesigned because they involve complex, entangled and enmeshed engagements and interactions with the lives of others, things, and physical environments. This demonstrates that, for example, Ayla’s drawing does not start with a pencil and a piece of paper. Before that, the schedule for the activity needs to be confirmed at least a week before the event takes place. Furthermore, as Ayla, Chaya and Daniella show, this does not mean they voluntarily or automatically engage in works of dementia. It is likely that works of dementia are created out of the same logic of collaboration and creative engagement, but because of the different skills, abilities, idiosyncratic characters and life histories of participants, including not only residents but also other collaborators, no two works of dementia will be the same, even for those who share the same disease, or who live in the same time and space.

(2) Anthropological Theory of Art and Agency
The paradox of rementia and the limits of embodied agency draw attention to Gell’s anthropological work on art and agency. Since Malinowski’s kula (2014) and Mauss’s gift (2002) described culturally varied and dynamic relations between people and things, anthropologists have continuously explored the features, processes and relations of two entities in any given time and space. Briefly speaking, things are often considered as having a certain distributed humanity (Chua and Elliott, 2013) depending on the socio-political, economic, religious, historical and material relations and context. Similarly, persons are also treated as things that can be sold. We can avoid this by taking a human-centred approach, which invites us to explore the dynamic process of the transformative social lives of things as well as persons. From being just a thing, to a gift, to a commodity, to becoming invaluable belongings and personified entities, things go through their own affective and transformative ‘social lives’ as they are circulated, reinterpreted and recontextualised by particular temporal and spatial contexts (Appadurai, 1988). This perspective which emphasises transformative ‘biographies’ and the affective power of things acting upon persons, other things and making new social contexts (Hoskins, 2006, p. 74) can be further extended to art. Gell identifies such agentic power in art as agency defined as ‘social relations in the vicinity of objects mediating social agency’ (1998, p. 7). He claims that there is no difference between people and art in that they both affect the viewer to bring about new social relations and consequences. Accordingly, Gell (1994) emphasises the importance of studying social process in the making, and the ways in which artworks are circulated, reproduced and have an effect on our perception, understanding and socio-cultural
imagination. Strongly objecting to the semantic, aesthetic and/or abstract understanding of works of art outside of the social context and relations, he stresses the agential intention, causal effect and transformation of works of art. It is therefore not surprising that he criticises people for using terms such as ‘object’ or ‘art objects’ on the grounds that they are used as mere ‘sign-vehicles’ or as kinds of ‘culturally endorsed aesthetic response’ (Gell, 1998, p. 5). In other words, he rejects aesthetic-centred evaluation dominated by art institutions or art professionals because they overlook the transformative and performative and more importantly mediatory and affective roles of works of art in social relationships. For him, works of art are not merely objects of societal aesthetic value or appreciation, nor are they just abstract, symbolic signs to be decoded; instead, they ‘embody complex intentionalities and mediate social agency’ (Hoskins, 2006, p. 75). Accordingly, to appreciate art he argues that in any given context, we should know the social relations and biographical transformation of social agents, what he calls ‘indexes’ and their effects in any given context.

Gell’s concept of agency can be useful in the dementia context by allowing us to revalue works of dementia based on their aesthetic dimension and to explore creators in terms of their agentic creative force. However, there are critical risks in his theory in terms of his assumption of personhood and the way he approaches works of art. First of all, Gell implicitly assumes that the subject who is doing, acting and practising is a person with intention and cognitive ability. He has understood agency as anyone or anything ‘who/which is seen as initiating causal sequences of a particular type, that is, events caused by acts of mind or will or intention’ and ‘causes events to happen’, so an agent becomes ‘the source, the origin, of social events’ (1998, p. 16). Coming back to the ethnography, the way works of dementia are organised and the ways in which those affected experience life are mainly ambiguous, contingent, prereflexive and collaborative. Needless to say, my understanding is also conditioned and limited. I only partially know how Ayla perceives me through her expressive performances. Despite her laborious efforts, I am barely recognisable in her portrait, other than as some abstract lines and shapes. Daniella’s delicate talent of crafting the Victorian Lady and putting it on the plate are unpredictable, improvised and contingent. The plate is removed for firing and unfortunately the figurine is never put back on the pedestal. Rachel, Daniella and Daniel’s obsession with particular things, images, colours or patterns can only be slightly explained through their aesthetic skills or intentional engagements. Needless to say, their neurocapacity, the capacity of exerting various cognitive functions, representing the state of health in the brain, cannot explain their embodied, prereflexive and social relations with things and environments. It is worth
remembering Strathern’s description of partial connection. She explains the ways in which the Melanesian people deal with the complexity of social life, saying that ‘it is neither singular nor plural, neither one nor many, a circuit of connections that joins parts that cannot be compared insofar as they are not isomorphic with one another’ (Strathern, 1991, p. 54). The present always remains an unknown moment only ‘partially connected’ with the past and the future by retrieving the here-and-now (Hastrup, 2013, p. 9). Likewise, the ethnographic present where works of dementia take place is uncertain, ambiguous and indeterminate in any given time and space. All actions, interactions and movements in works of dementia are inherently embedded, interwoven and in place in the condition of co-dwelling before residents with dementia even begin their works. Because of these entangled relations and openness, the making of works of dementia are not linear in succession, nor can they be set up on the spot; rather, it requires ongoing readjustment and response to the ever-changing biographical, organisational and material circumstances.

Secondly, the way in which Gell has traced this agency is based on abductive reasoning, or, what he calls, ‘abduction of agency’ (1998, p. 36), which starts from the final works of art. By referring to Klee’s definition of artists who do not just reproduce or repeat their own ideas but who ‘join with and follow the forces and flows of material that bring the form of the work into being,’ Ingold rejects Gell’s ahistorical approach in his unpublished paper Bringing Things to Life (2010b, p. 10). Whilst Gell’s conception of agency in art involves a ‘double reduction’ by ‘backwards reading’ in order to find the ‘causal connection running from the object to the agent,’ Ingold argues that art as ‘making’ emerges through ‘forward movement that gives rise to things’: not by abducting but by improvising (Ingold, 2013b, p. 21). Accordingly, this backward approach puts works of art as secondary agents, meaning that their agency is conditioned by the primary agency of agents, namely human intention and ability.

Thirdly, the stories of individual residents are no less complex than the materials or the environment. Residents with dementia whose artistic skills and abilities may have deteriorated or who have little or no experience at all in the making of works of dementia, require imaginative and creative improvisation above all else. While Gell’s understanding extends the concept of agency beyond humans by exploring the interactions between interspecies, his scope of agency has not focused much on the critical condition of the human, namely, the deterioration of bodily functions such as those that occur in dementia.
Works of Illness and Outsider Art

Over the past three decades we have witnessed how illness narratives represent a person’s struggle to live a meaningful life whilst enduring illness, beyond what biomedical stories have to say (Kleinman, 1988; Hydén and Örulv, 2009; Frank, 2013). Recent studies from the sociology of art and medicine also show how visual images can express the first person’s meaningful illness experience and make sense of them (Radley, 1994; 1999; 2002; 2007; 2009; Bell, 2002; 2006). These expressive and performative artworks play a significant role in giving meaning to the illness experience, providing a platform where illness allows us to communicate with the social and to influence social practice by mitigating social suffering, prejudice and stigma. By associating art, medicine and social action, medical sociologists shift from the study of ‘the artwork itself’ (Becker et al., 2006, p. xiii) or ‘art worlds’ to ‘arts-in-action’ (Acord and Denora, 2008, p. 223), asserting the important role of art as ‘a medium of social relations and a proxy for forms of expression’ in social life (Mangione, 2013, p. 31). In particular, Radley claims that illness is neither a shameful body experience, nor is it the object of stigmatisation. For example, by using the shocking images of removed women’s breasts from the Breast Cancer Fund’s Obsessed with Breasts campaign in 2000, he demonstrates alternative interpretations of the illness, arguing that the ways of seeing illness must be reconsidered not only aesthetically, but also politically, ontologically, morally and ethically through works of illness (Radley, 2009). However, just as with Gell’s theory of agency, Radley’s perspective is limited to the reflexive, cognitive and intentional capacity of the ill.

While works of illness focus mainly on the agentic abilities of art and the cognitive and performative capacity of the maker, Outsider Art (Cardinal, 1972) contributes to the critical development of the concept of art, reflecting individual and idiosyncratic aesthetic talent beyond individuals’ mental capacity. Art Brut, which first appeared and was theorised by Jean Dubuffet through the Art Brut exhibition of 1949, refers to artworks produced by psychiatric patients, and was later translated into the term Outsider Art by Cardinal (1972). It is characterised as a ‘mode of independent art making’ which is triggered by a strong idiosyncratic, subjective, secretive and creative impulse, reflecting a creator’s way of perceiving and understanding the world in their own consistent and coherent way, which is often deviant and strange to the public (Cardinal, 2009, p. 1461; Prinzhorn et al., 1972). In particular, Cardinal insists on characteristics of ‘the anti-conventional nature of the art making itself, its idiosyncrasy, its often unworldly distance from artistic norms, as well as from commonplace experience,’ that of an ‘art of unexpected and often bewildering distinctiveness’ (2009, p. 1460). It goes without saying that Outsider Art constantly attempts to include the
mentally ill in to society via their artistic and creative power (Andrada and Thompson, 2006). Indeed, it must be appreciated in terms of unravelling human aesthetic capacity, even with psychosis, arguing that art appreciation is not ‘a peripheral supplement to human experience but [...] a privileged medium of human contact itself’ (Cardinal, 2009, p. 1466).

However, the scope of Outsider Art is narrow and falls short of understanding the creator’s methods of engagement in art making in terms of the situational, relational, temporal and open-ended. It pays more attention to the characteristics of individuals’ artistic idiosyncrasy through backward reading from the final artworks. Accordingly, as Cardinal emphasises, ‘Not all autistic persons can be Outsiders’ due to, for example, the lack of idiosyncrasy (ibid., p. 1466). In contrast, as seen with Ayla, Rachel, Jacob, Daniella, Chaya and Daniel, the ways in which residents with dementia engage in and with works of dementia is diverse, improvised, and contingent; it is not only for the expressive and aesthetic, but also for interacting with, communicating with and corresponding to people, materials and the here-and-now surroundings. Namely, works of dementia cannot take place without the collaborative work of staff, other residents, things, illnesses and environments. Furthermore, unlike Outsider Art which is often created in isolation, works of dementia are particularly related to the here-and-now, to the temporal. The ways in which residents with dementia practice works of dementia vary in relation to personal biography, social and material environments and most importantly to the cyclical nature of dementia that is part of the condition of the here-and-now. Whilst Outsider Art can be appreciated in terms of its aesthetics, transcending time and medical condition, works of dementia are inherently conditioned by their idiosyncratic illness experience and their social and material relations with the surroundings. More importantly, while Outsider Art is limited to the person who has artistic talent and skills, works of dementia are open to every participant. They emerge in the process of interaction and encounter in the condition of co-dwelling.

4. Thinking Agency through Making and Line in the Context of Co-dwelling

How do we approach the complex and experiential dimensions of works of dementia? Do we have a language for understanding its complexity? Previous perspectives on art and agency are not helpful for demonstrating the complex, temporal, situational, and relational works of dementia. The following attempts to shed new light on agency in art in dialogue with Ingold’s concepts of making and line.
Building upon Klee’s idea of ‘form-giving’ (1961, p. 457), which brings something from absence into being, without falling into the temptation of simplifying the practice, Ingold understands making as ‘a process of growth’ and the maker is ‘a participant in amongst a world of active materials’ (italics in original), emphasising that:

Far from standing aloof, imposing his [sic] designs on a world that is ready and waiting to receive them, the most he can do is to intervene in worldly processes that are already going on, and which give rise to the forms of the living world that we see all around us – in plants and animals, in waves of water, snow and sand, in rocks and clouds – adding his own impetus to the forces and energies in play (Ingold, 2013b, p. 21).

Materials and environments do not just exist. They are ‘ineffable’ (ibid., p. 31) in that they cannot be predesigned in terms of their malleability and transformability beyond established ‘concepts’ or ‘categories’ – such as Daniella’s use of the plate for a pedestal – and affective force to the maker – such as Ayla’s feeling of anxiety caused by the environment. Given that understanding, I argue that works of dementia are made out of creative improvisation, bringing things to life and at the same time affecting things, people and the environment. As Ingold notes (2014), creativity is not the final outcome of unprecedented ideas, nor does it start from absolutely nothing; rather, it generates in the process of a continuous attending to the world in formation. It is not necessarily already given but is rather the action of engaging with a world that we are reaching out to from the unknown, and thus there is no mastery. Here is the point where culturally improvised creativity plays a significant role in this form-giving process: although residents with dementia may retrieve and call upon (remaining) skills, memories and abilities that have been sedimented and embodied within them, they all, to some extent, have to improvise as they enter a world, involving the use of untrained, pre-reflexive and/or socially embodied bodily apparatus. In this sense, engaging is a way of form-giving that always involves intersections, connections and encounters alongside obstructing, avoiding and parting with others, things and the environment. For example, drawing is not the simple stroke of a brush but requires diverse preparatory arrangements, such as scheduling, organising available staff, volunteers and materials, creating an appropriate environment, providing attentive care and so on. Accordingly, if we follow this performative enacting and responding, we encounter Ingold’s ‘lines’ of making and growing consisting of bodily movement, expressive performance and their trails (2007, p. 1). As the creation of works of dementia proceeds through interactions and encounters within one’s surroundings over time, the lines become more and more entwined - ‘bound together in the knots’ - and ‘become caught up with other lines in other knots’ (Ingold, 2007, p. 113; 2015, p. 15). The entangled lines of the web represent not only enmeshed relations between people,
non-human entities and environments through movement but also ‘the conditions of possibility’ that allow the lines within the web to grow: that is creating a ‘meshwork of entangled lines of life, growth and movement’ (Ingold, 2011, pp. 63, 85) or ‘lines of becoming’ in Deleuze and Guattari’s words (2004b, p. 323).

These heterogeneous, enmeshed and contingent relations in the field of action that generate new formations and conditions of the present in response to uncertain and undetermined circumstances are characterised as ‘assemblage’ (Deleuze and Guattari, 2004b) which has been further elaborated on by DeLanda (2006). Creative assemblages of drawing, for example, consist of particular kinds of social and creative components in practice that include materials, organisational bodies, staff, tools, the environment, music, wheelchair, coffee, biscuits, individual moods and residents in care home settings. As DeLanda mentions (2006, p. 40), creativity is based on ‘individual singularity’ in that ‘the ontological status of any assemblage, inorganic, organic, or social is […] unique, singular, historically contingent, individual...’ Within assemblages they are not just stand-alone but are entangled and interwoven in relation to one another and continuously changing through interaction and encounters. Because of such complexity and openness, the present is always unbounded and undetermined, and therefore always remains partially unknown. It is difficult to know what a person with dementia will choose to draw or which colour of paint or pencils she/he will use until we see them in action. In this regard, following bodily movements, expressive performances and their trails within creative assemblages is a useful tool for demonstrating processes and relations that allow the researcher to shed light on such complexity (Marcus and Saka, 2006).

5. Agency as Creative Entanglement

I have attempted to understand and illustrate the ways in which residents with dementia in institutional settings experience their day-to-day lives and one of the ways I approach this is through the use of their participatory everyday activities in art and their materiality as ‘works of dementia.’ To conclude, all residents experience works of dementia in a significantly different way, not only because of their idiosyncratic biographies and personalities, and the cyclical nature of dementia, but also because of the ways the Home organises and facilitates them in response to ever-changing individual situations and available social and material resources. More importantly, because of the condition of co-dwelling, works of dementia are experienced and facilitated not as mere individual aesthetic activities but rather as creative entanglements among people, things, and environments.
These assemblagic works of dementia are characterised as ambiguous, improvisational, relational and collaborative at the organisational level. They are ambiguous in that the way in which staff organise and facilitate activities cannot be predetermined. They are improvisational in that no original plan works as expected. There is no predesigned script to follow (Hallam and Ingold, 2007). It demands continuous improvising in response to ever-changing present situations. They are relational, referring to the way staff work - particularly when arranging seats and talking to residents - to residents’ relations with working partners as well as their biographies, personal preferences, personalities and the cyclical nature of the illness within the context of co-dwelling. They are collaborative in the sense that staff do not see a work of dementia as an isolated single activity or an individual task, but rather as something which is made up of the entangled interactions and encounters with the lives of others, things, and environments.

From the perspective of people living with dementia, it is true that they are to some extent lacking self-sufficiency with regard to their vulnerability and dependency. However, through works of dementia they participate in collaborative art-making, not only by using remaining or inherent talents, skills and abilities, but also by sharing and distributing their loss in the context of co-dwelling. Works of dementia are performed and enacted by individual residents who bring with them their own unique embodied skills, histories, illnesses, creative imaginations and untaught talents through diverse entangled relations and encounters with their worldly surroundings. In these processes, new forms of affective, expressive, performative and transformative works of dementia emerge through continuous interaction and encounter responding to the here-and-now situations of the personal, social and material. In this regard, I share Ingold’s critique of the recent disproportionate concern over completed products, their usages and circulations which result in neglecting the actual process of making. In *Making and Growing* (2014, p. xiii), Hallam and Ingold insist that our understanding of materials, design and creativity should focus not so much on the relations between makers and the finished objects, but more on the complex and entangled process of the ‘becoming of persons’ and ‘becoming of things’ in any given time and space.

The ways in which residents with dementia engage in and with works of dementia require us to understand not only the singularity of individuals based on unique medical and historical experiences, but also their co-responsiveness to people, things and environments. For Ayla, taking part in art-making is not just the object of the action, but the means by which she is able to interact with and attract attention from others. Likewise, for Rachel it is the means by which she can now communicate with her surroundings and more importantly with her family. At the same time, the process
of her engagement with works of dementia is a co-journey with her husband. However, because of the cyclical nature of her illness and Jacob’s own medical conditions, their journey is ambiguous and unsteady. This day could be their last but, hopefully, they will have many more, and so works of dementia for them are not just about aesthetics, but are also a medium through which to communicate and a testimony by which they pass through the here-and-now. For Daniella and Chaya, I have illustrated works of dementia in friendship that offer emotional support as well as maximising their co-creative force by being together. Daniella’s undefinable yet improvised creative art-making of putting her Victorian Lady on the plate cannot be explained without such contingent, improvisatory and creative entangled encounters, relations and interactions. Daniel’s engagement demonstrates not only his embodied skills and abilities but also untaught and prereflexive faculties.

Consequently, this ethnography reveals that the foundation of their creative force is different from other works of art across illness contexts in terms of their dependency and vulnerability as a result of the illness. The symptoms and signs of dementia are not always deteriorating, but as Christine Bryden (2005, p. 15) says, fluctuate between degeneration, maintenance, and recovery like a ‘roller-coaster.’ As people undergo different levels of dementia, their works of dementia are continuously transformed. In this regard, it is fair to say that approaching works of dementia requires a fundamentally different approach and understanding in terms of not only aesthetics, but also of the ways in which those affected engage with works of dementia in the context of co-dwelling.

Accordingly, I claim that the anthropology of art and agency in dementia needs to focus more on the process of interaction, relation and encounter, and the situation where works of dementia are practised and facilitated. As Hughes mentions, people with dementia are inherently situated and embedded in ‘dementia-in-the-world’ (2011, p. 215), and so are works of dementia. Neither of them are simply expressions of individual intention or remaining abilities, nor is the agency of the artist a self-fulfilling concept; instead, agency needs to be understood from a becoming perspective in the condition of co-dwelling. Accordingly, if a person with dementia is regarded as an agent, this does not simply consist of their remaining abilities, particularly of cognition, reflexivity and consciousness, because agency is immersed in a particular context of co-dwelling and emerges in the process of enacting or responding to the here-and-now personal, social and material surroundings. In other words, it should be understood as a situated-embedded-agency (Hughes, 2011). The trajectory of works of dementia is thus open and involves more rhizomatic becoming or lines of becoming, in that they are enmeshed in entangled relations where there is neither a start nor an end, but in
the Deleuze and Guattari sense (2004b) they keep generating something in unpredictable ways. Therefore, lines of becoming are not movements from point to point, but move along with lines of other movements while dying out, pausing, distorting, intersecting or knotting with one another.
CHAPTER 6 - HOME-DWELLING AND THE MAKING OF AFFECTIVE ATMOSPHERE

1. Placeless Worlds, Total Institutions and Non-places

I want to go home, I want to go home. This is not right. See these people [other residents]. They are not right. I don’t like them. They should not be here. See over there! That man! It’s awful! Disgusting! He needs to go to a hospital. I don’t want to see him here. I get very distressed seeing these people... I am totally in the wrong place (Ayla).

It is early morning in the communal area of the Abraham Unit. Ayla’s appeals to return home flood out of her as soon as she recognises me. She grabs my hands and rubs them, her head moving back and forth continuously. Her swollen eyes are weepy and red, and her voice trembles when she speaks. Leaning her body towards me, she says: ‘I don’t know what to do... I don’t know why this is happening to me. I haven’t done anything wrong... why?’

Like Ayla’s desperate utterances, experiencing ‘home’ within a Home in the forms of longing, reminiscence, expectation or imagination is quite common for people with dementia in institutional settings (Zingmark et al., 1993; Frank, 2005; Fukui et al., 2011). Obviously, for Ayla, home is not merely an assemblage of ‘bricks and mortar,’ nor is it just a container for social life; it is not the same as a household or house, nor does having a shelter mean having a home (Douglas, 1991, p. 289; Cieraad, 2006; Ogden, 2014). Contrary to her expectations, this new place does not appear to be stable or comfortable. To be precise, it is the place where she repetitively realises, experiences and forms why she lives there, how to escape and where, and at the same time she is recurrently reminded, re-counselling or required to adjust to the new environment.

Much study has documented the lives of residents (Gubrium, 1993; Henderson, 1995; Kahn, 1999; Paterniti, 2000; 2003) and of residents with dementia in institutional settings (Small et al., 1998; Barnett, 2000; Nowell et al., 2011). However, there have been few studies that specifically explore how residents with dementia perceive, feel, and adjust to care homes (Reed-Danahay, 2001; exceptions include Paddock, 2015). Previous research has insufficiently reflected the meaning and experience of care homes, conceptualising them as more or less collective, homogenous and static places, regarding those affected as mere passive recipients of care. Three notoriously well-known descriptions of institutionalised care facilities are typical examples: ‘total institutions’ (Goffman, 1961, p. xxi), ‘placeless worlds’ (Howell, 1983, p. 105) and ‘non-places’ (Milligan, 2016, p. 118). Of course, this does not mean these studies come to
incorrect conclusions, but they pay less attention to the complex, enduring and transformative subjective experiences of care homes within a dementia context.

It is worth highlighting two ethnographies, *Shelter Blue: Sanity and Selfhood among the Homeless* (Desjarlais, 2011) and *Vita: Life in a Zone of Social Abandonment* (Biehl, 2013), which shed new light on the precarious, entangled and transformative lives in institutional settings. While the former reconstitutes the subjectivity of the homeless mentally ill in Baltimore in the United States of America based on a phenomenological and discourse-centred approach (Wilce, 2000), the latter focuses on a woman’s life story in an asylum in Sao Paulo, Brazil in dialogue with Deleuze’s cartographic approach and microanalysis (Biehl and Locke, 2010). Desjarlais and Biehl do not portray people on the margins as victims of political and culturally driven stigmatisation or of social abandonment by the family and government due to their health deprivation. The two anthropologists instead show the openness, contingency, and entanglement in social life in the making of subjectivity by reflecting their continuous, idiosyncratic responses to and engagement with their immediate surroundings, on their own terms.

Likewise, individual residents with different expectations, imagination, affect, emotion and memory have diverse ways of experiencing Homes over time. Above all, their day-to-day experiences of the Home are always influenced by and transformed due to the cyclical nature of dementia, which is not just continuous but made up of fluctuating cycles of illness and recovery that can change instantly depending on a person’s neuro-physical, social, psychological and environmental conditions over time. In other words, the experience of dementia is not just neurological and personal, but more significantly social, relational and situational (Kitwood, 1997).

This chapter explores the ways in which the day-to-day atmospheres of Home are experienced, constituted and improvised among those living with dementia through ordinary interactions and encounters in Florence House, and its implications for co-dwelling. Building upon an ethnography of how those affected engage in the formation of the affective atmosphere of the Home, this study highlights how embodied sensory perception and knowledge forms this affective atmosphere, which in turn makes residents feel at home. Here I reveal the lived experience of the spatial in relation to time, biography and illness in the process of affective atmospheric Homemaking, arguing that these mundane bodily experiences are potential platforms where ordinary Homemaking is practised as a mode of co-dwelling.
However, these improvised and ongoing actions and responses, which are constitutive and essential to the everyday lives of those affected, are hardly voiced or studied due to our cognitive, linguistic, medical and therapeutic-centred approaches. To explore this, I call for an epistemological and methodological shift. I define such expressive performances as the ‘lived, whole body experience’ which indivisibly consists of inner voices, utterances, memory, emotion and bodily movements (Irving, 2010, p. 25; Robinson et al., 2012; Johnson, 2016), and I consider them without the use of predetermined concepts or classification. Rather than considering them as pathological symptoms or unknowable components of the illness experience, they are considered as the embodied, situated, relational and tangible properties of social life (Hughes et al., 2006; Hughes, 2011) that emerge in the process of experiential and affective practice and response to present circumstances, illness and personal history. Accordingly, I suggest that by drawing upon affective and sensory-focused ethnography (c.f. Stoller, 2004; Pink and Leder Mackley, 2016), we need to pay more attention to how they perform (say, do, and express) and make the affective atmosphere. Consequently, I offer a more appropriate language which staff, residents and researchers can use to communicate about the ways residents with dementia become emplaced without medicalising them, thus developing alternative and mutually beneficial interventions from an anthropological perspective.

In what follows, I shed new light on the three notoriously described features of Homes and then alternatively propose a new concept of Home and Homemaking focused on affect, embodiment and sensory perception. First drawing upon ethnographic examples from three residents, I then explore Homemaking as a process of making them feel ‘at home’ and ‘feel right’ in terms of ‘affective and embodied sensory ways of feeling’ (Pink and Leder Mackley, 2016, pp. 172, 185), knowing and expressing. In conclusion, my findings will be characterised as the generative, the relational, the situational, the temporal and the improvised.

2. Affect, Sense, Atmosphere and Home
As places, long-term care facilities are often perceived as closed institutions (Dupuis et al., 2005) where residents with dementia are not capable of communicating or interacting with others and the outside world due to their loss of bodily functions, language, memory and cognition (Resnick et al., 1997; Chen et al., 2000). Furthermore, those affected frequently experience difficulty in making sense of continuity in place, time and people caused by their unexpected transition into Homes (Woods, 2001; Reed-Danahay, 2001), leading to fragmented and confused experiences in terms of the self and identity (Eggers et al., 2005; Paddock, 2015). Linda Örulv (2010, p. 22)
demonstrates that they more often than not fall into ‘a black hole’ in which they are not sure where they are and have little reference to ‘what to do next or how to conduct themselves’ in unfamiliar environments, putting themselves ‘in a social void’ (Gubrium, 1975; Shield, 1988; Kahn, 1999; Killick, 2002). Accordingly, as dementia evolves, disorientation and discontinuity in everyday practice occur more frequently and medical and therapeutic interventions are gradually taken for granted. Individual private space inevitably and constantly intersects with public space. The boundaries between the two spaces become ambiguous with regard to their functional differences – that of residence and of providing health care, respectively (Rubinstein and Parmelee, 2012, p. 155). As Howell (1983, pp. 105-106) has elaborated in his idea of this ‘placeless world’, such space is characterised by having ‘no memory of self, event or relationship’ related to past experience, by the ‘uniformity of objects in daily use and of spaces’ and by the ‘neutrality of and absence of distinguishing characteristics.’ Residents have less power to personalise or modify spaces by applying ‘rules,’ and spaces are ‘defined only by the collective activities,’ such as conversing or playing chess in the dining room and TV lounge, rather than by personal activities. There is no cultural symbol to recall and share a past collective history (italics in original).

In this regard, personal experiences of the Home are restricted and instead the lives of residents are lives to be monitored, supervised and managed through a medical model, in Henderson’s terms, a ‘hospital model’ or ‘quasi-hospital model as home’ (1995, pp. 38, 124). Accordingly, residents with dementia lose their autonomy, independence and self-control. Their social lives are trapped within the institution. They are placed under the surveillance of a ‘total institution’ in the Goffman sense, that is ‘a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered way of life’ (1961, p. xiii). A number of ethnographic studies, although not wholly focused on dementia care, have extensively reported on the culture of total institutions and the consequences of that approach in institutional homes over the past half-century (e.g. Gubrium, 1975; Diamond, 1992; Dupuis et al., 2005; Wiersma and Dupuis, 2010). Among those, Gubrium (1975, p. 123) particularly criticises what he calls ‘bed-and-body work,’ which staff conduct by performing given tasks, such as administering medication, attending to bodily needs and making beds, which are scheduled by shift and timetable (Diamond, 1992; e.g. Henderson, 1995). It seems to be an inevitable corollary that such unfamiliar places cannot be perceived as residents’ own homes. As such, residents with dementia are frequently viewed as victims of the illness, as they cause a range of difficult situations not only for themselves but also for those who care for them, particularly other residents, family and care staff (Allan and
Crow, 1989). Any resident who interrupts routine or is slow is regarded as a ‘time consumer’ or as ‘troublesome’ (Paterniti, 2003, p. 63). Indeed, Goffman’s total institution has often been regarded as ‘a spatial solution’ by confining and excluding problematic groups of people including the disabled, aged and mentally ill (Milligan, 2016, p. 21). That is to say, the Home is characterised as a place to ‘include through exclusion’ by hiding the problematic from public view (Victores, 2002, p. 4).

In the same vein, recent research on care homes for dementia need to be critically reviewed. Indeed, their understanding is no more than what Marc Augé (1995, p. 104) calls ‘non-places,’ where recurrent interaction and communication remain relatively anonymous, and where the flow of people and things merely ‘pass through’ the environment. As a phenomenon of ‘supermodernity,’ using Augé’s own phrase, time, space, information and even the self are excessive, and individual perceptions remain partial, uncanny and incoherent. Unlike ‘anthropological place’ characterised as ‘places of identity, of relations and of histories’ (Augé, 1995, p. 55), Homes become anthropological spaces of transience and movement similar to supermarkets, airports, highways or hospitals; namely, ‘non-places.’ Accordingly, daily encounters happen in spaces not because of intentional actions and responses but because of the given circumstances shaped by predetermined tasks or daily schedules. In such spaces, life becomes more or less uniform and idiosyncratic individual life is not possible, and due to the constant movement and change, relationships become transient (Twigg, 2000; Reed-Danahay, 2001; Milligan, 2003).

However, in Florence House, residents with dementia surpass this institutionalised and medicalised culture in that different ways of Homemaking unfold along with their lives. Continuous negotiations and transformations occur over how the Home provides quality of care for residents, and the residents themselves, staff and family members continuously live, work, feel, smell, touch, listen, see and imagine the Home on their own terms. That is to say, the everyday lives of those affected and those who care for them are constantly enacted, experienced and improvised within limits and with implications, creating new versions of the Home over time, though the ‘affective qualities of atmosphere-making’ (Pink and Leder Mackley, 2016, p. 175).

To explore this complex and continual transformation of daily life, I understand Home as a continuously contested and negotiated place that is not merely a physical environment or geographical location but is rather intricately embedded in, interwoven with and related to day-to-day social practices, personal biography, situations and social relations at any given time (Gupta and Ferguson, 1997; Low and Lawrence-Zúñiga, 2003). As Rowles and Chaudhury put it:
As we inhabit, act, and exist in places, we create and recreate who we are to ourselves and to others. Being in a place is not to be static but to move around, to perform activities, and, more subtly, to grow into one’s self. And in this process of growth, places play an integral part by giving us the opportunity to express ourselves, to change the place around us, and to be part of a collective memory (Rowles and Chaudhury, 2005b, p. 31).

Needless to say, rather than just representing institutionalised bodies (Kontos, 1998; Wiersma and Dupuis, 2010), the Home in later life still provides the essential social, affective, sensory and material grounds of life experience (Rowles and Chaudhury, 2005a), even within a dementia context (Frank, 2005; Wiersma, 2008). In short, as Williksen and Rapport point out, Home is a place that:

[I]s not taken for granted, is not a given, is not a thing-in-itself, is not exclusively singular, and is not once-and-for all. Hence the necessary emphasis on ‘emplacement’: the way in which the place of identity, of self and society, is continually generated by acts of home-making (Williksen and Rapport, 2010, p. 3).

As such, this study reflects the individual experiential dimension of Home which has been largely unheard of and kept within the bracket of individuals demonstrating pathological signs or symptoms. By revealing the unspoken affective qualities of Homemaking, this ethnography enunciates the ways in which residents ‘undergo’ Home through affect, sense, memory, emotion, expectation and imagination, making new affective atmospheres (Ingold, 2013a; 2013b; 2014; Hallam and Ingold, 2014) during the dementia trajectory. Here, the process-oriented concept of affect, formulated by Spinoza, is particularly useful for exploring the transformative and complex process of Homemaking through on-going interaction, relations and encounters and at the same time to grasp the making of individuality in daily life. That is to say, affect simply characterised as ‘the power to affect and be affected’ allows us to grasp ‘the intensities of feeling that fill life, and form it, across its ups and downs’ (Massumi, 2015, pp. vii, ix). Alongside this, Gernot Böhme and Tim Ingold provide significant conceptual and methodological tools to understand relationships between people, things, and environments through the concepts of ‘atmosphere’ and ‘making.’ Böhme understands atmosphere as something that should not be isolated, but neither is it ‘free floating’; rather it ‘is the reality of the perceived as the sphere of its presence and the reality of the perceiver, insofar as in sensing the atmosphere she/he is bodily present in a certain way’ (1993, p. 122).

Taking the example of Ayla, her feelings of helplessness, hopelessness and anxiety can be understood as her affective atmospheric qualities through which her idiosyncratic illness experience in the Home is created in response to her biography, illness, and
social relation within a particular time and place. Böhme later extends his understanding of the ‘making’ of atmosphere by redefining the concept of ‘making’ to not necessarily mean to produce ‘a thing,’ but rather to make ‘possible the appearance of a phenomenon by establishing conditions’ (2013, p. 4). Accordingly, these concepts of atmosphere and making lay the cornerstone for exploring the social, embodied, sensory and affective dimensions of home in Human Geography (e.g. Anderson, 2009; Bissell, 2010) and Anthropology (e.g. Bille and Sørensen, 2007; Bille, 2015; Pink and Leder Mackley, 2016).

As Böhme focuses on atmosphere-making and its possible affordability from the perspective of ‘making possible’ in everyday life beyond arts and crafts, Ingold provides the ecological perspective. He defines making as a continuous process of integration and engagement with the lives of others and with biosocial surroundings through people’s own embodied sensory perception and knowing and through improvising embodied skills and abilities in relations to ever-changing circumstances (Hallam and Ingold, 2007; Ingold, 2013b; 2014). Therefore, he suggests that making is not necessarily understood as a process of producing a predesigned or finished product, it is rather ‘a process of growth,’ ‘a movement of growth or becoming’ whereby the makers also play a significant role in the ‘world of active materials’ (Ingold, 2013b, pp. 21, 34). That is to say, ‘atmospheres are not as such products but they are produced or emergent ongoingly as people improvise their ways through the world’ and thus they are ‘inhabitants and part of the environments of home they are constituting’ (Pink and Leder Mackley, 2016, p. 176). Likewise, people with dementia are already involved in the making of atmospheres of Homes as co-makers as well as active materials in the formation of co-dwelling.

In short, Böhme and Ingold’s approaches provide not only a new epistemological perspective based on the affective and sensory qualities of life but also new analytical and methodological horizons which emphasise the process and potentialities of homemaking in everyday interactions and encounters. Homes are embodied and experienced through individual affective and sensory bodies, and the atmospheres of home emerge in the process of everyday practice. As such, this understanding of ‘precessuality, atmospheres and environments’ allows us to explore home and Homes as ‘the processual state of place’ and to ‘situate movement both as an experiential and constituting element’ (Pink and Leder Mackley, 2016, p. 177). With such open and entangled lines of movement, embodied, sensory and affective experiences are generated and experienced, and can be understand as constitutive of the affective atmosphere of Home. Likewise, expressive bodily performances based on affect, sensory perception and embodiment are not merely responsive and realised in the
Home, but reflect the ongoing formation of its affective atmosphere. However, due to an individual’s different skills, abilities and ways of perceiving and knowing the world, and due to their situational, relational, biographical, and medical condition, the ways in which individual residents experience Home is both experiential and singular. In the following, I attempt to capture the ways in which the affective and sensory atmosphere of the Home of three residents with dementia are generated and circulated, and how they demonstrate the potentialities of co-dwelling.

3. Developing Home through Affective Atmospheres of Homemaking

(1) Homelessness at Home

This is not me. I used to be an outgoing person and liked to join outings and activities. But not anymore! Not anymore! I am worried... Please, don't desert me (Ayla).

Ayla strongly insists that the Home has never been comfortable, nor is it her real home; instead, it makes her feel frail, hopeless and anxious. At any given time, her desire to go back to her own home and her complaints about the Home are entangled in complex ways with her day-to-day illness experiences and in response to her biography and the unfamiliar and unfriendly social and physical surroundings. Although she has been on antipsychotic medication for a long time, their effects seem to be in doubt. What makes her feel so vulnerable and frightened? Why does she so desperately want to return to her old home? Are her repetitive utterances and behaviours just signs and symptoms of Behavioural and Psychological Symptoms of Dementia? What does the home she asks for actually mean? Is it the home where she was born and raised in Scotland, or the place where she, her husband and her adult children used to live in North London? How is her lived experience of home/Home perceived, circulated and transformed over time?

Ayla’s home no longer exists. The house was sold around the time she entered the Home to cover the fees, yet her house is still alive and keeps coming back to her in the forms of her desire, yearning or imagination, arguably partially caused by her loss of memory and cognition, and by her disorientation and confusion. Regretfully, the Home for her appears to be a fundamental ground on which she feels uncertain, frustrated and unsafe.

The other day I saw that my friend [Julia] was ill and lying down on her bed. She was pitiful... I saw it wasn't right... It was miserable... I am terrified and scared... I do not know what is happening... Just frightened... frightened.
After her friend Julia passed away in early 2013, Ayla often complained of the negligence of staff and was concerned about her own experiential crisis over whether she could be abandoned and sent to hospital to die alone. At that time, Julia - who was over 100 years old - was her only friend and lived just across the corridor. Despite the age gap, they became close friends and stuck together whenever they went out until Julia became ill and bedridden. Because of her critical condition, Ayla could not be with her anymore after she returned from hospital, nor did she get the chance to say good bye. Instead, what Ayla ‘saw and ‘felt’ over the last few days of her friend’s life was enough for her to become ‘terrified.’ Her negative opinions of the Home never changed, although staff tried to explain Julia’s medical condition and her palliative care. Since then, although she cannot remember exactly what happened, her feelings have become deeply sedimented in her body and keep coming back to make her feel vulnerable, insecure and uncertain.

Her emotions about the Home reach an extreme when she sees that her neighbour is in her bed with a nightgown on during the day:

*Look over there, a strange woman is sleeping on my bed. Oh, disgusting! Unbelievable! And no one listens to me. I do not like this place and she is not right. Something is wrong. She needs to go to a hospital or some other place. She is mad... gone already... Ah!*

In the afternoon, there is a festive Jewish ball in the dining room. For the event, Ayla does not want to be rushed. She already had her hair done the day before and has changed her outfit twice, eventually deciding on an indigo jacket with a blue skirt to fit the dress code. Her lips are coloured bright pink. She does not forget to check her accessories and finish her outfit with a watch, rings, necklace, bracelets, earrings, a white hat and a sky-blue scarf.

*I don’t know why it happens to me... I have a terrible fear. I don’t know what to do... I had a beautiful diamond from my mother... I have got a real diamond but now Tracy [her daughter] has it. I have nothing, nothing... I lost my earring... see I don’t have it...*

Although she briefly complains of ‘a terrible fear’ about losing her belongings - in particular, an earring and a diamond ring - these negative feelings are soon overshadowed by the exciting rhythm of music. Laughter rings out through the ball, something I have not come across in a while. However, Ayla’s joy does not last long. When she returns to her room to take a rest, she cannot believe what is happening and is at a loss for words. The ball is still going but her party has finished. To get help she has to walk back to the staff desk, which looks a mile away considering her difficulty walking with her Zimmer frame, caused by a fall and the subsequent hip
replacement surgery. She frowns, mumbling to herself all the way back to the desk. There is nothing I can do except listen to her mumblings and walk at her side. Listening to her, it is not hard to imagine what she is feeling. She desperately and repetitively appeals to me, ‘Can you take me out of this place?’

Since the loss of her friend Julia, I have never heard her using the word ‘friend’ in the Home again. Her attempt to build a *League of Scottish People* (LSP) has not progressed, although staff members encourage her to join social activities in order to meet other (Scottish) friends. Her first encounter with Daniel on the Joel Unit went smoothly, but their conversation did not continue for long. Although they do not intentionally avoid each other, they do not seek each other out either. By contrast, Chemda, who speaks ‘strong’ Scottish English on the same Unit, is slightly different. While Ayla likes to talk to Chemda, the latter seems to avoid her discreetly. The first two members of the LSP – the Head of Activity and an Activity Coordinator on the Abraham Unit – seem to be too busy to meet. These days she hardly sees them to even get the chance to talk to them.

Her frustration does not stop there. The recent physical deterioration of her hip, her eyes and losing a tooth makes things worse:

>See, I am walking badly. See? I never used a stick in my whole life. Ah! I hate it [shaking her Zimmer frame]. My left leg is badly swollen... I can’t walk anymore. Oh. Terrible! I used to be so active. I don’t know what to do. It’s terrible to come here. I need to do something for my leg. Do you know anyone who can see my leg? Look at my leg. My leg is getting swollen. I don’t know... Is it cold outside? I don’t like cold weather like this... If you can do something about it [her leg]... something must be done...

As soon as she grabs my hands, she starts to talk. She sincerely regrets moving into the Home. She describes it as a ‘terrible’ decision. What is worse, since residing in the Home she has consistently lost, been disconnected from and deserted by friends, family and other loved ones. The visits of her three best friends stopped in 2014 due to their personal circumstances, including their own ill-health.

> I don’t get many visitors because this isn’t the place my family and friends came from. They all come from Stanmore... far away from here. I hate this place. This isn’t my home, not like my home... I have a beautiful flat. I have one large bedroom, a sitting room, two more bed rooms... Yes, I have a lovely garden... Yes, I have oak trees, tomatoes... Oh. What a miserable thing my life is! Why does this happen to me? I want to die. I want to die. I will jump out of the window... I will... I will... I mean it.

She desperately and repetitively asks her daughter Tracy whether she can either return to her own home or live near her daughter’s house. She does not hesitate to tell me
she will ‘jump out of the window.’ To her friends she quite often says that she wants to die, and she said this even when she was still with her late husband. She continues to appeal to me about her situation:

Oh! My eyes are terrible... macular degeneration. It doesn’t help me at all... macular degeneration... Have you ever heard of anyone else getting it? My grandmother had it and so do I... I don’t know what to do... I don’t know why this happens to me.

A while later, she takes her bag from her walking frame. She rummages in it to find a mirror to check her lost tooth.

Oh. I lost my tooth... Look...

She hands her bag over to me to help out. The mirror is not there. There are some tissues, notepaper, a couple of outdated weekly programmes, and two fist-sized photo albums of her and her great-grandson. She reclines against the sofa and sighs. It seems as though she cannot bear a second more. Staff members do not seem to help, nor are they kind enough from her perspective; some simply add to her irritation and anger:

I go to speak to one of them [care staff], then they just walk away... They are doing nothing... just sitting down and writing and writing and writing... Ah, terrible...! When I’m going to have a meal they just say wait and wait and wait... awful! I don’t know what they are doing all day long... They are doing nothing! They are always sitting in a chair and writing and writing and writing... They have never listened to me... They are terrible. They do not treat me well... Some are very rude to me. Oh, no! I don’t deserve to be treated like this. It is horrible.

From her lived experience there appear to be few possible interactions with the Home and its staff. As her repetitive choices of words represent, for her, the Home is ‘terrible,’ ‘awful,’ and ‘horrible.’ To make matters worse, as mentioned, her daughter cannot come to see her every day because of her teaching job in a school and the physical distance, although she tries to visit every Saturday. Ayla often confuses the days. Additionally, as her dementia evolves, she has become unable to use the telephone and other electrical devices, such as the radio, TV and electric light-stand. She often attempts to press random buttons, hoping for some miracle, but this does not always work.

I have never thought about this situation. I had a lovely flat in Stanmore. My husband was a well-known gentleman. I was well-educated and elegant... and I used to be so active... and now nothing... Oh my God. It is miserable... I am embarrassed... What a shame! My lips are very dry. I don’t know why... What can I do for myself? I am depressed, I am terrified...
Indeed, Florence House was not her first choice of care home. According to Tracy, she was even worse in the first one, which was much nearer to her daughter’s house. Recently Tracy tried to transfer her from the Abraham Unit to the Christie Wing (a special dementia care unit) by organising for her to have meals and participate in social activities with residents during the daytime. At first, Ayla was quite satisfied with the physical environment, but it did not take long for her to say ‘No!’ As she explained, there were not many people she could talk to and, more fundamentally, she is not like them. Discussions with GPs, nurses and other staff for two to three months had no apparent result. In contrast to their expectations, these events gave her undefinable yet apparent doubts about whether her daughter, as well as the doctors and staff, would try to ‘put’ her away’ or ‘desert’ her without her knowing:

*Please don’t desert me... Don’t put me away... I hope they aren’t allowed to put me away. I am frightened. I am frightened about that.*

From the perspective of her lived experience, Ayla’s life in the Home is awful and unknowable. The reality she undergoes is different to the one she was expecting. Due to her medical condition, her utterances do not follow biographical events, and she cannot explain what has happened to her with clarity. As her dementia progresses, her memory becomes more fragmented and incoherent, her sentences are more often unfinished and repetitive and the boundary of time - of the past, present and future - has become ambiguous. She no longer calls me ‘John,’ as she named me when we became close friends and which substituted the proceeding ‘care boy.’ Recently, she requires more help with her daily routines, including with walking, bathing, eating and socialising. From her perspective, the reliability of people, things and the environment becomes more and more uncertain and ambiguous. Without her best friends or grown-up children, her world of illness does not appear to have a bright future. She is often depressed and withdraws within herself, away from the world of the Home. Her life is, now more than ever, precarious.

However, she is neither a victim of the disease, nor a person dying a social death in the sense of losing her self-awareness; instead she continuously expresses and creates the affective atmosphere of the Home, constituting the formation of its atmosphere in her own right. This is the way in which she feels, perceives, knows and constitutes the Home through her own body. However, because of her medical condition, there is always something inexplicable and unfathomable, yet decisive, to her existential crisis that cannot be defined by any pathological or rational explanation. Namely, it is the atmosphere that affects her in terms of her feeling insecure, hopeless and anxious and
which at the same time allows her to participate in the formation of the atmosphere of
the Home.

This calls into question how Ayla perceives and experiences the Home. First of all, for
her, the people, things and physical environment in the Home are not mere visible and
tangible (living) materials, but are experienced, perceived and known through the
sensory perceptions of seeing, hearing, touching, tasting, and smelling. In this sense,
she is not just an observer or bystander looking at a predetermined world, but
perceives and constitutes the Home through her affective and sensory experience,
projecting onto it her feelings, memories, imagination and desires. As I mentioned in
detail in the Introduction, her present room cannot be compared to her house in
Stanmore in North London. Her room is too small and she has no ‘beautiful’ furniture,
no oak trees or a dog, which she used to have before; above all, the Home is too far
from North London, so friends and adult children cannot easily come to visit her. The
food here has ‘no taste’ and chefs ‘don’t know how to make’ Jewish home meals. Of
course, it is true that her taste and appetite have gradually deteriorated which has
already drawn the attention of care staff. Nevertheless, her behaviour should not be
wholly understood as pathological, considering her different responses to the same
meals served in a different place: the Florence House cafe. The same chef makes all
the food in a newly refurbished kosher-kitchen and uses the same ingredients. The
differences between the dining room and the cafe are limited to their
geographical location and atmosphere. While the former often felt stuffy and humid,
caused mainly by the lack of ventilation and air conditioning,33 the latter is an open-
ended space, the balcony of which is connected to a dementia-friendly memory
garden. More importantly, it is the cafe in which she cannot only avoid her ‘unfriendly’
neighbours and staff, but where she can also meet ‘new’ people (and the ‘right’ people)
in the fresh air whilst eating a piece of her favourite cheesecake. As she puts it, there
are always comings and goings and people here are ‘friendlier’ and even ‘normal.’ In
this sense, her biosocial surroundings in the Home are experienced not only through a
mode of sensory perception, but also through affective atmospheres. Ayla is an actual
participant in a ‘world-in-formation’ (Ingold, 2011,p. 129).

From this understanding, we can infer that she is continuously integrating her here-
and-now sensory perceptions with her fragmented memories, imagination and desires
within her limited bodily skills and abilities. Yet, the inexplicable series of miserable

33 Due to the diverse levels of the illness condition among residents and their needs in relation to
temperature, the Window Safety in Care Homes states that all doors and windows are not allowed to be
fully open due to legal requirements guided by the Health Services Information Sheet No 5: Falls from
Windows or Balconies in Health and Social Care.
events - her unexpected move into the Home, the death of her dear friend, her fall and subsequent hip surgery, the trespassing of her neighbour into her room, eye surgery, losing a tooth and the trial of her transfer - overwhelm her feelings. Likewise, this emotional turbulence resonates within her ‘awful’ relationships with others and the Home. From her perspective, the care workers are all ‘doing nothing, just sitting down and writing and writing and writing’ and only say ‘wait and wait and wait’. In addition, these workers could never be friends, not only because of their unfamiliar ways of speaking and acting, their different attitudes and tastes - in Pierre Bourdieu’s term, their *habitus* - but because of the ways they work. As she says, they are ‘rude,’ ‘do not treat her well’ and ‘never listen to her.’ Her mourning over Julia’s death is still ongoing; although she cannot remember the detail of what happened when her friend died, Ayla’s ‘terrified’ feelings of witnessing Julia’s last days are still vividly embedded in her body. It is unlikely that she will be able to establish the *League of Scottish People* in the future. No one can seem to fill the void left by her dear friends: Julia and her friends from North London. No matter how she tries to avoid neighbours who are ‘not right’ and to make friendships with mentally and physically ‘right’ people whom she can rely on, her efforts always end in vain. She has no choice but to dwell with ‘horrible’ and ‘disgusting’ neighbours and environments. In this way, her frustration and hopelessness have sedimented in her affective body over the course of routine social interactions and encounters which means she does not need to intentionally think and retrieve from memory.

It is no wonder then that due to her progressive dementia and chronic depression she is partially disconnected from her past life and memories, and disoriented in terms of time and space from the perspective of persons without dementia. Yet, it is this very lived reality that she perceives, feels and knows. For her, she is unable to feel comfortable in a Home which is equal to ‘a prison’ that does not allow her to go home (see Heggestad et al., 2013). The air is not only stuffy but makes it difficult for her to breathe because of its hopeless, helpless and anxious atmosphere. Therefore, Ayla’s bodily expressive performances not only emerge in response to her existential precariousness, which is partially unknowable, inexplicable and inexpressible, but also reflect part of the ongoing appreciation and appropriation of the Home within her limited capacity. Accordingly, for Ayla, the Home is not only experienced through sensory perceptions but also through affective atmospheres in which her feelings, emotions, imaginations and desires are grounded and embodied.

More importantly, the ways in which she emplaces herself in the Home offers a site for her future-making in that the affective atmosphere of the Home moves her body forward, although the future, for her, does not look bright. A sequence of unfortunate
events and unfriendly people, of things and environments inherently encompass atmospheric qualities which have to be ‘felt’ (Deleuze and Guattari, 2004b, p. 525). It is with her indivisible body and mind, as Maurice Merleau-Ponty elaborates in his essay *Eye and Mind* (1964), that she feels the atmosphere, suggesting that the self is not a given, but neither is it the author or source of movement. Rather, the self is already and always situated and embedded in movement which emerges in the very process of interaction and engagement. In this sense, while Hughes’s concept of ‘dementia-in-the-world’ provides social, philosophical and moral grounds that are situated and embodied, Böhme and Ingold’s approaches provide a perspective of ‘making possible’ (Böhme, 2013, p. 3) through improvisory involvement (Hallam and Ingold, 2007). In this way, Ayla’s Homemaking is intricately interwoven with the fabric of her relations with others and her worldly surroundings, inevitably immersed in an affective atmosphere that is composed of ‘transpersonal or prepersonal intensities as bodies affect one another’ (Massumi, 2002; Anderson, 2009, p. 78). Although she endlessly seeks an answer to the question ‘why do these things happen to me?’ - whether her existential concern is caused by an inherited disorder or disease, whether her misfortunes are a ‘punishment’ from God (even if she believes she has not done anything wrong) or whether they are fundamentally influenced by people, things, and the surroundings she encounters and interacts with in her daily life - the answer is always ambiguous. It is impossible to know, except through her sensory and affective body, that is at the same time the very place where an affective atmosphere of Homemaking might emerge.

(2) Returning Home through Recollection and Imagination

When Daniel was publically baptized as a Catholic in his early twenties, he was cast out of his Orthodox Jewish family and community. Since then he has been not been able to return home, nor has he been forgiven, as far as he remembers. He was not invited to the funerals of his parents, losing his last chance to see his family and home again. As he says, he has lost all his siblings, his friends, neighbours, and particularly his parents. He still vividly remembers how neighbours and friends treated him at that time, saying ‘Don’t come to me. I don’t know you. Fuck off!’ even throwing water at him. His parents and seven siblings would not speak to him at all; he could not stay at home and they would not let him into the house. He was only given ten to fifteen minutes to ‘come and take away’ his clothes. He had to witness his belongings being packed in a case and ‘thrown out’ of the house. He had no money in his pocket and lost his job. It was a ‘frightening’ experience and a memory he has not tried to retrieve for a long time. For him, home is a paradoxical place he can physically visit anytime he wants with a cab fare as a citizen of this ‘democratic country,’ in his words, but because of his
expulsion and its psychological, cultural and moral burden, it has become an unapproachable place for him. Who thought that his displacement would last forever? In this subsection, based on his imagined journey back home, alongside a joint interview with his daughter Carole, I attempt to explore the ways in which he makes himself at home in the Home by integrating, negotiating and constituting his desires, memories and expectations in relation to the here-and-now institutional setting based on Jewish Orthodox belief and tradition. Concomitantly, I show the ways in which his beliefs and his relationships with his old and new family, things and the place are transformed in the process of his emplacement in the Home.

In his room, Daniel does not have photographs of his parents or siblings. Instead it is full of old books and CDs on the bookshelves, across the coffee table, the desk, and the windowsill and even on the floor and bed. The books are about language, music, theatre, arts and include some historical, psychological and religious texts. It is just like the small library he had at home. His room smells faintly of old books. On the shelves there are pictures of his ‘new’ family, his late wife, his three grown children and grandchildren. After introducing his family to me, he moves to a poster hanging on the wall, picturing a scruffy boy looking at a girl walking along a muddy path behind a three-storey terraced house. Daniel’s journey home begins to unfold as a contingent result of looking at this poster.

*What life does she live...? I have never known... but she looks very sad... the life she has is full of emotions. I love that child... If she’s still alive, she is now a woman of my age... I was born in a place like this slum area. I think this kind of environment does not exist anymore... this building was probably already taken down a long time ago.*

The poster is entitled *Men Should Weep*. Daniel wishes he ‘could cuddle her now.’ Although he is an uninvited guest at an imagined homecoming, his emotional memories are deeply shaped by his family, the home, the streets, and by school friends and neighbours. His eyes look at the girl in the poster and are full of tears. When he says, ‘If she is still alive,’ he pulls her into the present and the girl ages like him.

*When I talk about these things, my body and soul also go on a journey and I come back to you because these things are rooted in my body and memory.... I had an interesting journey below the surface of life and went on to the surface where I am today.*

Following the emotional memory sedimemted in his youth, he navigates his home, the streets and schools he desires to visit. His family was not affluent like his neighbours in the Jewish community, but it was enough for him to have a certain feeling of home,
family and community in his childhood. The whole family lived through a period of great poverty and deprivation during World War II, but also shared all family and religious events together. Rations at the time were commonplace, not a shame nor a disgrace.

I was born in a slum in Glasgow in 1928 just like this... My father was an immigrant from Russia and my mother was the daughter of refugees. She was born a couple of months after her mother’s arrival in Scotland... Queuing up for free food was ordinary at that time... My father was a foreigner without a work permit so he couldn’t work in any English shops... [Above all] because of his poor English... I went to a secular school... I didn’t want to go [but] my family were very strict... I needed to go to school... It was hostile... many times they threw stones at me... After school I used to run home and then rush to a small ‘school’ to learn Hebrew... There was not much time to play except on Sunday... I was not allowed to play on Saturday either.

Daniel’s education in a secular school was tough. Non-Jewish pupils who were taller and stronger than him often bullied him, especially when he was on his way to the synagogue after school. Nevertheless, the synagogue was the place where he could escape from the unfriendly world, get some peace of mind and cultivate his own way of life based on the reading and learning of the Hebrew Bible. A stormy period of adolescence soon followed. After his first ‘intellectual’ encounter with Christianity and several episodes of bullying, he did not want to continue with secondary school. This was his first rejection of home discipline and illustrated that he was unlike his other siblings. As soon as he could work in a local warehouse, he dropped out of school at the age of fourteen. Before he was conscripted to the Royal Air Force he had worked hard, not only trying to set himself up, but also exploring the new world of Christianity. Whilst in the military, he was dispatched to several African countries. It was a good time in terms of meeting people who had different cultures, beliefs and ways of life, enabling him to see the world around him from a broader perspective. He came back home after being discharged from service but his passion for studying Christianity did not stop. Instead, the ‘inner war’ and ‘inner calling’ to know Christianity intensified, leading him to visit churches in the UK - Catholic shrines and Christian heritage sites in Europe - and to experience Christian belief several times himself before being baptized. Because of this, his family and the Jewish community persecuted him. His intellectual journey in seeking the truth about God and humanity involved not only emotional memories, but also a visceral and somatic aching through his ‘mind and body.’

I have not thought about it for many years... it is full of pain for me. Because when I went on this intellectual journey seeking something, I thought, a truth about God and humanity... in doing so I found myself
alienated from my father, my mother, my brothers and sisters and from the community I was brought up in... I found it was all encompassing... your entire mind and body become involved... Even the small cells of your body become involved.

In the same way, he also studied and practised Buddhism, the ‘religion of peace.’ and visited a temple a few times to ‘cultivate love and respect.’

However, after his wife died, he lived alone for about a year and half, became more and more isolated and experienced loneliness. On the recommendation of a friend who was a psychiatrist, he moved to a small nursing home near his previous home in Eastbourne and stayed for about three years. However, due to the distance between the Home and the home of his daughters and importantly, because of the difficulty interacting and communicating with other residents due to their illness and disability, his two grown daughters strongly advised him to move into Florence House. Unexpectedly, his move brought double fortune to the family. Although he struggled during the first two or three months to grow accustomed to his new life in the Jewish Orthodox Home, he discovered new talents in pottery and drawing as well as making new friends. More importantly, his sisters, who were previously disconnected, have come to visit over the past few years, although he is unable to remember.

To sum up, Daniel was born a Jew - proudly ‘a circumcised Jew’ - and became ‘a Christian by intellectual commitment’ through solving his ‘internal, emotional and intellectual problems.’ The home of his youth provides intimate memories of times spent with his family, particularly of living together through harsh economic times, but these memories are overshadowed by his expulsion, making it difficult for him to really access his home again. Two of his sisters still live in Scotland but another sister and three of his brothers died a long time ago. He cannot remember when it was he gave up visiting his home and siblings. He believes it might be too late for him to recover his relationships with them and unfortunately his memory is not good enough to hold on to the near-past and present. Over the past decade he has barely tried to retrieve his memories of home and there have also been no attempts to visit his family in Scotland. Yet no one expected him to be visited by his sisters. He did not expect his journey home to be so emotional, to still be able to make his heart pound. Recently, Carole, his adult daughter, bought a second-hand car so they could travel together to see her father’s siblings and their family. Although he cannot remember exactly what has happened with his ‘old’ family and home in recent years, when he hears about his sisters’ visits from Glasgow to London and an invitation from them and their family, he is able to smile.
Marcus (2006) notes that as we live, work and get older, we develop relationships not only with people, but also with our physical environment in a psychological and emotional way, by remembering, yearning and connecting with a previous sense of self, particularly in old age. Among various places, home is considered the most significant in that it provides a shelter, as well as intimacy, safety, security and familiarity (Chaudhury, 2008, p. 7). Yet home can also be ambiguous, complex and uncertain in the way that it is often connected with unhappy memories or even danger, fear and insecurity (Olwig, 1998), calling for reconsideration of home as an exclusively safe or stable place. Indeed, during Daniel’s recollections, he does not return home but moves around the streets, the schools and the synagogue. It seems there is no particular place he can call his home. The remembrance of his expulsion keeps him from returning home, although this does not mean he lacks the desire to do so. Rather, as ‘a seeker’ for answers to inner questions, his journey home evolves through a place-making in the Home. Rather than just imaginatively being at home, he emplaces himself in the Home in response to his belief, biography, illness and the here and now institutional setting. This resonates with Massey’s notion of place, home and memory (1994, p. 119), where there is ‘no single simple “authenticity”- a unique eternal truth of the place - to be used as a reference, either now or in the past.’ Then Massey suggests that place is continuously renewed and regenerated by particular social interactions in relation to a specific location at any particular moment.

The place where Daniel was born, grew up, loved and played with his parents, siblings and friends is still there, but he can no longer go and visit. His personal beliefs and expectations still contrast with the norms of his Orthodox Jewish family. As Rapport and Dawson demonstrate (1998, p. 8), home is dynamic and complicated in the sense that it ‘brings together memory and longing, the ideational, the affective and the physical, the spatial and the temporal, the local and the global, the positively evaluated and the negatively.’ Given the inherent complexity of affect, memory and expectation, his expressive narrative provides not only an action and response to his illness, biography and biosocial surroundings in given time and space, but also the interpretation and appropriation of his fragmentary memory, emotion and experience in the here and now (Collins, 2003), particularly with regard to painful events and illness (Kleinman, 1988; Hydén and Örulv, 2009; Ryan et al., 2009; Frank, 2013).
discussions as I was once. [But] I am learning about my deterioration as an intellectual person so… That is alright. I am an old man and have lived my life and have done what I wanted to do.

As Daniel’s dementia evolves, his memory and narrative are continually retrieved and reinterpreted, creating new versions of his subjective experience of any given situation within his limited capacity (Carr, 1991). At the same time, due to his short-term memory, it means he must often ask what it was he did before, what the question was or what the last sentence he said was. In other words, he has to keep learning about his own deterioration. As he quotes from what people say, ‘cutting your coat according to your cloth,’ the way he lives, thinks and behaves is embedded in his beliefs while he accepts and adjusts to his illness.

I am a very religious man… I have no fear of tomorrow, no fear of death or illness… and I simply live every day as it is presented to me. When the time comes, when I won’t be able to walk… That is alright… I was born in 1928… money, sex, love affairs, travels… I had a good life. I will go without regret… And also when I die I believe I will encounter the creator that made me. The ‘ontological structure’ will be completed and I have no fear. I don’t want to be ill but I don’t fear it either… Having no fear is very fortunate for an old person… Do you know about ageing and death? I am not an ordinary person, but a unique person. I travel my own way consciously… and also as a moral person setting up value, which is Christian value.

Today he often faces unexpected and disruptive memories, such as those of his siblings’ visits and Carole’s conversion from Catholicism to Liberal Judaism. More fundamentally, he has to face the reality that he cannot practice his belief in the on-site Orthodox Synagogue, neither can he go to church alone without a guardian or carer.

I love to go to the synagogue because I am religious man. But I found I like the Christian God better than the Jewish God. But I can’t go to Church alone. I have a brother-in-law, my late wife’s brother, and he comes a few times a year. Last time he came, we went to a Sunday Mass… he is a churchgoer too… and then we went for lunch.

The way Daniel emplaces himself in the Home is based on his unique way of responding to his present circumstances and illness – acknowledging that ‘that is the way life goes.’ His final journey ends in the Jewish Orthodox care home. Ironically, although he has short-term memory loss, his dementia does not affect the memories of his youth and the Hebrew he learned at that time still seems to be vivid today. He regularly attends Shabbat services in the synagogue and the dining room. He does not need to see and read Kaddish (a hymn of praises to God) because prayer is embedded within his body. Praying Kaddish at religious events is one of his duties at the service.
Of course, he believes that being able to attend Jewish Orthodox religious services is fortunate for him as ‘God is always with me.’ For Daniel the invisible is far more important than the visible. Reading, hearing and praying in the synagogue create a new way for him to communicate with God and practise his belief in an awkward place. As he says, belief, feeling and emotion emerge from his ‘belly,’ his embodied experience, permeating up into the surface and not necessarily from the brain.

For him, dwelling in the Home with his ageing body and illness does not simply mean staying put; he still continuously engages with the experiences of others and his worldly surroundings in relation to his illness, personal history and here-and-now situations. Unarguably his life is now, more than ever, full of schedules, ranging from having a light breakfast, crafting pottery, tasting resident-made soups and joining outings in the afternoon to reading books whenever he has time. He has also become popular among the staff. His short-term memory loss does not interfere with his speech at fundraising events and when celebrities visit. Overall, he is enjoying himself and actively integrating into and engaging with diverse social activities and communities in and out of the Home. There is almost no need to ask him where his home is. That is to say, for him, Home is not simply an outcome of being there, but rather it emerges in a complex process of Homemaking. His home exists in the form of absence - in imagination and expectation because of his exclusion - and in turn, this has enabled him to create his new home in the Home. Accordingly, this absent presence of home is not a conflicting state of being, but is rather an element that he utilises in his formation of the Home.

(3) **Learning, Acknowledging and Recognising**

Deborah, Dorona’s daughter, thought her mother would be strict, determined and domineering for the rest of her life. She still remembers the day she sold her mother’s car. It did not take much to persuade her not to drive at the age of ninety, but when she sold the car, she was surprised at how much her mother ‘nagged’ her about it. Dorona stood up for herself, even with early Alzheimer’s and Parkinson’s disease, speaking to her daughter with a calm strength. Using the bus was not a problem for her but the car was more than just a thing that took her from A to B. For Dorona, it encompassed all the valuable experiences, memories and emotions which cannot be measured, and which are not disposable or for sale. Similarly, Deborah presumed her mother would feel the same about her house. Even after that event, Dorona managed her life independently and relatively well for a further couple of years, thanks to the help of her grown children and of the social workers who came twice a week. However, once her medical condition deteriorated, Deborah was forced to take it seriously. Her
two siblings and her husband discussed what the best option would be. It was not easy and it took a significant amount of time to decide whether or not she should be moved into a care home. The whole family met for almost three weeks without making a decision, primarily because Dorona would always respond with a firm and resounding, ‘No!’ This is why Deborah, her husband Peter, and other family members were quite surprised when they heard that Dorona voluntarily wanted to move into the Home. In this subsection, I attempt to explore the ways in which spaces in the Home are transformed into personally meaningful places in the process of social interaction with others and the environment over time. In addition, I show how this transformation not only influences Dorona and the people around her, particularly within the mother and daughter relationship, but also how it affects Homemaking as her dementia develops. I then argue that positioning oneself in a place like a Home is a social process strongly interwoven with its social and physical surroundings, interactions and relationships. This subsection is based on daily conversations with Dorona and a joint interview with the couple.

It is obvious that moving into a Home in old age is ‘painful’ ‘even under the most favourable conditions’ (Groger, 1995, p. 138). Therefore, Dorona’s decision to move into the Home was an unexpected yet crucial life event for all family members. Indeed, Deborah’s family was planning a three-week holiday, and so Deborah asked her mother to stay in the Home for some respite. Surprisingly, during that time, Dorona made friends with Simon, a ‘giant’ in comparison to her small size. When Deborah and the family came back, Dorona surprised them by saying that she wanted to move permanently into the Home. At first, they doubted her because, like her car, they all knew how Dorona felt about her house. Every corner of its four-bedrooms and garden had been touched up, re-touched and polished by her hand. The apple trees, which she fearlessly harvested at the age of ninety by stepping on a rocking chair, were still there. ‘Mum, don’t scare me again!’ her daughter would say, to which Dorona would answer that she simply did not want them to be wasted. This was not long before she decided to enter the Home. They may have underestimated her, not knowing what she was capable of or what she really liked. Dorona had fixed her hair with pride for her whole life before settling down at the Home. All her memories were embedded within her house, as her daughter described:

She loved her house and garden because she did all the gardening and the housework. She said she would never ever leave it.

However, Dorona suddenly changed her mind during her three weeks’ respite. The couple realised they had to make sure her mother had the appropriate advice and
information to help her make the right decision, even though she had already moved into the Home:

My brother and I [Deborah] couldn’t believe she was happy to leave her house... because she always said “No, Never!” So we thought we should bring her back to make sure she wasn’t making a mistake. We took her home for one night, but she didn’t like it... She wanted to go back... When we left we expected some tears, but no... Nothing...

What surprised the couple was Dorona’s detachment from her home. She simply did not want to stay any longer and returned to the Home straightaway. In addition, the couples were surprised when they got the call from Dorona only a few of months after she entered the Home to say she wanted to get married to Simon. Deborah explained:

She [Dorona] first made friends with Simon... They then became a couple... He was very dominant and on one occasion she rang us from there [Home] and said “he wants to marry me”... “We think we need permission to get married.”

In the end, the marriage never took place due to their medical conditions. In early 2014, Simon had to be transferred to the Meir Unit for more intensive dementia care.

Did the story end there for the elderly couple? What happened to her home as the place where her meaningful life experiences took place, where her memories were strongly embedded within her family, and where numerous events, people, things and environments were interwoven into the fabric of her life? Furthermore, what was it that made her want to move into the Home and to then rush into marriage so eagerly? What now renders her so silent and indifferent? Could these dramatic changes be explained by the deterioration in her medical condition alone? And in what ways can the home be situated in daily conversations between families over time?

According to Deborah, it was Dorona who used to enjoy ‘the night to the full,’ something which is no longer possible due to her medical condition. Dorona always took the lead and cared for her younger twin sister out of the duty given to her by her Orthodox family discipline, even though Dorona was smaller than her. It was Dorona who brought her sister to work at a department store after she started to work there herself as a window dresser at the age of fourteen; it was she who took care of her sister when she came back from social gatherings at night; she who dedicated herself to her country and survived as one of the Women’s Land Army, more commonly known as the Land Girls, milking cows and growing potatoes during World War II; she who invited her husband into the world of Bridge after his retirement, encouraging him to become a Bridge teacher in social clubs; and she who led her husband to
volunteer with her in several social and fundraising societies: the Ladies Guild, the Social Functions Committee, the Unattached Group, the Theatre Group, the Alyth Bridge Club and the Jewish Association of Cultural Societies alongside the Monday Club, helping with synagogue administration. Her family never expected this active woman to become so unbelievably calm and quiet as her dementia evolved.

Howell (1994) indicates that elderly women whose life experiences are strongly interwoven with their domestic activities construct much of their identity and self through their families and homes, creating strong affective bonds between them. In general, the majority of women who have been housewives and who spent most of their time at home show ‘a home-centred attitude and preference’ and ‘emotional association’ with their homes (Chaudhury, 2008, p. 39). As homemakers, their ways of life are deeply sedimented in their bodies and embedded in the home. Therefore, it is not surprising that household chores are still at the core of their life even with dementia (Hellström et al., 2015). Above all, when their identity and social roles have been compromised due to an unexpected life event, such as the transition to a Home, the phenomena of belonging to, longing for or searching for a home, which provides persons with a sense of continuity and a feeling of safety, are further increased (Zingmark et al., 1993). Yet, as Dorona exemplifies, home is contested, negotiated and transformed as social interactions and relationships with social and physical environments evolve in the course of life and the development of dementia.

These days, as Dorona’s dementia with Parkinson’s disease gradually progresses, it makes it difficult for her to manage her daily routines, for example, for her to eat food by herself, due not only to her faltering hands but also to her loss of appetite, cognition and memory. It is an unavoidable and irreversible fact that Dorona is unable to avoid the shadow of her illness. Her biographical memory and related emotions have gradually eroded and become overwhelmed by her illness, and her physical movements have become much slower. Contrary to her adult daughter’s memories and hopes, Dorona has become quieter. She cannot remember Simon at all, nor can she retrieve what has happened over the past few years of her life at the Home.

Meanwhile, as Dorona’s perception, memory and imagination of home change over time, the daughter and mother relationship is transformed too. It is a dynamic process of learning, acknowledging and understanding through interaction and communication not only dementia itself but also the person with dementia called ‘Mother’ (Taylor, 2008; Malthouse, 2011). It is a transformative and persistent process of care that moves from seeing ‘the person-with-DEMENTIA’ to seeing ‘the PERSON-with-dementia’ (Malthouse, 2011, p. 225). For Deborah, Dorona’s indifference to her house goes
completely against her expectations. The photographs of her mother’s house and sound recordings of her memory of the home, which Deborah made for her mother during her first two years at the Home, quickly lose their importance and do not seem to be relevant for Dorona today. They are kept in a box untouched. The surprising call from her mother to get Deborah’s permission to get married was another unexpected event. Needless to say, Deborah has to witness, undergo and endure the gradual changes in her mother’s personality, as she becomes somebody who could be characterised as shy, calm and passive. Previously, Deborah thought that she knew her mother well, but the reality is quite different. As her mother’s dementia evolves, the more she finds she has developed uncanny behaviours. As Shin describes in her novel, *Please Look After Mom* (2011) - describing the journey of grown children searching for their lost mother presumably living with dementia, and finding out previously unknown things about her life, identity and personality - for Dorona, caring for her mother is also a process of learning, finding a method of co-dwelling with this uncanny person. Furthermore, as Shin intentionally uses the pronoun ‘you’ rather than the third-person pronoun ‘she’ or ‘he’ in order to be with her readers, Dorona’s story is not about her journey home alone, but rather a journey that she and her grown children move along together throughout her dementia trajectory. Thus, it inevitably includes not only the practice of ‘staying connected while letting go’ (Braff and Olenik, 2005) but also one of ‘recognition’ (Taylor, 2008) and co-dwelling.

4. Homemaking as a Site for Futuring Dementia

Developing upon the becoming-centred approach in dialogue with concepts of affect, atmosphere and creation, this chapter has highlighted the dynamic, relational, situational, temporal and generative dimensions in the making of an affective atmosphere in the Home. Findings show that the Home is not a one-dimensional or fixed place, but is rather an open-contact zone where diverse meanings and modalities of practice play out in the forms of affect, yearnings, imaginations and expectations. As Harvey says, Home as ‘place’ ‘has to be one of the most multi-layered and multi-purpose words in our language’ (2012, p. 4) in terms of its fluidity, diversity, complexity, multiplicity and unboundedness.

In particular, this study has revealed three residents’ idiosyncratic ways of creating an affective atmosphere through Homemaking in everyday practice, relating to people, things and the environment in a given time and place. For Ayla, the Home mostly remains a void, hopeless and miserable because of her unmet demands and preferences, which are closely connected to her here-and-now medical condition. Although there is nothing she can do herself, her repetitive and desperate appeals not
only represent her own way of dwelling in an unfamiliar place, but also comprise the formation of the affective atmosphere of the Home that influences the lives of others and vice versa. For Daniel, in spite of the fact that his imagined return home brings up painful memories, it offers him the opportunity to reconfirm his way of living and believing as a Christian in an Orthodox Jewish Home, which is barely revealed in daily interaction and communication. However, when he touches the poster, the attachment, belonging and desire embedded within him to return home pours out. For Dorona, the Home is not only a place where she has to emplace herself in a new environment, but also where her family members are required to recognise, learn and dwell with an illness experience they were unaware of before. Above all, Dorona’s story reveals the dramatic transformation in her relation to home and the Home as her relations with Simon develop and as her dementia gradually progresses.

This study has also revealed an on-going process of Homemaking through which residents with dementia emplace themselves in the Home, although it does not always result in happy endings. What is important to acknowledge is that the world experienced, perceived, and realised by people living with dementia is ‘the real world’ (Fukui et al., 2011, p. 46) for those affected, regardless of whether or not their experiences are delusional or confused. This world exists in the ‘here and now’ (Kolanowski et al., 2002, p. 30), rather than being one of ‘living in the past’ (Chaudhury, 2008, p. 100). As Chaudhury describes, ‘it is “now,” the present, that endears the past and creates the future, and in this process the present becomes eternal’ (ibid., p. 100). In this regard, the situational-relational-temporal perspective is vital to understanding the process of Homemaking, over and above simply relying on medical and therapeutic understanding.

Last but not least, this study suggests that residents with dementia do not just live in the Home, and nor does it simply represent what those affected and those who care for them already experience; rather, it demonstrates the ways in which they, as co-makers, as well as co-dwellers, undergo, experience and constitute the Home by creating unique individual, as well as communal, affective atmospheres. Due to the way they engage with the lives of others, things, and their surroundings, Homemaking is always open, contingent and indeterminate in co-dwelling. It implies ‘the possible’ (Pink and Leder Mackley, 2016, p. 183) and allows us to imagine through an improvised involvement (Hallam and Ingold, 2007) that is part of its affective atmospheres. Rather than looking at the moments of transition and transformation as closed events or temporalities that can be measured and analysed, they emerge in the process of making affective atmospheres of the Home. People move through their worldly surroundings by using embodied sensory perception and by improvising their
embodied skills and abilities in relation to ever-changing circumstances. This finding suggests two important facts, that moments of change are already made by those who participate in the events, and more importantly, that they reveal a potential site for those ‘to affect and be affected’ in the way that ‘one always affects and is affected in encounters... through events’ (Massumi, 2015, p. ix) in the condition of co-dwelling. For Ayla, repetitive appeals demonstrate not only her feelings of existential insecurity, but also allow alternative social binding, attachment and belonging to someone or something she can trust. For Daniel, his imagined journey home leads him to realise his displacement, re-confirming his mode of co-dwelling with his belief in an unexpected place. At the same time, living in the Orthodox Jewish Home surprisingly brings him back to his ‘old’ family and home, although he does not remember them due to his loss of memory. In the case of Dorona, the relationship between daughter and mother, or between caregiver and care-receiver, are never static, nor are they linear or determined. The relationship can become combative, custodial, cooperative, and cohesive (Ward-Griffin et al., 2007). In other words, it is an open-ended and ongoing dynamic and their relationship is continuously re-defined, re-imagined and re-constituted in the course of day-to-day interaction, although in ways that are often unpredictable, strange or unknowable.
CONCLUSION: LIFE CONTINUES WITH DEMENTIA

1. Futuring Dementia: Loss as a Condition of Co-dwelling

Dementia is often taken for granted as loss caused by a trajectory of bodily and mental degenerative abnormalisation in language, rationality, personality and behaviour (Brown, 2016). Fear becomes the ever-present synonym of dementia and is deeply embedded in our value judgement, perception and understanding of the illness, making those affected and those who care for them socio-culturally, politically and medically marginalised, stigmatised and vulnerable.

However, as Margaret Lock (2013, pp. 5-11) points out in The Alzheimer Conundrum, even Alzheimer’s disease - ‘the most commonly diagnosed subcategory of dementia’ - is ‘an elusive phenomenon’ due to its ambiguity and complexity in terms of localising the cause, and the entangled and ambiguous relations between dementia and mind, and between dementia, ageing, and numerous other genetic, political, pharmaceutical, socio-cultural, economic and environmental factors. In other words, there is no simple and single causal relation between the numbers of neurofibrillary tangles and amyloid plaques in the brain and the signs and symptoms of dementia (Rose, 2009, p. 76).

Over the past three decades, the work of Kitwood and his successors have contributed remarkably to revealing the continuous vitality of the enduring body. By demonstrating remaining intact normality, they show that people are able to cope with an irreversible illness beyond physical, linguistic, cognitive and psychological degeneration. As Hydén, Lindemann and Brockmeier (2014) insist, Kitwood’s legacy contributes to shedding new light on the multi-layered transformations of subjectivity, agency, identity and personhood ‘beyond loss,’ providing new empirical, practical and theoretical approaches. It seems to be a corollary that critically developing upon Kitwood’s personhood, most previous studies of dementia focus mainly on discovering remaining intact bodily abilities and functions, seeing individuals not as sufferers but as active survivors over the course of dementia. In particular, rather than asking what those living with dementia are, they pave a new way of approaching dementia epistemologically and methodologically by focusing on what and how they act, speak and respond in relation to their ever-changing worldly surroundings.

However, this is the paradox of Kitwood’s legacy as I have strongly argued throughout this thesis. By transcending loss, his assurance of rementia - a belief in the possibility of physical, neurological and even mental recovery if conditions were met - has ironically led him and his successors to focus mainly on inherent human potentiality that has not been damaged or still functions. As a result, in his autobiographical essay Taylor (2007,
p. 106) criticises, the ‘half empty’ illness experience of loss is undervalued and even stigmatised as abnormal.

In contrast to prevailing perceptions and understandings of loss, my decade-long involvement with the Home has raised a central doubt: *Neither those living with dementia, nor those who care for them have ever been beyond loss; rather, they are always alongside it.* In other words, loss is not neutral in the dementia context. Unlike a malignant tumour or cancer, it cannot be removed from the host body. Instead, dementia is a term that is value-laden in that it not only refers to bodily deterioration but also embraces socio-cultural, historical, political and medical judgements that ought to be controlled, managed and governed. This complexity of dementia calls for a seismic change in the ontological, epistemological and practical, all closely interwoven.

A pivotal question in this study is therefore how to challenge the taken-for-granted concepts of loss and abnormality. I do this by problematising the familiar in five different dementia contexts: ethics, repetition, time, agency and emplacement. Accordingly, the long, ongoing and experiential processes of learning, knowing and reflecting have been intensified by Canguilhem’s understandings of the normal and the abnormal. Rather than disregarding loss as abnormal, I have reconceptualised it in the process of making a new state of normativity in response to endlessly changing personal conditions and worldly surroundings. However, as Nikolas Rose (2009, p. 80) points out, it is impossible to maintain the distinction between the vital normativity of the body and the norms of the social because they are not ‘naturally’ separable. In other words, perceiving and understanding this vital normativity is intrinsically embedded within a broader social context. Here, we witness a calling for a broader understanding not just of biological but also historical, social, political and even ethical ontologies. In dialogue with Ingold and Deleuze’s concepts on dwelling and becoming, this study has critically developed what it means to live with dementia in everyday life. Dementia does not come with a definitive boundary, nosology and classification, nor is the subjective illness experience of dementia fixed or pre-formed. Rather, living with dementia is continuously transformed through processes of interaction and encounter, and in response to the ever-changing biosocial surroundings.

Consequently, this ethnography is an autobiographical and ethnographic testimony to my past decade living, volunteering, researching and most importantly, learning with those living with dementia. Without the participation of those affected and the co-presence of significant others, things, and the surroundings, this work could not be accomplished. Therefore it is also a collaborative co-production with those affected in care home settings. Of course, this has involved an ongoing reflexive journey exploring
the immanent and transformative possibilities of co-dwelling with others. Last but not least, this study focuses in particular on affect, the senses and movement. This does not mean I have excluded inarticulate, fragmented or often out-of-context verbal expressions. I have rather paid more attention to individual expressive and transformative movements from the perspective of bodily affective and sensory resonance with one’s immediate surroundings. I see these movements both as objects of ethnographic study and simultaneously as its tools.

2. The Web That Has No Weaver

Recognising Margaret Lock (2013) and Nikolas Rose’s (2009) perspectives on the ambiguity and complexity of dementia, I have explicated that perceiving and understanding dementia - ranging from the level of DNA and the cell to society - requires us to consider the very human condition of co-dwelling. This calls for a reconsideration of the question of agency or agentic ability based upon autonomous and self-sufficient capacities in the dementia context, arguing that the question is ontologically incorrect because through co-dwelling, we have never been alone. This demands an epistemological shift, asking what works of dementia actually do, rather than asking about what those affected have lost over the course of dementia. Drawing upon Ayla, Rachel, Daniella, Chaya and Daniel’s works of dementia, this study has thus demonstrated the limits and implications of prevailing understandings of agency. What they have in common - Daniel’s repetitive crafting of the head-figurine, Chaya’s reciprocal co-presence with Daniella, Daniella’s Victorian Lady on the cake plate, Rachel’s metaphysical and enigmatic painting, and Ayla’s portrait of me - is that these works of dementia are already situated in a particular social, historical, medical and organisational context. Through storytelling and exhibitions, the processes and relations of works of dementia are densely interwoven, unbounded and ever-changing, even after the session has finished. Here, we witness those involved in works of dementia use not only their remaining bodily abilities and functions, but more importantly, using loss itself either through reciprocally sharing this loss with others, such as Josiah’s modelling for the drawing, or by using it as a tool for generating unexpected, imaginative and creative works of dementia, such as the Victorian Lady. In this sense, works of dementia show that loss is indeed a condition of enmeshed creative entanglement and that those affected are not mere passive spectators but potential co-creators in the making of a dialogue and works of dementia.

In brief, agency in the dementia context is situated and embedded in ‘dementia-in-the-world’ (Hughes, 2011, p. 226) across all situations which involve repeating, waiting or crafting. However, because of the taken-for-granted implications of agency and any
consequential confusion, in this study I would rather not use it. Instead, I suggest agency is perceived, understood and approached in the context of *becoming-dementia*, which is characterised as temporal, relational, contingent and generative. In other words, becoming-dementia is temporal in that those affected as well as those who care for them experience dementia only one step at a time through individual idiosyncratic perpetual resonance in response to ever-changing biographic, social, environmental and medical conditions. It is relational because bits and pieces of the illness experience never form a whole, nor can the individual constitutive be isolated; no part has an ontological (or pathological) significance separate from its surrounding conditions. It is contingent in that just as life is inherently open and unpredictable, living with dementia is inexplicable, indeterminate and often challenging. It is generative in that just as life is inherently open and unpredictable, living with dementia is inexplicable, indeterminate and often challenging. It is generative in that loss in the dementia context is absent yet present (see Leder, 1990) in the sense that those affected may be disconnected, fragmented and lost in terms of their bodily abilities and functions, but their affective and sensory bodies still resonate and engage with the world within their capabilities in a mode of co-dwelling. They are constantly transformed and transforming, simultaneously affected and affecting. That is to say, this ontological character of becoming-dementia holds immanent potentialities to become otherwise.

Accordingly, further research findings in other contexts are summarised as follows. Firstly, becoming-dementia intrinsically implies a central question, which is not what becoming-dementia is, but rather an ethical question of: what kind of becoming-dementia do we think becoming-dementia should become in a co-dwelling condition? As the ethnographic vignette of Ayla’s sleep disturbance and its related care shows, ethics in the Home is far beyond normative ethics and ethics-in-the-committee. Indeed, this ethnography has pushed beyond Foucauldian ethical subject-making so as to reveal the everyday ethics that are embedded, situated, contingent and generative in daily care practice. Ayla’s minute interactions and responses along with her stubborn and desperate appeal to call her daughter, which resonate with the immediate surroundings and with the response and interaction of staff, are intrinsically indeterminate and contingent because of her open and entangled relations with the lives of others, things and the surroundings. This kind of indeterminate contingency and openness inevitably calls for the reconsideration of our limits of understanding which guide us to the inexplicable and uncircumscribable. Namely, ethics emerges through attentive acts and responses where the formation of the ethical subject is taking place, rather than by observing normative ethics.

Dorona, Daniella and Ayla’s repetitive and routinised bodily sayings and doings en route to their morning meal are reconfigured as performative subjectivity by attending
to their singular sensory perceptions, affect and movements which perpetually resonate with their immediate surroundings. In particular, by applying Deleuzian cartographic microanalysis rather than perceiving repetition as challenging behaviour, I have demonstrated the transformative abilities of the body in establishing a new order within its capabilities, reflecting its imminent ontological crises or demands. Repetitive behaviours, gestures and speech are not so much repetitive as recurrent, and more specifically ‘modified, in the sense not of transition from one state to another but of perpetual renewal’ (Ingold, 2017, p. 16). Accordingly, repetition is a critical moment of revelation which emerges in the process of a continuous subjective making through repetitive differentiation.

Temporality in care home settings has also been challenged, arguing that time is no longer meaningful. Indeed, it seems plausible on the grounds that there is no clock on the wall in the Home. Ayla’s watch has also been out of order for more than three years, Gevira has not put hers on for three years and Daniella often behaves as though she is out of time and space. Drawing upon an ethnography of waiting in the communal area, I have demonstrated the ways in which Gayora, Gevira, Ayla, Basha, Chaya, Emmanuel, Yedida, Daniella, Raphael and Ariela interact with and respond to the staff, the Home’s schedule, and their environmental surroundings. Remarkably, rather than just killing time, individual residents with dementia perpetually resonate with the biosocial surroundings in their own time, rhythms, tempo and scale. In this sense, the Home is neither a ‘timeless world’ (Edwards, 2002) or ‘total institution’ (Goffman, 1961), nor a ‘placeless place’ such as an airport, where only transient encounters take place (Twigg, 2000). In fact, waiting is the spatial-temporal revelation of being affected and affecting by those involved.

Last but not least, this study has explored Ayla, Daniel and Dorona (and her daughter)’s Home-making at the Home. It is not surprising that as their lives unfold, the Home, both as a physical foundation of residence as well as an imaginary horizon, is not only lived through but also experienced with affect, emotion, memory, belonging, attachment, imagination, identity and even reverie in the course of daily life. Of course, I do not deny their Home-making may end in frustration (Ayla), fantasy (Daniel) or disappointment due to a loved one’s unexpected and strange behaviour and personality (Dorona). However, as Ingold asserts (2011), undergoing does not mean just to do or to perform; rather, it refers to making or creating something in a different way, even if one is doing and expressing the same activity repetitively. Life moves on alongside dementia.
OPENING A NEW CHAPTER

After submitting the first draft of my thesis, I revisited Florence House one week after Passover (Pesach) in 2017. It had been almost 2 years since I returned from fieldwork. I do not deny a sense of expectation on my part that residents with dementia might recognise me and thus be able to talk about their stories in my thesis. However, my hope was shattered: no one recognised me, except Yedida. Many residents, including Rachel, Ayla, Gevira, Gayora and Jacoba on the Abraham Unit had been transferred either to the Christie Wing or to the Barry Unit depending on their medical conditions and need for medical appliances and staff (Gayora was transferred to a hospital) so as to provide them with the best possible quality of care and life. And then Ariela, Ayla, Gevira, Jacoba, Chemda, Devo rah and Daniella had recently died. Emmanuel was in palliative care. Does this mean that their stories of becoming-dementia have come to an end? I would say ‘No!’ and argue that their lived realities including death are continuously circulated and remembered in daily and social life and constitute its fabric.

Just as she lived on the Abraham Unit, Ayla never became accustomed to her new environment on the Christie Wing. Her appeal to return home increased and she asked staff to call her adult daughter more than ever. As Lynn, activity leader on the Christie Wing, says, we often take for granted that as dementia progresses, the identity, personality and behaviour of individuals dramatically transform, yet from Ayla’s perspective, she maintained her desperate demands until she died. She may have realised her body and self through her lived experiences of vulnerability, hopelessness and threats to health at every moment of her ontological crisis, responding to them in the forms of repetitive shouting, banging, appealing and frowning (see Leder, 1990). In Canguilhem’s sense (1998), this seems to reflect her own way of establishing new norms within her physical and mental capabilities. As Lynn points out, Ayla’s life in the Home consisted of perpetual striving in order not to be overwhelmed by dementia by continually acting and corresponding to her ever-changing surroundings in the modes of, often resistant, bodily performative expression, actions and movement. I feel an indefinable sense of sadness when I hear that her last act could not be peaceful. What I am sure of is that her death does not directly lead to her disappearance, absence or becoming forgotten. Indeed, she continuously reappears in ordinary conversations reminding us of her singular way of dwelling with dementia and her artwork (for more detail, see Chapter 5), although she was often stigmatised as being demented by significant others. Her portrait of me is now no longer an abstract, inanimate and fixed object but something that continually comes to life in the mode of a ‘creative
entanglement.’ As the portrait unfolds towards the world so its relations and interactions continue to grow and entwine (Ingold, 2010b).

Likewise, for Gevira, I am not surprised to hear that until her last moment, her morning walks barely stopped despite significant deterioration in her bodily abilities and functions. Indeed, her walk was gradually limited to the Christie Wing and then her own room during her dementia trajectory. Yet, as she wished, with the help of staff, her daily walk and participation in the religious service were rarely missed. In contrast to Ayla, Gevira chose to live the last stage of her life at the Home and successfully adapted to a new lifestyle as a ‘fearless’ walker. As she gradually lost her language skills, hindering her participation in social gatherings, she adjusted herself to becoming a listener and, thanks to the friends and staff she met in the Home, she was acknowledged as an ‘honourable member’ of the Florence community.

Daniel has become a key figure not only by forming a minyan (quorum of 10 Jewish adult males) for the religious service, but also because of his active participation in the Kiddush: the ritual prayer and wine blessing that marks the start of the (Sabbath or Holiday) meals. More often than not, he forgets and struggles to retrieve yesterday’s memory, but the memories of his youth seem still to be there. As long as his pancreatic cancer and pacemaker do not stop him, he may dance as well. Of course, he does not miss the chance to advise me that I should improve my competence in English if I want to communicate with English people. As usual, I do not complain about his repetition. Meanwhile, in contrast to other residents’ symptoms of dementia which are more or less ‘progressive and pathologically degenerative’ (Davis, 2004, p. 369), for him, living with dementia is an opportunity in that it stimulates his untouched creative aesthetics in painting, drawing and crafting, resulting in contributing to gathering his family together through collaborative artwork. Needless to say, with Daniella and Chaya, their works of dementia are displayed on the shelves and on the wall in the Art Centre. Although recently Chaya has more time to sit alone and read a novel in the communal area, their artworks play a significant role in formation of a dementia-friendly environment in the Art Centre.

Dorona is wheeled into the communal area. Her weakening hands and stiff legs put her into the wheelchair more often than not. Her loss of hearing deters her interactions with her surroundings too. Similarly, Ephraim spends more time sitting in a chair, often dozing. His wit and humour gradually diminish according to his mental and physical deterioration. Yet, communication with him has become more diversified among significant others, ranging from the sound of words to tactile and visual media, such as eye contact and touch.
After Gayora’s hospitalisation, Yedida no longer has cat-and-dog relations with any resident in the Home. Guinea pigs and rabbits are now regularly invited into the Unit, so she keeps collecting a good amount of leftovers for the pets. Of course, another round of hide-and-seek between her and the staff is still expected.

For Jacob, watching Rachel’s deterioration is heart breaking, but he undergoes this difficult time, just as he and his wife have lived together over the past sixty years. Visiting his wife in the Christie Wing becomes a daily routine, just as it used to be for Ephraim. Moreover, over the past four years at the Home, he has studied Jewish life and customs and tried to retrieve memories of his youth. As he asserts, we only live once, and so does his wife’s dementia, which cannot be numbered or represented by statistics. There is no reason not to try a new life before they lose the chance.

In brief, there is no one kind of dementia in the world, so an individual experiences an idiosyncratic dementia in their life only once, but has the possibility of experiencing many different modes depending on how we perceive, understand and approach it. Becoming-dementia is open and thus characterised as one and multiple (c.f. Mol, 1998).

There are new residents continuing to come into the Home, although many of them are much more vulnerable and frail. In response to this, some social activities have had to be adjusted. For example, the Florence House Day Centre (2014), Man’s Discussion (2015), and Reminiscence (2016) are no longer available due to the low participation of residents caused by their cognitive and bodily deterioration, but also because of the bodily frailty of the volunteer organisers of those activities. However, new social gatherings and care programmes keep emerging, such as Namaste, and others develop and rediscover their potential therapeutic and social benefits among participants and their families, such as cooking, crafting, drawing, singing and dancing. In 2016, the Home also introduced paperless care work based on a mobile application that allows staff to input residents’ notes digitally, and Wi-Fi will be installed in individual rooms in 2017. Again, life carries on with dementia and thus my writing never ends.
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