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**Tacit knowledge, time and practice in two
dementia services: an ethnography**

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Abstract

This inquiry considers the importance of tacit knowledge, and how it might be characterised in an NHS memory service and a local authority day-care and respite service for people with dementia.

When investigating the sorts of knowledge that might be valuable in helping individuals affected by dementia-type memory problems, service settings offer good prospects for locating empirical enquiry. Interactions between people with dementia, practitioners and carers invariably occur at points such as assessment, diagnosis and care-giving.

Through in situ observations of interactions between health and care practitioners, people with dementia and carers, the knowledge repertoires of each were considered. This thesis explores how these knowledge repertoires differ, yet when they come together in practice situations it becomes apparent that each individual's knowledge is potentially valuable for making sense of the situation.

In the memory service knowledgeable accounts from individuals and carers regarding when and how memory problems first appeared are imparted to the clinician. This knowledge, along with the clinician's knowledge, is brought to bear in determining memory status. In the social care setting 'getting to know' individuals - whose abilities to articulate their own accounts may be fading - requires spending time together during which a sense of the individual can be gained.

The explicit-tacit knowledge mix in any practice situation is unproblematic unless an account of, or justification for practice is required. Qualities of knowledge that render this impossible are that tacit knowledge is inarticulable linguistically; and, in any given instance there are no known means of differentiating between the involvement of either tacit or explicit knowledge.

To attend to these difficulties an alternative way of seeing tacit knowledge is explored, whereby different understandings of tacit knowledge are surfaced when its relatedness to 'time' and 'practice' is considered. A set of notional knowledge-time-practice convergences are put forward.

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Dedication

This thesis is dedicated to Doug Molesworth (1932-2007) and Barbara Molesworth, my parents to whom I feel immensely proud to belong.

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I would like to thank all of my family for their support, especially Chris, Jono, and Alistair as my proof-readers; and to my wonderful sister Jan for all her practical support and for listening.

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Who Knows Where the Time Goes?

(Sandy Denny)

Across the evening sky, all the birds are leaving
But how can they know it's time for them to go?
Before the winter fire, I will still be dreaming
I have no thought of time

For who knows where the time goes?
Who knows where the time goes?

Sad, deserted shore, your fickle friends are leaving
Ah, but then you know it's time for them to go
But I will still be here, I have no thought of leaving
I do not count the time

For who knows where the time goes?
Who knows where the time goes?

Cloud Atlas (David Mitchell)

“Power, time, gravity, love. The forces that really kick ass are all invisible.”

Fieldnote: 'Kate' talking with a lady with dementia at Oak Hall whilst doing a crossword

"There's things you don't even know you know."

Chapter 1: Introduction

Hidden 'value' in organisations: the background to this PhD journey

In 2005 I worked as a research assistant in an NHS mental health trust on a one-year study of a self-directed teams approach called 'Team21'. The trust's decision to implement self-directed teams was heavily influenced by the Brazilian businessman Ricardo Semler whose story - recounted in his book "Maverick" (1993) - describes the transition of his company Semco from an autocracy to a form of radical democracy. One of Semler's fundamental ideas was about assimilating into his company a set of philosophical ideals that included: personal freedom; individualism; control [of] greed; sharing information and power; flexibility; and employee advancement based on competence (Semler, 1993:5). Semler estimated the way to achieve this assimilation was by moving away from a hierarchical organisation, a process he described as "rounding the pyramid". In the trust where I worked, copies of "Maverick" (1993) were widely distributed amongst staff. It was Semler's account that provided the main inspiration for the trust's then chief executive to describe a trust-wide vision for self-direction, which became known as "Team21". Team21 was premised on the idea of self-directed clinical teams. Efforts to support and develop teams were underpinned by the recognition -

"that these teams, working with carers and users, have the knowledge and skills needed to improve services and gives [teams] the tools and responsibility to make a difference". (Team21 Support Unit, 2005)

The chief executive's characterisation of teams was distilled in a particularly memorable PowerPoint slide from his regular presentation on Team21. The slide of a simple drawing of several stick people represented a team comprised of staff, service users and carers, all with differing roles and experiences yet all members and contributors to the team. The question 'who is in my team?' became something of a mantra during this time, designed to trigger thinking about teams in a broader and more inclusive way.

Implicit in the widening out of the team to include patients was the redefining of the role of patients, service users and carers from being not just recipients of services but also *contributors* to the team. This aspiration was important because

it signalled an idea: that patients and carers bring their own repertoires of knowledge and expertise to the encounters they have with clinicians in a healthcare organisation. Enmeshed in patient and carer knowledge is 'lived experience', a dimension unique and personal to an individual.

The implementation of Team21 was informed by a set of guidance materials for teams on how to implement self-direction. Discussions I had with two colleagues from the organisational development department had started with talking about issues relating to the mechanics of *how* teams were being asked to work. Over time our reflections turned to what this way of working might mean for the organisation. What unintended outcomes might 'pop up', and did a self-directed way of working offer particular benefits that might be conceptualised as a form of value?

Semler assumed the competence, expertise and motivation of the workforce, believing that employees knew best about their area of work and could be trusted to make decisions about what worked best.

"I don't think a company's success can be measured in numbers, since numbers ignore what the end user really thinks of the product and what the people who produce it really think of the company." [...] "Another way of looking at Semco is to say that we treat our employees like responsible adults. We never assume that they will take advantage of us or our rules (or our lack of rules); we always assume they will do their level best to achieve results beneficial to the company, the customer, their colleagues, and themselves." (Semler, 1994:64)

An important idea expressed here is that success does not necessarily equate to a realisable, quantifiable value such as profit. Semler highlights that it is both the end user and the employee, in terms of their respective valuing of an end product and its actual production, which matters.

An interesting point about the Semco phenomenon was that Semler's multi-faceted philosophy was practically operationalised in encouraging and giving permission to employees to organise themselves, and to use their knowledge, know-how and expertise to produce goods on time and to the satisfaction of the end customer. Without the parameters of what might be considered to be usual

organisational rules, employees *did* get jobs done on time and to customers' satisfaction. This raises interesting questions about what knowledge and motivation employees draw on in work settings when they are 'left to get on with it'.

Team-based working - which had become interesting to the NHS trust where I worked - was the subject for research by Professor Michael West from Aston University. West had visited the trust shortly before I started in post. West's pioneering work echoed Semler's basic premise about a flattened hierarchy for supporting teams:

"In team-based organisations the emphasis is not on vertical power relationships, but on achieving a shared purpose and understanding and the integration across teams (West & Markiewicz, 2004). In effect, the hierarchy that dictates power is flattened, and autonomy is distributed across the organisation via horizontal integration. Furthermore, while traditional organisations emphasise stability and continuity through the reinforcement of rules, regulations and bureaucracy, team-based organisations welcome change, flexibility, responsiveness and innovation, allowing them to adapt quickly and competitively to their external environment." (Carter et al, 2008:2)

My exposure to these various perspectives on self-directed teams led me to elaborate on my own 'take' on the interlinked ideas about self-direction, value, and non-traditional forms of teams in healthcare organisations. These thoughts eventually gave rise to the spark of an idea for a PhD. At the end of the evaluation of self-directed teams I had settled on the following thought: since clinical teams are the main human resource of NHS organisations, they as individuals and what they do (i.e. diagnose, treat, and provide all aspects of direct care to patients) represents a form of value that is qualitatively different to the value commonly understood as residing in other assets such as computer systems, buildings, and equipment. For estimating the worth of tangible assets like equipment and buildings, straightforward equations (how many, current and future market value) are appropriate. However, applying this same approach to the valuing of

human resources will provide only a partial account of worth. An equation cannot explain the spectrum or the multi-faceted nature of value in an individual encounter between a member of clinical staff and a patient. In a practitioner-patient interaction it seems that there is something happening that is about the countless possibilities and permutations associated with individual knowledge, past experiences, skills, and the hoped for outcomes that individuals bring to the encounter. In other words, something complex is happening, the entirety of which cannot be articulated or accounted for. The knowledge involved is applied practically, yet is not readily defined through vocabularies currently available:

"Practical knowledge is never tidy, an appropriate language for handling much of it has yet to be developed" (Eraut, 1985)

The interweave between essential components in clinical work of knowledge, experience, practice, and decision-making was the topic for Gabbay and Le May's (2011) ethnography. "Inexpressible knowledge" (Gabbay and Le May, 2011:71) was used to describe the nature of the work which was talked about by practitioners during interviews. Inarticulable dimensions of knowledge are also of significance in relation to epistemic communities - 'Communities of Practice' (CoPs) being one such form, defined by Lave and Wenger (1991:98).

In the run-up to starting a doctorate my interest was the possible value implicit in self-directed team models and how might this translate into worth to the organisation. I pondered on how (or even whether) healthcare organisations 'recognise' the parts of their business that are difficult to articulate, such as intangible components of clinician-patient encounters, ideas, innovations, know-how, and ways of working that are in people's heads. An annual report is one of the key means through which healthcare organisations provide an account of the organisation's work and financial activity, yet these intangible elements are rarely, if ever, alluded to in annual reports.

However, when details of the MERITUM Project (2002) came up during my initial literature searches about intangibles I realised that there was research activity in this field. The MERITUM Project was funded by the European Union and involved researchers from a number of European universities in Denmark, Finland,

Sweden, France, Norway, and Spain. The role of the researchers was to develop guidelines for companies for managing and reporting on intangibles in organisations. In the resultant guidelines developed from the project it was suggested that in practice the terms "intangibles", "intellectual capital" or "knowledge" are used interchangeably to refer to "a set of factors that represent sources of corporate earnings." (Cañibano et al, 2002:10).

In the literature the term 'intellectual capital' is used as something of a shorthand for summarising the entirety of an organisation's value in the terms of its intangible resources and assets. Under the umbrella of intellectual capital is encompassed several forms of capital, defined as human, structural, and relational capital. Intellectual property (IP) is value arising from innovation occurring in any of the domains of intellectual capital. The World Intellectual Property Organization defines IP as referring to "creations of the mind: inventions; literary and artistic works; and symbols, names and images used in commerce." Certain forms of IP such as 'know-how' seem particularly interesting because they are embedded in human beings and therefore may be idiosyncratic and difficult to specify, as well as difficult to replicate.

As I read around the concept of intellectual capital I came across a paper by Habersam and Piber (2003) which I viewed as relevant to my particular interests in intangible aspects of interactions between clinicians/practitioners and patients/service users. The paper reported on two qualitative case studies of hospitals: one in Italy and one in Austria. Through interviewing hospital staff about dimensions of their day-to-day work the researchers aimed to explore and try to surface the intangible dimension involved in curing patients (Habersam and Piber, 2003:758). During interview staff were asked what of their day-to-day work could be quantified; what could be written down; what could be explained/transferred to others; and what could not be explained/transferred to others. It seemed to me that this enquiry represented a thoughtful approach to the empirical study of intangible aspects involved in the provision of healthcare to patients.

My initial forays into reading about intellectual capital and its dimensions seemed to augur well. The idea that intellectual capital was the 'sum' of intangible sources

of value appeared to promise an easy and unproblematic route into the appraisal of intangibles in organisations. This 'promise' did, however, unravel. On further reading, and from discussions with my main supervisor, I began to see that the concept of intellectual capital concept is problematic for several reasons. There is no consistent consensus or agreement about what intellectual capital is or constitutes, a point highlighted in a paper by Nerantzidis and colleagues (2013:169) concerning the myths of intellectual capital (IC):

"There is still an abundance of definitions reflecting different perspectives, roles, component parts and viewpoints that justify the IC definition conglomeration."

Marti (2007:248) suggested that applying a frame of reference used for tangible assets to intangibles is problematic because it creates an impression of: "“intangibles” as assets that can be entered in the books as if they were tangibles". This suggests that there may be grounds for a reconsideration of the term intellectual capital. Traditionally, the term 'capital' resides in the field of financial accounting, yet this may not be wholly appropriate as a descriptor for value associated with intangibles.

The final point to make, perhaps the more critical, is that there is no overarching or central theory for intellectual capital. In a recent systematic review by Evans et al (2015) of 37 published papers on intellectual capital (IC) within healthcare a helpful critique is provided of intellectual capital research and theoretical impediments to the advancement of empirical research in this field:

"Many of the conceptual hindrances outlined above can be linked to the need for stronger or more explicit use of theory in future studies. Although several authors refer to IC as a 'theory', the IC framework does not meet formal criteria for theory development as outlined by Whetten. Rather, the tripartite IC framework is a typology. Furthermore, while the RBV [Resource Based View] and KBV [Knowledge Based View] help contextualize IC as a concept and highlight its importance, they do not offer insights on how IC influences organizational performance and how IC can be developed and supported. Alternative theories are needed to guide hypothesis development". (Evans et al, 2015:6)

The decision I made to discard intellectual capital as my topic seems, in hindsight, a wise one, given that some of the difficulties I may have faced are presaged in Evans and colleagues' (2015) systematic review.

My thinking had moved through several stages. I started by envisaging at a team level the greater freedom afforded by self-direction to exercise expertise to create positive outcomes for patients. I ended up by thinking about inexpressible elements in practice within practitioner-patient encounters, and whether the potential worth of intangible elements in practice might be realised by the wider organisation. The challenge was in how I might focus these ideas and make something out of them for a research project.

My selection of topic and focus

Once I had decided that the challenges involved in empirical investigation in an under-theorised field would be substantial and beyond the scope of what was achievable in a PhD, I took action to redefine the topic and focus for the research. Conversations with my supervisor led me to look more closely at 'tacit' dimensions of knowledge, a topic that had cropped up in my reading of the literature on intellectual capital.

Although my initial focus on intellectual capital had turned out to be something of a dead end I was able to carry some of what I had learned forward: an appreciation of challenges involved in studying intangibles; a greater awareness of the concepts within the field and of the ways that researchers had attempted to investigate intangibles; and some clearer ideas about the components for a study on tacit knowledge and how such a study might be framed. A significant challenge I predicted for my own work related to whether and how it would be possible to declare findings about tacit knowledge given the ineffable characteristics ascribed to it.

When I began to try to formulate my project I had several ideas that I thought of as interconnected. I was interested in the idea that not everything a person knows can be articulated linguistically, and I reflected on the implications of this for interactions between practitioners and service users in service settings. Connected with this, I thought about certain types of impairment that ultimately

bring about the demise in a person's ability to articulate linguistically; dementia being an example. A diminishing ability to articulate must mean that, at some stage, the individual is no longer able to give an account of self. When reaching this point the individual may become increasingly reliant on persons who 'know' her/him to take over the management of particular aspects of life such as managing finances or keeping the person safe. Given that this ability to articulate begins to be lost in individuals with dementia, what sorts of knowledge and ways of knowing might be helpful within services that are supporting individuals with dementia?

An idea that I considered was that the term 'inarticulable' could be viewed as both characterising something about *dementia* and something about *knowledge*.

Dementia, as it develops, reduces a person's ability to articulate. We might say that inarticulation is a characteristic of dementia that becomes more amplified as an individual progresses along a dementia trajectory. Regarding knowledge, it is its tacit dimension that is commonly described as inarticulable.

To summarise my line of thinking: I wondered whether focusing enquiry on a population which experiences articulation as a problem might be helpful for surfacing empirical data about articulation more generally which, in turn, may open up insights into the broader topic of articulation of tacit knowledge.

As my interest had been sparked by ideas about intangible aspects of the practitioner-service user encounter, it seemed an obvious choice to locate my fieldwork in practice settings. From previous and current employment I was *au fait* with the work of memory services and day-care services. I knew that a person's ability to articulate what effect memory problems have on them is likely to be greatest at the early stages of memory problems. A GP with concerns about a person's memory is likely to refer the person to a local specialist memory service for further investigations – usually a memory assessment. I regarded specialist memory services as representing a key point at which practitioners start to make sense of the experiences of people with dementia and draw on their own repertoires of knowledge.

I came across a small number of clinically oriented case studies reporting on the preservation of knowledge in individuals with dementia (Crystal et al, 1989; Miller et al, 1998; Hsieh et al, 2009). A possible way of describing the nature of

preserved knowledge is that it involves the retention of certain abilities such as playing the piano or painting, which represent individual 'know-how'.

"Previously learned skills or talents can be conserved in the setting of dementia, and demented individuals have been described who maintained card-playing skills, musical skills, painting talent, and word game skills."
(Miller et al, 1998:978)

"Patients with dementia, such as Alzheimer's disease, can continue to play the piano skilfully despite profound cognitive impairment. It has been suggested that this may be because these skills have been well-rehearsed and become automatic motor movements." (Hsieh et al, 2009:301)

These case studies highlight that before becoming cognitively impaired the individual had acquired particular skills or talents, and even in a state of severe cognitive impairment the individual continued to demonstrate these talents. For example, the creative practices of musicianship or painting were preserved even through the period of irreversible cognitive decline these individuals had entered into. These case studies bring to attention a seeming discrepancy between cognitive status and retention of certain capabilities. Even though the passing of clock/calendar time appeared to mark a decline in the cognitive capabilities of these individuals with dementia, the same passing of time seemed not to be a predictor of deterioration or diminishment of these individuals' talents.

Findings from Snowden's (2003) report on the famous longitudinal "Nun Study" of 678 Catholic Sisters in Notre Dame Congregation (aged from 75 to 107) are similarly puzzling. The Sisters who participated in this research underwent cognitive testing in older age and had given prior consent to brain donation after death, meaning that their physical brains could be examined for evidence of dementia pathology at post-mortem. Sister Matthia, a woman who up until her death at 104 years was fully *compos mentis*, was subjected to post-mortem which revealed that her brain showed stage 4 pathology of Alzheimer's disease present in the entorhinal cortex and hippocampus areas (Snowdon, 2003:450-451).

Likewise, in the case of Sister Bernadette, who died from a massive heart attack at age 85, at post-mortem her brain scored the maximum of 6 on the Braak and Braak scale - indicating the greatest spread of Alzheimer's disease pathology

(Snowdon, 2003:452). Yet, during annual cognitive tests at ages 81, 83 and 84 Sister Bernadette had consistently scored highly and there were no indications of mental deterioration. When she was tested at age 84, without looking at a clock or a watch she stated the time within 4 minutes of the actual (clock) time.

Findings from the case studies and the Nun Study establish the following possibilities: that there can be dissonance between individual cognitive performance and the health of the physical brain; and that there can be disparity between an individual's performance in cognitive tests and that individual's expression of particular talents or know-how.

My vision and motivation for the research

My vision for this research was to try to 'trace' tacit knowledge in service settings: to be in situ and actively look for enactments or expressions that might infer tacit knowledge. Trace is an expression that Mol (in Mol et al, 2010) used as a metaphor to describe her explorations of meanings of care.

My motivation to conduct research on the topic of tacit knowledge and within defined service settings relates to several factors: my personal interest in people's lived experience of dementia; curiosity about tacit knowledge as implicit in individuals, perhaps not resting on cognitive capabilities; and an interest in how tacit knowledge may be involved in practice within dementia services.

I started from the perspective of fully acknowledging that tacit knowledge is unseen and ineffable, yet it is enmeshed in phenomena that *is* observable or, at least, accessible to empirical investigation such as everyday practices and conversations. Going into situations of daily, routine practice to observe in situ the essentially 'ordinary' is a typical ethnographic approach and this was the line I adopted. I anticipated that this would allow me to observe and/or listen to aspects including different sorts of practice; the conversations and interactions between people at the respective service settings; arrivals and departures; and behaviours and routines. I also anticipated that I would be talking with people with dementia, staff, and possibly family carers of people with dementia, and that conversations I may have with people would be important in my orientation towards trying to comprehend tacit knowledge.

I considered that my proximity to such interactions, encounters between people, and conversations would provide scope to construct a sensemaking account to represent the data from each service setting.

The location of this research within broader work

Theoretically, my PhD research is essentially located in ideas and conceptualisations of tacit knowledge in Michael Polanyi's work on personal knowledge (1958; 1961; 1966; 1967), from which I have drawn insights about qualities of tacit dimensions in relation to particular practices (e.g. diagnosis), as well as ideas about the interrelatedness of tacit and explicit knowledge.

Harry Collins' (2010) important reappraisal of Polanyi's work in his book entitled *Tacit and Explicit Knowledge*, and also discussed in Collins' chapter in Schatzki et al (2005), cannot be disregarded. Collins' main challenge to Polanyi is that at least some of what is termed tacit knowledge *could* be explicated if there was need or requirement. This said, Collins concedes that not all knowledge can be explicated. The capability of humans to 'improvise' according to the social context (Collins, 2005:125; Collins, 2013:123) Collins considers to be evidence of tacit knowledge, in a form that cannot be explicated.

Empirical and theoretical literature which addresses knowledge as accumulated through, and sedimented in, health and care practice is another important reference point for my work. This includes work by Gabbay and Le May (2004, 2011); Eraut (2002); Liaschenko, in Thorne and Hayes (1997) and Benner (1982; 2001). Their understandings of tacit knowledge seem closely associated and also aligned with Polanyi's conceptualisations of tacit knowledge. Benner expressly espouses Polanyi's conceptualisation of tacit knowledge in her scholarship on nursing knowledge and expertise in practice.

An important empirical text - *Ethnographies of Diagnostic Work: Dimensions of Transformative Practice* by Buscher et al (2009) - is another location for my work. In Goodwin's chapter on anaesthetic practice the conceptualisation of knowledge as embodied is an important understanding in working with people who are in the semi-conscious state of being anaesthetised, that is, temporarily non-verbal. More directly, Moser's chapter about the *Marte Meo* approach in dementia care

settings discusses making sense of behaviours, demeanour and actions of people with dementia who have lost the capability to convey their experiences linguistically.

My work is also located in ideas from Fuchs concerning embodied knowledge, the lived body, lived time, continuity of self, and memory of the body (Fuchs, 2003; 2006; 2016). Specifically, Fuchs' work provides philosophical orientations towards memory, the knowing body, and time as experienced individually. These conceptualisations open up ways for making sense of some observable actions, verbalisations and conduct of people with dementia in my fieldwork settings. Glaser and Strauss' theory of status passage (1965; 1971) and the temporal dimension of passage is another location for my work in that it offers a way to conceptualise important aspects such as turning points, transitions, and the idea of "becoming a person with dementia" (Dhedhi et al, 2014:3). Aspects of my work that consider health and care professionals involved with individuals with dementia I relate to Glaser and Strauss' (1971) notion of 'legitimators' of passages.

A relatively small body of empirical literature has considered temporal dimensions in aspects of the lives of older people, and I locate my work in this body of literature which includes studies about people with dementia (Marshall, 1975; Orona, 1990; Nygard and Johansson, 2001; Vernooij-Dassen et al, 2006; Beard and Fox, 2008; and Svanstrom and Sundler, 2015).

I locate aspects of my work concerned with knowledge performed in health and care practices and its temporal dimensions in recent empirical work by Hopwood and colleagues (Falk et al, 2017a, 2017b; Hopwood in McLean et al, 2014).

It is in terms of ethnographic method that I have come to describe my work, both in respect to the method used, and the how of approaching writing an account of my study (Golden-Biddle and Locke, 1993; Willis and Trondman, 2000). As a researcher engaging with temporality through the doing and writing of an ethnography I align myself with Dawson's (2014) thoughts on temporal sensemaking and the need in fieldwork to accommodate (and live with) different conceptions of time. I have also found Hannerz' (2003) fascinating insights about "site temporalities" (Hannerz, 2003:209) to be helpful in recognising how the

ethnographer faces challenges in acquiring understandings of the field setting, and building relationships in a timeframe that is frequently short when considered against durations of time that those who occupy a setting have for acquiring similar comprehension.

My choice of research settings

My vision was to do my empirical work in two dementia services - one health and one social care. Having identified a social care day and respite care service and an NHS older people's community mental health service I approached the relevant service leads with a summary of my proposed project. Both my 'first choice' requests were granted.

The two services were located in the town of Northwreston in the neighbouring county to the one where I was employed. The NHS specialist memory service was part of the older person's community mental health service. The staff team had offices in the CSD Centre from which some of the clinics and group sessions were run. The rest of the team's work was conducted through home visits and clinics in other NHS premises. The other service was a council-run day-care and respite service for people with dementia, co-located with an intermediate care service and with a respite service for people with learning disabilities in a council owned building called Oak Hall. Service settings for people with dementia, I anticipated, would provide opportunities for me to observe practices in which knowledge was (potentially) significant in care processes, interventions, diagnosis, and treatment. I knew broadly what the parameters were that differentiated statutory health from statutory care services, but went into the field with an open mind to differences and similarities in the two services.

At this stage I was, in a rough sense, conceptualising the services as two places on the service pathway for people with dementia. As a researcher one of the service settings (the NHS service) was used to having students of various disciplines on placement, and it transpired that there was at least one active research project (other than mine) in the service during my fieldwork. Regarding the council-run social care service, my PhD project was the first research project of any kind that the service had hosted.

Method and overall data collection strategy

Ethnography was the method I employed, chosen in favour of other approaches that may have qualified as being suitable. A panel member at my Progression proposed that an observational approach might be suitable, but I was drawn to the essential narrative, storying tradition of ethnography. I anticipated that the conversations I would have and the interactions and everyday activities I would observe during fieldwork would lend themselves to being told using a narrative-led genre. An ethnographic approach also seemed to align with my motivation to 'give voice to' tacit knowledge.

The vision to 'trace' tacit knowledge might be likened to picking out the form of something, or finding signs to suggest some activity or mechanism is operating. Conversely, tracing would not be associated with attempting to isolate something or extract it from its surrounds. My overall data collection strategy was, therefore, to deliberately expose myself to as many opportunities as possible for observing and noticing the details of activities and interactions within these two practice settings, so that ultimately I could build a narrative that would carry these ideas and possibilities in story form. I was aiming to get a feel for everyday activity and business as usual at both settings through observing and listening. Prior to entering the field I envisaged that in the social care setting people with dementia may strike up conversations with me, and that I would have opportunities to engage in conversation and also to join in with activities. I imagined that the NHS memory service setting would afford me opportunities to closely observe clinical practice relating to memory assessment and diagnosis. My intended way of working was to take fieldnotes in situ (or shortly afterwards) to describe what I had seen and heard. Supplementary to this I hoped to conduct semi-structured interviews with practitioners.

How this thesis is structured

My thesis is structured around the account of my data collected in the field, which are presented as case narratives in chapter 4 (NHS site) and chapter 5 (council site). These are prefaced by two chapters - an account of the theoretical and empirical research underpinning the field research (chapter 2), and an account of

the research approvals process and methodology (chapter 3). Following the case narratives are a discussion chapter (chapter 6) and a conclusions chapter (chapter 7).

Chapter 2: Perspectives from theory and from empirical literature

Introduction

In chapter one I began by describing the background for starting a PhD, and how I had become interested in the 'indefinable' aspects of what was happening during the interactions and practices between healthcare staff and patients and service users; and the possible value or worth of these essentially intangible aspects. These ideas had grown out of conversations with colleagues and my personal reflections about one organisational setting and its practices and day-to-day operations.

The main aim for *this* chapter is to develop a characterisation of knowledge for health and care practice settings which is fully encompassing of a tacit dimension of knowledge. How I set about achieving this aim is to work on a number of fronts, which I introduce here.

I explore an idea which is particularly significant for locating my project, both theoretically and empirically: the idea of the dimensional nature of knowledge. In my introduction I cited Marti (2007) who asserts that it is problematic to treat intangibles using the frame of reference used for tangibles. Differentiating between tacit and explicit dimensions of knowledge is similarly problematic, although some scholars have attempted this by framing the differentiation between tacit and explicit as either dichotomous, or on a continuum. I consider these approaches to configuring knowledge, and what new insights can be drawn regarding the relationship between tacit and explicit dimensions.

I examine Michael Polanyi's perspective on the tacit dimension of knowledge and I highlight particular insights that may be pertinent to my later chapters in terms of what, within facets of practice, might signal performative aspects of tacit knowledge.

The idea from Polanyi that all knowledge is fundamentally tacit, and that this tacit dimension of knowledge is essentially ineffable, has implications when considered in the context of health and care practice. Through reflecting on theoretical and empirical bodies of work I develop a problematisation of tacit knowledge that then provides a frame of reference for subsequent chapters. The knowledge

performed in or through 'practice' might be envisaged as oscillating between being tacit and being explicit (as codified knowledge). The enmeshing of tacit knowledge and practice is highlighted in work by, for example, Eraut (2002) who refers to the "intervisibility of practice"; Gabbay and Le May's "inexpressible knowledge" (Gabbay and Le May, 2011:71); and Amin and Roberts' (2008) four modes of "knowing in action".

I give attention to the acquisition and accumulation of knowledge, which is interesting and relevant when thinking about practices in health and care services. Ideas about the transition from novice to expert are discussed by Benner (1980, 1982) and Dreyfus and Dreyfus (1980), and further insights into how expertise is gained through formal training and experience are provided in Nettleton et al's (2008) study of doctors becoming consultants.

The notion of *accumulation* of knowledge through years of formal training interspersed with time in practice placements highlights ideas about acquiring knowledge and skills for practice over time. The relatedness of time and practice is also considered by Hopwood and colleagues (Falk et al, 2017a, 2017b; Hopwood in McLean et al, 2014) in empirical work that explores temporal dimensions of healthcare knowledge and practice.

One idea about time that is relevant to researchers conducting empirical research is from Hautala and Jauhiainen (2014). They draw attention to the idea that a sense of calendar/clock time becomes apparent during sensemaking, *after* data collection in the field:

"Time is not usually explained explicitly. Its linear existence becomes clear in the analysis of empirical material". (Hautala and Jauhiainen, 2014:658).

In addition to temporal aspects of knowledge and practice, are temporalities of care recipients and carers. Literature which considers time in the lives of people with dementia includes empirical work by Svanstrom and Sundler (2015) of the experience of time passing for people with dementia living alone; Vernooij-Dassen et al (2006) on the experiences over time of receiving a diagnosis of dementia; Nygard and Johansson (2001) on the sorts of temporal 'problems' that people with dementia experience; Orona (1990) on the temporal aspects of carers'

experiences of changes to their family member with dementia; and Kvale (1974) who developed a temporal conception of memory.

Temporality is a dimension of the formal sociological theory of 'status passage' (Glaser and Strauss, 1971:3) - a theoretical lens through which can be envisaged as 'passages' all types of transitions people make in their everyday lives: those which are unavoidable and have a 'natural' quality (e.g. fundamental transitions in life such as from childhood into adulthood, or from agedness to death) and those that have the appearance of being chosen and self-initiated (e.g. transitioning from unemployment to getting a job). The interrelated topics of health, illness, and ageing provide rich grounds for considering status passage, and transitions from one status to another. Vickers (2010) considered the illness onset of multiple sclerosis as passage; Marshall (1975) compared organisational features of two congregate residential facilities for older people, and explored residents' senses of their "dying status passage" (Marshall, 1975:350) in terms of how perceptions were influenced by how dying trajectories were constructed through organisational features; Glaser and Strauss (1965) considered dying as an example of non-scheduled status passage.

The fieldwork for this PhD sensitised me to the transitions of people with dementia and their carers, and events that punctuate transitions - such as diagnosis. The concept of status passage and its temporal dimensions represent an important theoretical lens that I suggest is useful for envisaging different aspects of dementia. Although temporal aspects of dementia have been explored empirically (as I have made mention of) such studies are rare, as Nygard and Johansson have pointed out (2001:85). I identified only one article (Tolhurst and Kingston, 2013) which critically evaluated the theoretical contribution that status passage may provide to an understanding of dementia. I was unable to identify any empirical examples of studies on dementia that had used status passage as a framework for analysis. Only in one ethnographic study that I located (Beard and Fox, 2008) was the diagnosing of Alzheimer's disease referred to as marking a status passage.

How I engage with 'time' in *this* chapter is by giving thought to ways that temporality might be conceived in practice settings, and the different ways that scholars have engaged with temporalities theoretically and in practice settings. Following both my fieldwork, and my sensemaking and analysis of empirical data, the dimension of time took on a compelling and germane potency. I thought about time becoming important in the lives of people affected by dementia in instances such as the looking back to how life was before dementia, and the looking forward to how life might become following an official diagnosis. Time seemed relevant to certain practice dimensions, such as time together - the time afforded to care staff during which they get to know individuals and what mattered to the person; or in timeliness of an intervention - such as noticing that a situation was changing and required either immediate or pre-emptive action to avert a crisis. Time seemed implicated on occasions when individual temporalities seemed to collide with organisational rules or policies. Another way I thought about time was how it was implied in the accumulation of experience and expertise for practice.

When I approached the field I was not thinking specifically about 'time' except in a chronological sense: how it framed my moving through a PhD, and marked various milestones such as obtaining ethics and research approvals. A much fuller appreciation of time emerged during data analysis when time conceptions became a key strand in my sensemaking process. Particular time conceptions which I felt were insightful in offering me ways of making sense of my data are: Abbott's (2001) thoughts about time relating to an individual life course; Bluedorn's (2002) insights about how people connect with their futures; and Barbara Adam's conception of the 'Timescapes' perspective (Adam 1998; 2004; 2008), particularly her list of "irreducible elements" for understanding time. (Adam et al, 2008)

Dimensions of knowledge

Turning now to the view that knowledge has more than one dimension, a way to explore this is by considering our everyday life: what do we have knowledge about that we can confidently represent linguistically; and, of what we know, we feel is not possible to represent with the linguistic tools available to us. This line of thought is elaborated on by Johannessen (1990:152) who suggests that there are different types of knowledge, or at least different contexts which place different

constraints on the claim to know something. Johannessen (1990:151) provides a situational example of a scientist claiming to have made an important discovery in chemistry yet is unable to articulate this verbally or provide the evidence for the basis of the claim. It is easy to think of other fields of work where there is an expectation to produce appropriate evidence to substantiate a claim of knowledge. A legal prosecution may rely on material forensic evidence being available; or claims made about the efficacy of a particular treatment protocol are validated by an explanation from research conducted in the field. Nonetheless, explaining the basis for a claim to know might not be straightforward in every situation. Diagnosis is one such example. The two main diagnosis errors that can occur are missing a serious disease (and diagnosing it as something not serious), or diagnosing a serious condition or disease that is not there. Kohn (2014) writes that strictly speaking "diagnosis" is defined as the naming of the disease causing the person to be ill, yet in practice:

"The cognitive process of assigning this name is a mysterious combination of pattern recognition and the hypotheticodeductive approach that is only remotely related to the mathematical process of using test results to update the probability of a disease." (Kohn, 2014:39, 41)

And, that

..."diagnosis involves integrating information from history, observation, exam, and testing using an ill-defined combination of knowledge, experience, pattern recognition, and intuition to name a patient's illness." (Kohn, 2014:40)

Kohn's account highlights that making a diagnosis is characterised by the factors of implicit uncertainties; the weighing of probabilities of a person having a particular disease or condition; and considerations about the ability of a particular test for determining the particular disease or condition that is in the frame as a potential candidate.

In relation to knowledge Kohn indicates that the precise knowledge-experience-pattern recognition-intuition combination is opaque and may not be fully known or described.

One provisional conclusion we might draw from this is that if we cannot articulate everything we know, it then becomes impossible to *fully* account for our basis of knowing, and only a partial account can be given.

Thinking about knowledge in clinical practice helps to animate Johannessen's (1990:152) suggestion that there are different types of knowledge.

To develop this further, one explanation that has been put forward is that knowledge is dichotomous, being of one type or another - *either* explicit (thus codifiable) *or* tacit. This dichotomous standpoint is what Hislop (2002:166) has stated - "represents one of the most widely accepted distinctions between different types of knowledge and is embedded in the vast majority of the contemporary writing on knowledge in organizations". This perspective assumes that there are two forms of knowledge, separate from each other and with individual characteristics. Characteristics that Hislop (2002) suggests have been assigned to tacit knowledge are: that it is personal, residing in individuals as embodied (Hislop, 2002:167); and in some contexts it may be regarded as being collective, such as shared values relating to a social context where a set of ideas are circulating, or the collective knowledge within Communities of Practice (Hislop, 2002:167). Characteristics ascribed to explicit knowledge are that it is assumed to exist independently of human bodies, codifiable as documents or embedded in machinery, tools, and other such physical artefacts (Hislop, 2002:167); that it is considered to be objective and "free from individual subjectivity" (Hislop, 2002:167); and that developing and creating explicit knowledge is separate from using and applying it. (Hislop, 2002:168).

Importantly, the dichotomy perspective assumes that tacit knowledge can be split away from explicit knowledge, and this is a perspective that I will return to later in this chapter in setting out a problematisation of the tacit dimension of knowledge.

Whilst the dichotomous version of knowledge is considered problematic by some scholars (e.g. Grandinetti, 2014; Hislop, 2002; Dienes and Perner, 1999), it may nonetheless hold some usefulness for bringing into focus enquiry about what is the basis for, and constraints on the claims that are made to know something (Johannessen, 1990:152). It may also be useful in providing some of the basic

ground for problematising tacit knowledge, specifically in relation to health and care practice.

An alternative to the view that knowledge is either tacit or explicit is set out in Michael Polanyi's theory of knowledge. Polanyi considered that there is a form of knowledge that is tacit, and that its existence is justifiable through the principle that *all* knowledge is "fundamentally tacit" (Polanyi, 1961: 467) being "either tacit or rooted in tacit knowledge." (Polanyi, 1966:7). Tacit and explicit dimensions of knowledge are "not sharply divided" (Polanyi, 1969:144). The nature of the interrelatedness of tacit and explicit dimensions of knowledge is given further explanation in Polanyi's publication entitled *Sense-giving and sense-reading* (1967:314):

"The ideal of a strictly explicit knowledge is indeed self-contradictory; deprived of their tacit coefficients, all spoken words, all formulae, all maps and graphs, are strictly meaningless."

Unlike the dichotomous view, here the tacit dimension of knowledge is hidden in the 'mix' of comprehensive knowledge, and there is a sense of it being taken-for-granted, assumed. The quotation from Polanyi draws attention to this unspoken tacit dimension of knowledge, and serves to undermine the dichotomous position that views explicit knowledge as 'unmoored' from tacit knowledge. Brown and Duguid (2001:204) confer with Polanyi in suggesting that it is impossible to "shake off" from the explicit the tacit dimension:

"in use the explicit nonetheless always possesses this other, implicit dimension." (Brown and Duguid, 2001:204)

From another position, seeing tacit and explicit knowledge as related has been expressed in terms of their situatedness on a 'continuum' (Nonaka and von Krogh, 2009; Grant, 2007; Jasimuddin et al, 2005; Leonard and Sensiper, 1998).

Leonard and Sensiper (1998) first proposed the continuum idea, referring to Polanyi's idea that all knowledge has tacit dimensions as a "messier assumption" than the one they assert:

"Knowledge exists on a spectrum. At one extreme it is almost completely tacit, that is semiconscious and unconscious knowledge held in peoples' heads and bodies. At the other end of the spectrum, knowledge is almost completely explicit, or codified, structured, and accessible to people other than the individuals originating it. Most knowledge, of course, exists in between the extremes." (Leonard and Sensiper, 1998:113)

Leonard and Sensiper's perspective assumes the knowledge continuum to be linear and with spatial dimensions, as suggested in references to "ends" and "extremes". Jasimuddin et al's (2005: 107) perspective follows a similar idea:

"[T]he position of knowledge on the tacit-explicit continuum is determined by its tacit-explicit mix".

In both the knowledge continuum and the dichotomous perspective, tacit is viewed as being distinct from explicit knowledge, either through polarity or by virtue of characteristics that differentiate. A propositional frame of reference such as this creates artificial distinctions between tacit and explicit. An important consideration about the idea of gradations of tacit/explicit knowledge is that this implies there is a point where tacit and explicit 'meet' which, in turn, suggests 'start' and 'end' points.

Grandinetti (2014:339) has referred to the confusion that arises from theorising about how knowledge is constituted:

"In actual fact, hypothesizing a variety of tacit knowledge configurations characterized by a decreasing content of tacitness hardly reduces the amount of ambiguity and uncertainty; if anything, it increases it because we fail to understand what exactly occupies the space in between the two extremes, which becomes a grey area where tacit and explicit are generically mixed together."

Hautala and Jauhiainen's (2014) conceptualisation of knowledge accepts the ideas that knowledge is made up of tacit and explicit elements, and exists in an "explicit-tacit continuum" (Hautala and Jauhiainen, 2014:665), but their view of knowledge also considers how temporal and spatial dimensions are relevant:

"To reveal processes of comprehensive knowledge, one has to adopt a theoretical and empirical framework accordingly. Such a framework addresses three aspects. First, knowledge creation is a process connected to multiple dimensions of time. Comprehensive knowledge is not only connected to linear time but also to relational experienced time [...]. Second, comprehensive knowledge is contextual and inseparable from multiple dimensions of space [...]. Third, as we will show in the results section, within these dimensions, complex and comprehensive knowledge creation addresses many combinations of space and time." (Hautala and Jauhiainen, 2014: 656).

How temporal and knowledge dimensions in healthcare practice are brought to the fore (e.g. ideas that practice is embodied and situated; referenced to a particular time and place; and performative aspects of knowledge) is the focus of recent work by Hopwood and colleagues (2017a, 2017b) and Hopwood (2014). Individual temporal experiences of people with dementia have been considered in empirical work by Nygard and Johansson (2001). Their work illuminated aspects of knowing by people with dementia in relation to everyday life: e.g. inner temporal rhythms that alerted people it was time to get up, and "lived knowledge" (Nygard and Johansson, 2001:89) of the time an everyday activity took.

Perspectives on knowledge as personal and tacit: Michael Polanyi's theoretical work

The first listed definition of the word "tacit" is from the early 1600s, its meaning given as "silent, unspoken" (originating from the French *tacite*) and, from the Latin word *Tacitus*:

"that is passed over in silence, done without words, assumed as a matter of course, silent." (Online Etymology Dictionary: Douglas Harper)

The term tacit *knowledge* (a shorthand for, or packaging of the construct 'tacit knowing') is attributed to Michael Polanyi who expounded ideas about knowing into a theory of *personal* knowledge (Polanyi, 1958; 1961; 1966; 1967) - a knowledge residing with individuals. In the years prior to Polanyi's theoretical work on knowledge there were indications that he was already interested in and

thinking about some threads that may have been early formulations for his later work. During his schooling in Hungary a letter written by Polanyi contained a reference to *Ding an sich* from Kant's philosophy, which literally translates as "the thing in itself" - that which is perceived via mediation through our senses, but which is itself essentially unknowable (Blumenau, 2001).

Scott (1997), referring to Polanyi's letter, wrote:

"Discussing the scientists who judge the world by appearances and cannot get at the *Ding an sich*, he conjectured that this reality behind appearances might be movement, energy, aether or molecules and observed that this ultimate cause affects him although he has nothing to do with it." (Scott, 1997:12)

A point to draw out from this is - on the basis that the *Ding an sich* is unknowable it would reasonably follow that the account a person can give of what they have apprehended of it would be a partial account. Polanyi used the term "defective articulation" (Polanyi, 1958: 88) as a way of referring to situations in which it is possible for a person to *speak* about the 'what' of performing an action or series of actions (for example: 'I am swimming backstroke'), but not possible to linguistically articulate the entire 'know how' of that set of actions. Polanyi's "defective articulation" represents this idea of incompleteness of account. In further elaboration Polanyi proposed that whilst a person is fully aware that she/he knows how to perform a set of actions (for example - riding a bicycle) the particulars of this are known only in an instrumental manner, whilst focally the person remains unaware of the particulars. Attempts to articulate the comprehensiveness of swimming backstroke by isolating the particulars would not result in full articulation. A focus on particulars would necessarily mean overlooking complex interplays between the constituent parts. This similarly applies to becoming skilled at something: this is not achieved through learning the constituent motions of a skill because breaking a skill into constituent parts is likely "to paralyse its performance" (Polanyi, 1961:460). Referring back to the respective continuum and dichotomous perspectives on tacit-explicit relatedness, neither perspective speaks to nor addresses the problem of articulation to which Polanyi refers.

Grandinetti (2014) has noted that Polanyi's (1958: 87) position was that tacit knowledge is not "something difficult to articulate, but something impossible to articulate". (Grandinetti, 2014:338)

I highlight this point as being important for two reasons. Firstly, in the field of management studies interest has been directed towards trying to capture and quantify tacit knowledge - often by means of proxy measures. Scholars who have attempted this have been defeated by both the elusiveness of the concept and the lack of current research techniques that would meet this challenge. Castillo (2002:47) illustrates, citing from the work of Pfeffer and Veiga (1999):

"despite querying, testing, and surveying even the most helpful and divulging employees, any effort to harness an employee's stock of tacitly held knowledge is pointless, as this knowledge cannot be differentiated from the explicit knowledge that that person holds."

Secondly, if attempts to study tacit knowledge by 'isolating' it have so far failed, do we need to adopt different approaches that appreciate and take account of what might be termed 'in situ', inseparable, and embodied characteristics of tacit knowledge? And, might tacit knowledge be 'animated' and made sense of by viewing it through other conceptual lenses which themselves have noteworthiness in the field setting where tacit knowledge is being investigated, for example: 'practice' and 'time'?

A point made by Hautala and Jauhiainen (2014:657) that knowledge is "inseparable from the one who knows" expresses something of the significance that Polanyi placed on the idea of the individual as the knower. Knowing is profoundly associated with the implicit nature of the mechanisms of the body. The workings of "internal actions and stimuli" (Polanyi, 1961: 461) (i.e. seeing, hearing, touching) integrating to form perception, are what results in 'knowing'. The body, using the sense organs, is the "vital instrument" for the knowing of anything and everything outside of the body (Polanyi, 1967:15). Seeing outward and 'knowing' in such a way is fused with awareness of our knowing self (Polanyi, 1961:468).

If the body is the "vital instrument" for knowing (Polanyi, 1967:15) this infers that knowledge is mediated in and through the body. This idea represents a challenge

to both the dichotomous and the continuum perspectives on knowledge, on the basis that both these represent disembodied views of knowledge. The main challenges Polanyi's perspective presents to the dichotomous view are that there are no current means of distinguishing between cognitive, sensorial and physical activities in the body that are involved in knowing; and no means to determine which (and at what stage) tacit or explicit forms of knowledge are being performed in and through the body.

Polanyi's ideas about the body's role in knowing prompt another thread of enquiry: the activation and performance of knowing in practice settings. Polanyi offered many examples from practice for illustrating his theoretical principles. He himself studied medicine and practiced as a field doctor in Serbia during World War I for a period of about eighteen months, so it seems plausible that his theoretical work was influenced by his first-hand experience of practice. Although in illustrating the dimensions of tacit knowledge Polanyi borrowed from diverse fields such as topography of landscapes, human vision, and physics, it was his illustrations from medicine that seem to have been given particular importance as exemplars of application of his theory:

"The structural kinship of the arts of knowing and doing is indeed such that they are rarely exercised in isolation; we usually meet a blend of the two. Medical diagnosis combines them about equally." (Polanyi, 1961: 461)

The process and conditions for acquiring knowledge Polanyi viewed as extending beyond learning from books and lectures into practice, practice being a site where knowing and doing become blended. In order to deepen her/his knowledge of a disease a medical student will focus on the individual symptoms and their variance, "but only clinical practice can teach him to integrate the clues observed on an individual patient to form a correct diagnosis of his illness, rather than an erroneous diagnosis which is often more plausible." (Polanyi, 1961: 460)

In diagnosis the *particulars* and the *whole*, and the juxtaposition between the two, are suggested as significant by Polanyi. A physician looks at a person's symptoms, initially without knowing what is wrong. When a diagnosis of the condition is reached the symptoms become meaningful in terms of the whole, but without

becoming less noticeable. (Polanyi, 1961: 463) Through this example the notion that there are two types of meaning is illustrated. One meaning is that when isolated particulars are looked at in relation to the whole it can be noticed or appreciated that the particulars and the whole are not separated from each other in space. The individual symptoms reside in the patient (whole and embodied) and no space exists between the particulars and the whole. Symptoms (the particulars) need to be enquired about in order to start to build a provisional hypothesis about the meaning for the whole of a particular set of symptoms. The other meaning this illustrates relates to the physician's visual perception alongside the use of tools and probes:

"where the uncomprehended particulars are inside our body or at its surface, and what they mean extends into space outside". (Polanyi, 1961:463)

Through the physician's sense organs (i.e. visual perception through the eyes) vital information is gathered from what is available that *can* be seen. Tools and probes may be simultaneously used for gathering data about particular aspects of the patient's health status that cannot be perceived and determined through visual perception alone (e.g. a Sphygmomanometer is used for measuring blood pressure; a thermometer for measuring body temperature; or Beck depression inventory as a screening tool for depression).

Mullins (2006:28) cites from the original 1957 "Preface" to Polanyi's *Personal Knowledge*, in which Polanyi wrote:

"I regard knowing as an active comprehension of the things known, an action that requires skill. Skillful knowing and doing is performed by subordinating a set of particulars, as clues or tools, to the shaping of a skillful achievement, whether practical or theoretical."

"Active" knowing suggests *at least* attentiveness and some sort of dynamic quality to knowing. A characteristic of a skilful performance of knowing seems to involve spotting "clues", which then shape the accomplishment. This knowing, Polanyi seems to be saying, involves apprehending an entity using personal sensorial faculties; and the *nature* of one's senses functioning in a performance of knowing

are indescribable, because of their implicit interwovenness with the internal bodily system.

An example in Polanyi's *Knowing and Being* (1961) concerns knowing what kind of seizure a patient was having:

"A few years ago a distinguished psychiatrist demonstrated to his students a patient who was having a mild fit of some kind. Later the class discussed the question of whether this had been an epileptic or a hysterio-epileptic seizure. The matter was finally decided by the psychiatrist: 'Gentlemen,' he said, 'you have seen a true epileptic seizure. I cannot tell you how to recognise it; you will learn this by more extensive experience'. (Polanyi, 1961:123)

This example of 'diagnosis' opens another idea about a tacit dimension of knowledge which is that correct diagnosis of the type of seizure is achieved only through exposure to extensive experience of seeing many seizures of this type, ideas which are echoed in Kohn's reference to the "mysterious combination of pattern recognition and the hypotheticodeductive approach" (Kohn, 2014: 39,41) involved in diagnosing. The example also brings to light another of Polanyi's concepts which he terms "comprehensive entity" to refer to what might also be described as the completeness and all-inclusiveness of (in the instance given) the human entity. The comprehensive entity is discussed in depth in Mullins (2006) wherein he describes how the effort of concentrating on the particulars of the entity (e.g. symptoms, and features of a condition that are manifesting) "weakens for the moment a knower's sense of the coherence of the entity". (Mullins, 2006:32) Conversely, efforts to grasp a more complete awareness of the whole will tend to engulf the particulars so that they appear to recede back into the whole. Citing from Polanyi's *Knowing and Being* (1961), Mullins (2006:32) draws attention to how making a discovery about something is "by a see-saw of analysis and integration similar to that by which our understanding of a comprehensive entity is progressively deepened". (Polanyi, 1961:129-130)

Tacit and explicit knowledge dimensions: health and care practice

I begin this section by thinking about health and care practitioners themselves, in terms of their personal, individual knowledge. As I have already highlighted from

an example from Polanyi (1961: 460), experience gained through practice seems to provide experiential knowledge that may reinforce knowledge acquired via formal and academic learning.

The acquiring and shaping of knowledge for practice is discussed in influential work by Benner (1982) and Dreyfus and Dreyfus (1980). Benner (1982) cites the Dreyfus model of skill acquisition based on their study of chess players and pilots (1980). This model asserts that acquiring and developing a skill involves passing through five levels of proficiency: novice, advanced beginner, competent, proficient, and expert. Benner elaborates further:

“The levels reflect changes in two general aspects of skilled performance. One is a movement from reliance on abstract principles to the use of past, concrete experience as paradigms. The other is a change in the perception and understanding of a demand situation as that situation is seen less as a compilation of equally relevant bits and more as a complete whole in which only certain parts are relevant”. (Benner, 1982:127-128)

In interpreting what might be happening as a person moves from novice to expert level, Benner resorts to allegory, referring to 'the whole' and 'the parts' and the shift in perception from focusing on the parts towards attention to the whole. The quotation from Benner echoes Mullins' (2006) interpretations of Polanyi's ideas about the deepening of understanding that is achieved by alternating one's focus on the whole and the parts successively. The movement from novice to expert which Benner discusses suggests inner change (i.e. in perception), and the idea of 'change' might be viewed in terms of the temporal aspects of becoming proficient. When thinking of formal education and training routes into various health and care professions temporal aspects become plain. For example, in England a Bachelor of Science in Nursing (BSN) takes either three or four years to complete, and clinical placements are an integral aspect of the training. Medical students generally spend five or six years doing their degree, followed by two years doing their postgraduate foundation course, then three to eight years in specialist training. Clinical placements are undertaken throughout. The three year Bachelor of Arts in Social Work typically takes three years during which time students undertake practice placements. A way of understanding time in practitioner

training is as chronological, objective time which is measured through clocks and calendars. This mode of time has been named 'chronos' by the ancient Greeks. It might be said that an appropriate duration of time is actually necessary and required for specific courses of study (e.g. nursing, medicine, social work) in order to ensure proper preparation for practice. Yet practice situations themselves (as placements, or employment following completion of formal practitioner training) are where expertise and knowledge may be further refined. In Nettleton and colleagues' (2008) study, for example, interview data was collected from physicians doing higher level training to become consultants. One consultant surgeon who was interviewed drew attention to how knowing what to do and how to do it increased through repeatedly performing a practice:

"The first, second or third time you do something you're going to feel insecure, by the time you've dealt with it 20 or 30 times you're fine."

(Nettleton et al, 2008:340)

This quotation highlights how, in the particular complexities of medical practice, performing a practice (e.g. a set of procedures) a few times is insufficient to achieve a status of competence. Only by repeatedly performing the set of procedures are confidence and competence acquired.

Thinking back to Benner's words about "skilled performance" (Benner, 1982:127-128) alongside this quotation from Nettleton we start to build up a sense of the dimensionality of practice. Two seemingly obvious dimensions of practice are the skills involved in performing, and knowledge. In the first section of this chapter I explored an idea about the dimensions of knowledge being explicit and tacit, and an idea from Polanyi that all knowledge is fundamentally tacit. A competent practitioner 'knows' what to do and how to do it, and this blending of what Polanyi termed "skilful knowing and doing" (Polanyi, 1958; 1961) represents an intertwining of different types of knowledge with practice to produce skilled performance. Even though the precise mechanics of knowledge and skills enmeshing in a skilled performance are essentially indescribable through the linguistic means available, some insights, which follow, have been offered by scholars as to how knowledge and skills might converge.

Knowledge in healthcare is picked up by Sturmberg and Martin (2008) who describe it as "a multidimensional dynamic construct". Referring to Kurtz and Snowden's (2003) 'Cynefin' framework they offer a conceptualisation of knowledge in healthcare that encapsulates knowledge as "complex", "knowable", "chaos", and "known" (Sturmberg and Martin, 2008:769). They assert that each domain is value-free, with no one being superior to another:

"[H]owever, each uses different thinking strategies to generate knowledge and to problem solve, which has inherent legitimacy and utility within that domain". (Sturmberg and Martin, 2008:770)

From the field of social practices Reckwitz (2002) provides a perspective suggesting that practice is that which has become integrated activity of the body:

"Practices are routinized bodily activities; as interconnected complexes of behavioral acts they are movements of the body. A social practice is the product of training the body in a certain way: when we learn a practice, we learn to be bodies in a certain way (and this means more than to 'use our bodies'). A practice can be understood as the regular, skilful 'performance' of (human) bodies. This holds for modes of handling certain objects as well as for 'intellectual' activities such as talking, reading or writing." [...] "A 'practice' thus crosses the distinction between the allegedly inside and outside of mind and body". (Reckwitz, 2002: 251-252)

In a similar vein, van Manen (1995:11), cited in Toom (2012:631) offers the view that tacit knowledge is "embodied in skills that are located inside practices, ways of doing things, knacks, sensitive touches, etc." This is a perspective suggesting that tacit knowledge is deeply ensconced in practice, and concealed in skills.

Eraut (2002) described the vacillations inherent in practice, likening it to:

"a continuum of possibilities from a situation where almost none of a person's practice is visible to a colleague (psychoanalysis would be a good example) to one where nearly all their practice is visible." (Eraut, 2002:179)

Eraut coined this phenomenon as the "intervisibility of practice" (Eraut, 2002:179) in usual working conditions.

The notions of 'embodied' practice and the 'intervisibility' of practice come together in an obvious way pre and during surgical procedures when the body is being worked on. Writing about anaesthetic practice Goodwin (2009:73-91) in Buscher et al (2009) points out that an anaesthetised person is not able to speak and practitioners in this setting rely on the reading of bodily signs. Goodwin describes this process as "intensely collaborative" (Goodwin, 2009:73), illustrated by the combination of (a) information supplied by the body and captured by technological augmentation (i.e. heart rate, oxygen saturation, carbon dioxide levels, and so on), and (b) the sensations involved when a practitioner has contact with the body, such as "the *feel* of a needle being inserted indicates something of its location in the body", or that certain "breath-sounds" can indicate respiratory distress. Knowing something of the status of the patient through using one's sensorial faculties and through additional tools that connect the anaesthetist to the patient's body is elaborated on by Polanyi (1961):

"The actual impact of the tool on our palm and fingers is unspecifiable in the same sense in which the muscular acts composing a skilful performance are unspecifiable: we are aware of them in terms of the tool's action on its object, that is in the comprehensive entity into which we integrate them. But the impacts of a tool on our hands are integrated in a way similar to that by which internal stimuli are integrated to form our perceptions: the integrated stimuli are noticed at a distance removed outward from the point where they impinge on us". (Polanyi, 1961:462)

Ways of knowing the patient are explored by Liaschenko, in Thorne and Hayes (1997) in the context of nursing practice. One way of knowing the patient is *as the case* - a way of knowing that is virtually all biomedical, and represents a disembodied manner of knowing:

"No particular physical body, nor indeed any body, is required for a nurse to have case knowledge. Knowing the case is what Arney and Bergen (1984: p 8) call the 'disappearance of the experiencing patient'". (Liaschenko, 1997:25)

Case knowledge is:

“limited to objectified physiological and psychological data, and the relationship between person and nurse focuses on the functioning and monitoring of physical and psychological processes”. (Liaschenko, 1997:24-25)

By definition, case knowledge represents a removal of, or disregard towards human agency that is the patient's. Liaschenko sets out what knowledge might be involved in knowing the patient as a person, beginning with acknowledging that knowing, whether it is directed towards a patient or to anyone, is not motivated merely by what the knower can gain in terms of getting the person "to do something." (Liaschenko, 1997:27). Rather, within the practice there must be commitment to individual agency:

"Knowledge of a person is partly a knowledge of how that person lives, as well as what she or he lives for. Disease and illness threaten and sometimes change drastically a person's agency and therefore the kind of life she or he can lead [Charmaz, 1991]." (Liaschenko, 1997:27-28)

Although case knowledge requires and depends on time (in terms of time needed for reading notes about the person or discussing a case with a colleague), time here perhaps is qualitatively different to time spent in talking with or listening to the patient.

Time also comes to the fore in points made by Nettleton and colleagues (2008) specifically in relation to the training of doctors. If insufficient time is allocated for being exposed to the situations of clinical practice then it cannot be guaranteed that the required expertise will be reached during training. Reforms in the NHS have included new regulations for the training of doctors, one consequence being the reduction by seventy-five percent in the number of hours' training completed by doctors before qualifying as consultants. Doctors are thus qualified but inexperienced. (Nettleton et al, 2008:339, 340).

"It's purely inexperience because they haven't seen it. I think that no matter how bad the training was, because you'd seen it all, because you'd done it all so many times, *you got a feel for it* and that was only with experience. I

suppose most of the time you were working on automatic pilot." (Interview with female consultant in Nettleton et al, 2008: 340)

The notion that is raised in this interview is that getting "a feel for it" comes with experience of doing something many times, and that frequency of the experience of immersion in practice could in some sense 'make up' for poor training. Experience through practice was key (in a way that training appeared not to be) in enabling performing of practice in an automatic unconscious manner. This is not, though, to suggest that practice is devoid of conscious purpose or forethought. Kjeld Schmidt has written about practice in work and draws attention to the purposefulness of practice:

"2.1. When conceived of as a practice, work is not reduced to executive activities (i.e., mere activities), such as sequences of operations, but is taken to also encompass sundry conceptual activities such as envisioning outcome, devising methods and planning, identifying tasks, preparing and allocating tasks, as well as activities of evaluating, instructing, learning, etc." (Schmidt, 2015:99)

Practice has a theoretical and conceptual basis - these aspects of practice generally introduced, taught and conveyed to the individual 'novice' within a formal learning type setting. However, as noted by Johannessen (1990) it is not enough to comprehend the theory and concepts of a practice. Rather, these need to be applied to and tested in practice in order for individuals (and presumably their teachers and supervisors) to establish whether "adequate mastery" has been achieved (Johannessen, 1990:162).

However, an important point is surfaced here about this notion of "adequate mastery". It becomes problematic in the context of knowledge and skills being deeply enmeshed in practice, because of how the issue of appraisal of mastery may be approached when what we understand to be its constituents (knowledge and skills in performance) defy being separated out from practice. The question of mastery *is* important in health and care services, since historical examples show some of the negative effects and consequences of incompetent practice. The seemingly opaque nature of personal knowledge used by clinicians in practice is

discussed in Gabbay and Le May's *Practice-Based Evidence for Healthcare: Clinical Mindlines* (2011). "Clinical mindlines" refers to:

"internalized, collectively reinforced and often tacit guidelines that are informed by clinicians' training, by their own and each other's' experience, by their interactions and their role sets, by their reading, by the way they have learnt to handle the conflicting demands, by their understanding of local circumstances and systems, and by a host of other sources". (Gabbay and Le May, 2011:44; 2004:3)

The emergence of clinical mindlines was described by clinician interviewees, and points were distilled by the researchers. Clinical mindlines:

"were grown from experience and from people who are trusted; they were 'stored in my head' but could be shared and tested and then internalised through discussion, while leaving room for individual flexibility." (Gabbay and Le May, 2004:3)

In interview, when asked to give an account of the reasoning behind how a clinical condition or situation had been addressed, practitioners either could not articulate this, or were able to answer only through recounting a memorable incident from practice, or by alluding to something they had heard or read. Gabbay and le May (2011) noted that it seemed curious that highly trained and competent clinicians were unable to describe in any concise way their praxis. "Inexpressible knowledge" was a term Gabbay and Le May (2011:71) coined for the ineffable nature of the work which practitioners at one of the research sites spoke about during interviews.

Another way the idea of competence in practice has been looked at is in the context of Communities of Practice (CoPs), a form of epistemic community defined by Lave and Wenger (1991:98) as:

"a system of relationships between people, activities, and the world; developing with time, and in relation to other tangential and overlapping communities of practice".

Wenger (2010) defined competence as involving three elements combined. The first two are collective understanding of the nature of the community of practice, and mutual engagement reflecting in interactions. The third expresses competence as involving access to a repertoire of resources such as language, routines, sensibilities, artefacts, tools, stories, styles and, significantly, the ability to use this repertoire properly. (Wenger, 2010:80)

Based on an in-depth review of the literature on CoPs Amin and Roberts (2008) delineated four modes of "knowing in action" according to activity of knowing, and type of knowledge. Thus, for example, "craft/task-based" activity is characterised by aesthetic, kinaesthetic and embodied knowledge; and "professional" activity is characterised by specialised, expert knowledge acquired through extensive training over time, is declarative, and has aesthetic and kinaesthetic dimensions. (Amin and Roberts, 2008:357)

Strati (2003) proposed that knowing in practice may be understood by approaching it with an aesthetic sensibility; that there is a "close interweaving between aesthetics and tacit knowledge". He defined aesthetic knowledge as "the form of knowledge that persons acquire by activating the specific capacities of their perceptive-sensorial faculties and aesthetic judgement in the day to day lives of organizations." (Strati, 2003:54). Applied to practice in the care professions an aesthetic and sensorial approach might involve a practical dimension such as 'seeing' how a person looks physically (e.g. pallor of skin); and also involve more abstract dimensions: perhaps a sensing of the person's emotional state, and awareness of one's own feelings or instincts about the person and their situation. In respite and day-care settings where people may remain for anything from one day up to a protracted assessment stay of weeks or months, recognising and staying aware to variations in an individual's state is important and necessary in order to be able to support the person if they become distressed, disorientated, agitated, or angry. In health settings such as clinics or home visits, the timeframes are different and contact may last for minutes rather than hours. Practice is likely to be focused on assessment, diagnosis, treatment and review. A key moment such as an assessment or diagnosis represents what Beard and Fox (2008:1512) describe as "a specific episode, or turning point" which is likely to be momentous for the individual and their carer. Such potentially life altering moments require

clinical knowledge to be mediated or 'softened' by a knowing of how one might feel if one were in the same situation as the patient. Kissel and Carpenter (2007: 279) have highlighted the often idiosyncratic and complex calculation physicians use to select which words to use (and those not to use) when giving a diagnosis of dementia, the implication being that great variance in the directness, clarity, or lack thereof, exists in the delivery of a diagnosis.

Thinking of settings that are focused on care Ahrenkiel et al (2013) investigated how professional competence unfolds in preschool day-care centres for children, using methods of observation, staff interviews, and workshops. Facets of work in these settings include welcoming children on arrival, mealtime and bedtime activities, dressing and undressing, and cleaning up. Such aspects tend to be overlooked and not considered as part of professional competence. Also explored was the notion of "gestural knowledge" (a term used for representing the relation between body and mind which asserts that these are not sharply divided but also not entirely one); and how gestural knowledge was involved in smoothing transitions from one situation to another, such as transitions between home and the centre. (Ahrenkiel et al, 2013:83) The authors assert that the ongoing functioning and operation of preschool day care centres:

"is dependent on professional competences that can be conceived as "unnoticed". These aspects of professional competence are embedded in routines, experiences and embodied forms of knowledge". (Ahrenkiel et al, 2013:79)

The authors drew on the notion of "unnoticed" (coined by the Danish researcher Bech-Jorgensen, 1994) as a way for describing "dimensions of work that often escape the eye that looks for measurable and easily documented curriculum-oriented activities". (Ahrenkiel et al, 2013:82)

Moser in Buscher et al (2009) provides an account of a way of practicing care that is explicit in its concern to harness the knowing of individuals with dementia in order to improve and produce meaningful outcomes for those individuals. This is a practice approach called *Marte Meo*, which is worthy of a full description here for its illustrating of commitment to knowing the person as a person, the

importance of which has already been highlighted (e.g. Liaschenko, 1997). The Marte Meo approach:

"makes visible and explicit an alternative and care-based definition of the problem of dementia, with wider possibilities for action in terms of care, patient agency and subjectivity, than the biomedical one allows". (Moser, 2009:194)

Fieldwork was conducted by Moser in a Norwegian nursing home and was "sensitised" towards tracing care approaches to dementia. From a study of the application of Marte Meo to the situation of one man with dementia Moser concluded that in Marte Meo diagnosis and action were thoroughly entwined: each shaped and transformed the other. It also seemed to be the case that in care practices dementia may be known and acted upon in ways that are different to those supported by a biomedical approach. Marte Meo provides an example of -

"how care practice and care approaches to dementia may transform what by biomedicine was given up as a deplorable, but unsolvable problem into a 'solvable', or, at least, a bearable and liveable one." (Moser, 2009:194)

Moser provides an account of a Mr Lang, a man with dementia who was admitted into a nursing home. He arrived with a history of moving between institutions for elderly care and dementia care, and there had been a failure to provide a permanent place for him in a care home. He had been diagnosed with advanced dementia with additional psychiatric conditions. Nursing home staff were aware that they were taking on a difficult and potentially unsolvable case. Permissions were sought to adopt the Marte Meo approach and, once granted, a 24-hour "deviation log" was introduced enabling the logging and coding of various forms of unrest, aggression, agitation and problematic behaviours on an hourly basis. This produced over the next few weeks colourful maps that suggested little in the way of *patterns* of behaviour, but did indicate certain behaviours including "little and irregular sleep." (Moser, 2009:196)

The interactions between Mr Lang and the staff who were mainly involved in his care were videoed, then these were played back to staff whilst being analysed,

involving pausing the video at points and giving an explanation of what was happening. (Moser, 2009: 198)

Moser suggested that video recordings and their subsequent analysis help to "give voice" to care approaches - a narrative that is often made silent or eclipsed by a biomedically oriented view of dementia. Importantly, the Marte Meo method supports a commitment to "finding what the language of the individual is rather than assuming that the person is empty." (Moser, 2009: 198-199)

The combination of care staff piecing together details from Mr Lang's past (before he was diagnosed with dementia), continuing to provide care to him, and also reviewing the video materials, built up a repertoire of knowledge about Mr Lang in which *knowing* him was a part. The evidence that Mr Lang was becoming 'known' by staff seemed to be shown in the new ways that they were working with him, based on blending and incorporating what they knew of details of his past with the practices they now adopted with him. The vehicle for change was the Marte Meo method, and applying this, Moser suggests, made:

"things that used to be hidden and invisible in the flux and the tacit, embodied practices of care, visible *also* in everyday care interactions".
(Moser, 2009: 204)

Practices and the way a health condition is defined - Moser suggests - are importantly related, and both may contribute to how individual agency is perceived. In relation to Mr Lang there was a 'somaticising' definition of dementia: either it was individual (located in the individual's brain) or it was relational and interactional. The diagnosis that Mr Lang arrived with at the nursing home defined him as though he was 'lost' in the dementia: dementia was the active agent in creating problems and challenges in care. Mr Lang's situation was powerfully re-framed and reconstructed through applying the Marte Meo approach.

This sort of knowledge that is both appreciative of human experience, and how disease and illness create disturbances to getting on with everyday life, Liaschenko (1997) suggests is integrated into the practice of nursing:

"Much of the work of nursing practice is concerned with creating and managing routines of lived experience. We attempt to take the disruption of

disease and illness and render it a manageable element integrated into the life experience of the person”. [...] “Knowledge of the routines of lived experience is knowledge of how people live in a temporally structured existence; it is attendance to how the ordering of their lives gives meaning, and it is attendance to the disruption of those orderings”. (Liaschenko, in Thorne and Hayes, 1997:28-29)

From the examples I have given from health practice and from care practice some overlapping concerns and shared themes become evident. It is notable that a central aim of practice in both health and care settings is to maintain and improve wellbeing. Fundamental to this is the knowledge and knowing of the practitioner regarding how the individual is in the present time: the individual’s mental wellbeing and physical health status; risks; key relationships; the social context in which the person lives including the immediate living situation; and even the person’s motivations in life.

Thinking about the variety of different sorts of practice across health and care it is clear that in many instances practice contains formal and process-driven elements, such as tests, assessment, protocolled interventions, procedures, and prescribing of treatments.

For example, the work of staff in dementia care settings will invariably involve: using hoisting equipment for which they have been trained; adherence to any risk or behaviour management plans specific to individuals; following of correct safeguarding procedures and reporting processes in cases where a member of staff suspects an individual with dementia is being abused; correct administration of individual medication; and adherence in practice to such policies as prevention of falls. These are all instances of explicit knowledge which is codified as a procedure, protocol or operational policy. Adherence in practice to such policies, protocols and procedures can be monitored and checked either during an event itself (through observation) or afterwards through auditing of records. If something goes wrong in a practice the provision of evidence that the procedure was correctly followed should exonerate the practitioner(s) involved.

Thinking of examples of knowledge codified within a health care context in which the needs of people with dementia are being addressed, an obvious example is lines of treatment. The current drug treatments recommended for persons with Alzheimer's disease are the three acetylcholinesterase (AChE) inhibitors - Donepezil, Galantamine, Rivastigmine, and another drug, Memantine. (National Institute for Health and Care Excellence/NICE: Technology appraisal guidance [TA217]). The guidance sets out clinical guidelines and recommendations for which drugs are suitable for which stage of Alzheimer's Disease (which might be considered to be a temporal dimension of prescribing); in which circumstances Memantine should be prescribed rather than a AChE inhibitor; under what conditions a drug should be prescribed; considerations of treatment cost; equality of access to treatment; and consideration of factors other than just cognition scores when deciding on treatment.

These clinical guidelines are essentially dealing with those aspects of treating a condition that *can* actually be circumscribed. These guidelines relate to another body of codified knowledge about specific drugs which is the British National Formulary (BNF) (2017). This details the drug dosage, side effects, monitoring requirements, directions for administration, patient and carer advice, and so on. The NICE guidelines and the BNF are codified knowledge that is evidence-based, presented in a protocolled format. The guidelines inform certain practices such as prescribing. Because prescribing is a practice in which there are innate risks to the patient, such as incorrect dosage, side effects, contraindications, and so on, safety of practice is paramount. Knowledge codified in protocolled formats, if such protocols are followed, provides a means by which certain elements of certain practices can be accounted for. This becomes important if something goes wrong (e.g. an adverse drug interaction) as the actual records of prescribing in a patient's notes can be checked against a given protocol or best practice guidance to establish whether practice adhered to the protocol.

Another example is to think about the interpretation of a particular type of codified knowledge which memory clinic practitioners commonly encounter: a brain scan (e.g. generated by a computerised axial tomography/CAT). In the clinic setting, as I observed during fieldwork in an NHS memory service, the clinician

with sight of the scan results can then decode this by correlating details in the visual display with codified knowledge of different types of memory problem. One instance of knowledge being decoded was observed in the clinic setting where the clinician saw that the scan showed no evidence of cerebral infarction, which she then interpreted to the patient as being indicative that there had not been a stroke or mini stroke.

The point to draw from these respective examples of drug treatment for dementia and brain scans is that these illustrate the utility of codified knowledge for treatment of a health condition, or for establishing the status of the health of the brain which, in dementia, provides key evidence for diagnosis.

Shifting the focus slightly from frontline practice itself to think about the overlapping nature of health and care needs, and the service contexts in which practice occurs, NICE in association with SCIE (Social Care Institute for Excellence) provides explicit and comprehensive recommendations regarding supporting people with dementia and their carers directed towards providing support that is integrated across health and social care:

"This guideline covers preventing, diagnosing, assessing and managing dementia in health and social care, and includes recommendations on Alzheimer's disease. It aims to improve care for people with dementia by promoting accurate diagnosis and the most effective interventions, and improving the organisation of services." ([nice.org.uk/guidance/cg42](https://www.nice.org.uk/guidance/cg42)).

Recommendations made concern integration of health and social care; risk factors, prevention and early identification; diagnosis and assessment; interventions for cognitive and non-cognitive symptoms; palliative care; and interventions and support to carers. The recommendations, it could be said, involve bringing to bear different but overlapping repertoires of knowledge (from health and social care practice) to people with dementia and their carers. One situation that hovers around the fringes of dementia diagnosis is that of people with mild cognitive impairment (MCI). MCI is defined as a pre-clinical stage of dementia, representing a risk factor for conversion to dementia. These individuals may be diagnosed with MCI (placing them in a high risk group for developing

dementia) but are then discharged because they do not meet the criteria to access dementia services.

The same NICE/SCIE guideline states:

"1.1.1.6: People who are suspected of having dementia because of evidence of functional and cognitive deterioration, but who do not have sufficient memory impairment to be diagnosed with the condition, should not be denied access to support services. [2006]" (nice.org.uk/guidance/cg42)

Not being denied access to support services is contingent on such support services existing and people being signposted to those services.

In terms of individuals who *have been* diagnosed with dementia, input from specialist NHS memory services starts to fade out once medication (if appropriate) has been prescribed and the individual is stable on the dosage.

Further input at this point is most likely to be limited to signposting to support organisations (e.g. domiciliary care or organisations that can help with benefits applications), or referring on to another health practitioner such as a dietician or occupational therapist. Once the objectives of assessment and diagnosis are completed individuals are generally discharged from specialist memory services. Health knowledge performed in practice within realms such as diagnostic services, signposting, and follow-up/review for people with dementia transmutes into quantifiable costs for the NHS. Service inputs and indicative costs in a particular "memory protection" service model spanning primary and secondary care (Hawkins, 2015) were estimated on the basis of an average pathway per patient as £877.00. For another service model - an entirely specialist led memory service - the total average pathway cost per patient was estimated as £491.00. For social care including domiciliary care and day-care, a social services assessment determines whether and how much an individual with dementia and their family must pay towards needs-assessed social care provision.

I highlight the costs aspect in health and care services for people with dementia and their carers in order to bring attention to the nature of 'valuableness' or worth to people with dementia of knowledge performed in practice; and also as a preface to the next section where I open up the idea of repertoires of knowledge of people with dementia themselves.

Transmission of knowledge through the knowledge repertoires of 'knowing' patients and service users

In this section I consider knowledge and knowing located in or with people with dementia. I borrow a characterisation of individual knowledge from Nygard and Johansson (2001:89) - "lived knowledge of" (a subject).

Individuals' knowledge becomes a particularly intriguing line of thought when considering a practice situation such as a memory appointment or in day-care. Here, the individual with dementia is present and is articulating her/his experiences and self-knowing of living with dementia. Dementia - in terms of defining what it involves and its nature - has no single definition. A 'query' about the nature of dementia may likely generate different answers depending on who it is posed to (i.e. someone with dementia, a carer, a neuroscientist, a dementia nurse, a GP, an activities coordinator at a day-care centre, and so on). However, some perspectives about dementia are privileged and considered authoritative over others. The biomedical perspective of dementia (as I found during the preparation and submission of an ethics application for NHS review) is pervasive in discourse about dementia, imbuing the language of medicine and nursing. Cheston and Bender (1999) describe a "formulation" of dementia that is oriented around a definition of dementia as a disease of the brain. Changes in the brain occurring over time and associated with dementia are linked to a progressive, staged route towards decline in the person's memory. This path begins with early stage changes and destruction occurring within the physical brain. This gives way to the appearance of psychological features, notably where cognitive function is affected by damage to the brain and the person becomes more and more impaired. The symptoms associated with this severe impairment are varied and usually negatively framed, using terms such as confusion, wandering, aggression, and disorientation. (Cheston and Bender, 1999: 68-69) This essentially deficit model of dementia represents a perspective where individual identity is closely aligned with cognitive capability. This is used as the rationale for explaining that increasing memory impairment (affecting cognitive ability) results in a person's identity (or self) beginning to disappear. Neuroscientists, Squire and Kandel (1999:9) are cited in Fuchs (2016:6) stating:

"We are not who we are because we think. We are who we are because we can remember what we have thought about [...]. Memory is the glue that binds our mental life, the scaffolding that holds our personal history and that makes it possible to grow and change throughout life. When memory is lost, as in Alzheimer's disease, we lose the ability to recreate our past, and as a result, we lose our connection with ourselves and with others".

This viewpoint correlates *thinking* (an activity it is assumed as undertaken by the brain, although the emerging viewpoints of 'embodied cognition' may call this into doubt [e.g. Wilson, 2002]) with *memory*. A further claim is the close interlocking between individual identity and memory: when memory becomes affected by dementia there is a fragmentation of identity that ensues.

Chatterji's powerful and poignant ethnographic case study of a Mr Rijder in a nursing home in the Netherlands explored whether patients with Alzheimer's Disease can be thought of as "experiencing subjects" (Chatterji, 1998:355) and exposed from Mr Rijder's situation that multiple and often conflicting perspectives may exist towards an individual with dementia but that the individual lived experience is singular. 'Identity' has been explored by Thomas Fuchs, a philosopher and also a psychiatrist who works with people affected by schizophrenia and people with dementia. The notion of the 'continuity of self' is particularly interesting as an argument for framing the question of identity in cases where the experience of time, memory, or thinking may become fragmented related to one's mental health. Fuchs proposes the idea of "a continuous awareness of *oneself-as-subject*" - the awareness of self in the terms of "a background certainty which need not be made explicit, examined or verified". This is a pre-reflective self-awareness which is "part of the first-personal givenness of every experience". So there is a continuous self-awareness, not dependent on self-observation, self-reflection or remembering (Fuchs, 2016:8). If continuity of the self was about consciously remembering of earlier experiences this would only amount to cognitive continuity, and there is in any case a question mark over cognitive continuity related to human capacity to *consciously* remember certain earlier experiences. In the course of everyday life individuals drift in and out of cognitive acuity - for example, when driving a vehicle on a

familiar route it is not uncommon to 'lose' a chunk of the journey and be unable to recall it. This suggests that realisation of *conscious* cognitive continuity is probably inconceivable. Fuchs suggests that the basis for selfhood should be physical existence through time (Fuchs, 2016:1) rather than being linked to any requirements for a person to remember their past. For people whose memory is significantly impaired, being in a state of memory impairment does not diminish or change the certainty of the person having had those experiences and continuing to have them. (Fuchs, 2016: 7-9). From the perspective of *not* having a memory impairment:

"One could argue that we instantly become aware of who we are, and in a Lockean way, through activating our memory, reconnect with the day before. However, this is not necessarily the case: frequently, a moment of confusion may arise, for example on my travels, when it takes some time to remember where I am, what time of day it is, or even who I am. And yet even before I explicitly remember all this, in the first moment of awakening, there is already a basic bodily self-awareness in which I find myself. To this end, there is no need to remember falling asleep the night before, nor to recall my name or any other autobiographical knowledge." (Fuchs, 2016:9)

A point to make in terms of knowledge and knowing is that the biomedical perspective is not attuned to knowing the person *as a person*, but is focused on the person as a case, and this represents a notion of a person with dementia as disembodied. Fuchs' ideas about knowing being located in the body, and selfhood being essentially dependent on the body's existence seem to offer weight to cognitive status *per se not* being the basis for knowing.

'Continuing to have experiences' (Fuchs, 2016) is a useful point to develop in terms of lived experiences of people with dementia. Attending to the lived experience of dementia is captured in the summation:

"knowledge of how that person lives, as well as what she or he lives for".
(Liaschenko, in Thorne and Hayes; 1997:27)

These points from Cheston and Bender, Fuchs, and Liaschenko, draw attention to the "positioning [of] people with dementia" (Beard and Fox, 2008:1511): where

and how people with dementia and their lived experiences are situated in practice, and in discourse. In chapter 3 of this thesis I consider the positioning of people with dementia in research, from my own experiences of the NHS ethics review process for this PhD project. I raise the point that vulnerability is part of the dominant discourse about people with dementia, and that labelling people as 'vulnerable' can result in their exclusion from participation in research, thus can "be deeply silencing" (Boden et al, 2009:742).

Individual narratives of people with dementia, Collins (2015) suggests, may be important in countering the biomedical perspective of dementia where the prevailing view is that disintegration of the self is considered inevitable. Collins writes:

"Individual perspectives of AD [Alzheimer's Disease] not only help in understanding the subjective experience of AD, but insights can also be used to improve the system of care and to critically challenge societal views of AD. Individual perspectives of AD provide insight into how people experience and navigate the condition. They provide fundamental understandings of how people negotiate death and illness." (Collins, 2015:2)

Empirical work about lived experiences of dementia appears to be a burgeoning area of research. A meta-synthesis of qualitative research about lived experiences of people with dementia by Górska et al (2017), for example, initially identified a large number of studies (3427 records) out of which 34 papers were suitable for review. Findings of particular note are: the awareness people with dementia had of changes in their cognitive capability, including memory; the importance to people of their sense of agency and maintaining control over their own affairs; and the idea that identity is maintained through personality traits, beliefs and opinions, actions, and activities. Particularly interesting was the finding that loss of skills was a risk to continuity of identity in terms of uncoupling the person's past from their current situation.

Empirical work has been reported by Kontos and Naglie in O'Connor and Purves (2009) detailing clinicians' accounts concerning bodily expressions in people with dementia that were interpreted as knowing based on past personal experience.

One example was from a physiotherapist working with a resident who was a war veteran and also had dementia:

"There are a lot of war veterans who live here and I'll never forget this one resident who I worked with. I had a hell of a time getting him to stand up from his wheelchair so we could work on his walking...He refused. One day I was thinking about who this man was and what his life experiences were and started singing the national anthem. Well you wouldn't believe it but he stood up from his wheelchair and saluted me! So from then on we began our physio sessions with the national anthem." (Kontos and Naglie, 2009:192)

Published literature *by or involving* people with dementia about their lived experiences is relatively sparse. This might, though, be changing. An articulate account detailing aspects of what it feels like to experience dementia has been recently broadcast on BBC Radio 4 by the author of the publication 'Somebody I used to know' (2018). The author, Wendy Mitchell, was diagnosed with young onset dementia in 2015 at the age of 58.

I conclude this section by noting that it brings together a set of viewpoints that converge in a rather uncomfortable way, revealing some tensions between dominant discourses from biomedicine and lived experiences of people with dementia.

Status Passage: characterisation for dementia

Beard and Fox's (2008) paper is the only empirical example that I located which frames receiving a diagnosis of Alzheimer's disease as marking a status passage (i.e. Glaser and Strauss' theory of status passage, 1971). However, not unrelated - and therefore worth briefly mentioning - is "master status", a term which has been used in empirical research to conceptually frame dementia in discussions of identity. A finding from an ethnographic study in a long-term care setting for people with dementia by Doyle and Rubinstein (2013) was that a dementia master status was a characteristic through which people with dementia were perceived as and dealt with by staff as 'other', which the authors refer to as "othering".

Diagnosis might be viewed as one way through which a dementia 'status' may be assigned. Implicit in any diagnosis is the notion that there is something wrong, but in a dementia diagnosis there is the further factor that what is wrong is irreversible. Something has been lost that will not be regained, and the naming of the problem as 'dementia' signals to other people that the individual's identity is now changed in some irrevocable sense. Goffman (1963) used the term "spoiled" identity to refer to how identity becomes marred when certain negatively valued characteristics such as criminality, poverty, and physical or mental impairment become associated with an individual. Grouping people according to certain characteristics they are perceived, by others, to share is evident in most health and care systems, including in the NHS research ethics system. Here, it might be said that there is a categorising of people according to particular characteristics they are viewed as sharing such as 'vulnerability' and 'lacking capacity'. Blanket terms such as 'vulnerable' become categories to describe people at a group level rather than at an individual level. The applying of terminology collectively might appear harmless, yet if a label such as 'vulnerable' becomes the accepted way to define a whole group of people this has possible consequences and repercussions for individual identity.

The undesirability of a particular individual passage may be seen in relation to its reversibility or non-reversibility (Glaser and Strauss, 1971:14-32). Dementia as a passage is in most cases (though young onset dementia is an exception) simultaneous with an ageing passage. Although a dementia passage is not inevitable nor is it currently reversible, an ageing passage is inevitable whilst being non-reversible. The nuance between these statuses might be defined in the terms that ageing per se is a 'normal', expected passage. Even though ageing is non-reversible, it cannot be assumed to be undesirable from the perspective of an individual. The passage of dementia is also non-reversible, yet may well be looked upon *as undesirable by the individual and their loved ones*. Governments may view dementia as a drain on resources, and pass this responsibility to agencies such as health and social care who must make special provision for people in this passage. The phenomenon of status passage originated with Arnold van Gennep's *Les rites de passage* (1909), and its properties were subsequently expounded on and extended by Glaser and Strauss (1971).

Status passage is a rather rich concept, and with wide utility so that it lends itself as a way of looking applicable to any imaginable status, or to any passage associated with any status. Very few authors have drawn attention to status passage in relation to dementia, Tolhurst and Kingston (2013) and Beard and Fox (2008) being rare examples of those who have. The desirability of different passages is framed by Glaser and Strauss' (1971) words, and these take on a rather poignant significance if oriented to a particular event such as being diagnosed with dementia:

"The passage may be considered in some measure desirable or undesirable by the person making the passage or by other relevant parties. Going from unmarried to married status generally is thought desirable; becoming a prisoner is generally undesirable." (Glaser and Strauss, 1971:4)

A characteristic of status passages is that they may be either "non-scheduled" meaning that a passage is not subject to any "man-made or imposed schedule" (Glaser and Strauss, 1965:48), as in the case of dying; or "scheduled". Dementia, if viewed as a health condition with a trajectory that is unpredictable in respects such as the rate at which an individual will become impaired, what skills will be retained the longest, and so on, is a non-scheduled passage. (E.g. Tolhurst and Kingston, 2013)

Of particular interest for my research is the temporal dimensions of status passages: the notion that a status passage is in constant motion, moving with time. This opens up ideas about transitions - that a person in passage transitions between statuses, and within a status the passagee transitions, so that s/he is not static, "not just 'in' a status." (Glaser and Strauss, 1971: 47). Transitional phases may be brief, so for a person with dementia an example might be a day per week scheduled to attend a day-care service, or regular periods scheduled for going into respite care. These transitions occur between home and 'institution'. Entry to permanent care represents a transition, but also may be looked upon as the gaining of an additional status whereby the person becomes a resident or a patient of an institution.

The timings, sequencing and stages of passages may be overseen by those who Glaser and Strauss (1971) term official "legitimators": authorised persons who

have roles in announcing timings, and may be crucial in temporal handling of a passage (Glaser and Strauss, 1971:36). Thinking about legitimators in relation to different aspects of my research project, these might include staff at the university who oversee doctoral passages; members of ethics committees who process and oversee sequencing of projects; memory services staff who oversee various aspects of healthcare for people referred with memory problems (e.g. the events of initial appointment, referring for scans and tests; diagnosis; prescribing; review; discharge); care service managers who are involved in overseeing the assembling and holding of information about individuals, their needs, their medication, care arrangements, and so on; frontline care staff who handle transitions such as arrivals and departures from institutional settings, as well as the scheduling and timing of activities and events and individuals' transitions through these.

I have oriented these selected insights from status passage to the situation of people with dementia. In doing so some points have been highlighted which seem helpful for conceptualising particular aspects that 'follow' a diagnosis of dementia. These aspects are: impact on identity, moving through time, transitions, and legitimators.

Problematisation of tacit knowledge

In problematising tacit knowledge I have chosen to weave this argument around one of the defining characteristics of tacit knowledge which is 'articulation'. I consider articulation of tacit knowledge through orienting it to a practice context: services for people with dementia.

I begin by restating Polanyi's conceptualisation of knowledge that all knowledge is "fundamentally tacit" (Polanyi, 1961: 467). In this case, the assertion is that there is no knowledge that lacks a tacit dimension/ all knowledge has a tacit dimension. This serves to ground the claim that it is not possible to differentiate tacit knowledge from the comprehensive knowledge in which (theoretically) it is a dimension. Theoretical frameworks that express the possible relations between tacit and explicit such as the tacit-explicit dichotomy and the tacit-explicit continuum do not solve the basic problem that, for all practical purposes, 'pure' tacit knowledge cannot be differentiated from explicit knowledge. From this

standpoint neither can it be possible to say with certainty which mode of knowledge is being performed in a given instance (Pfeffer and Veiga, 1999, have argued this point about differentiating tacit from explicit based on empirically driven attempts to extract tacit knowledge from employees).

Turning towards practice, van Manen (1995:11) has noted that tacit knowing "is embodied in skills that are located inside practices, ways of doing things, knacks, sensitive touches, etc." This embeddedness is problematic in two senses: (a) that tacit knowledge is so subsumed in the 'naturalness' or 'expectedness' of actions and skills in practice that it seems virtually indistinguishable from that which is natural, and ordinarily expected (i.e. its sedimentation in what might be observed as 'responses' to a situation); and (b) its absorption into the doing of practice then renders it "inexpressible" (Gabbay and le May, 2011:71) linguistically.

This characteristic of being inarticulable may render tacit knowledge as problematic in certain conditions in health and care practice. These conditions are the occasions when it is required or demanded that an account, explanation, or justification of practice be provided. One such circumstance could be the carrying out of a review of the rationale for care practice and variations in practice, where practitioners are asked to formally account for practice. The "defective articulation" which Polanyi (1958: 88) speaks of refers to the limitations of representation (linguistically) of the entirety of what we know in any instance, because the tacit dimension of knowledge defies articulation in this way.

Chapter 3: Methodology and research process

Introduction

The structure for chapter three reflects my own progression through various interlinked stages which, collectively, formed the research process. I begin by briefly describing how I came to the method of ethnography. I then provide an account of the processes and procedures for NHS ethical review through which my research project was scrutinised, and provide some critical reflections on this. A section about the terms that framed how I approached and undertook ethnographic fieldwork is next. In this I reflect on the importance of attunement to conceptual frameworks for approaching research involving people in late life and the issues that may accompany this including those of cognitive frailty, dementia, and caregiving. I consider my own positionality to participants and in relation to method. I consider 'time', introducing perspectives on time in relation to ethnography.

This chapter concludes with some brief reflections on undertaking research in a memory service and a day-care and respite service and approaching the writing of the thesis.

Ethnography: appeals for, and appeals to

Imaginatively, it might be envisioned that ethnography is a research method that puts out an appeal to researchers to tell stories that have not yet been told and, in this endeavour, to shed new light on a topic and reveal aspects about it that are new or may be presented in a different way. By the same token, for a researcher to choose to use ethnography for a research project s/he needs to be drawn to it, find it appealing, and recognise its unique utility for a specific project.

Willis and Trondman (2000) press home the potency of the method of ethnography for tracing and revealing new understandings about every-day, in situ occurrences and happenings. They introduce the first issue of "Ethnography" (2000) with a Manifesto for Ethnography, anchoring it in two contexts described thus:

"First are the symbolic forms, patterns, discourses and practices which help to form it and give it shape, so that the ethnographic enterprise is about presenting, explaining and analysing the culture(s) which locate(s)

'experience'. Second, and more widely, for us the best ethnography also recognizes and records how experience is *entrained* in the flow of contemporary history, large and small, partly caught up in its movement, partly itself *creatively* helping to maintain it, *enacting* the uncertainty of the eddies and gathering flows dryly recorded from the outside as 'structures' and 'trends'." (Willis and Trondman, 2000:6)

This beautiful description points to something about 'inseparability'. Firstly, in the nature of what is being investigated - that experience is caught up in, and indivisible from discourses and practices and so follows and maintains the flow of culture(s). Secondly, in terms of the *how* of conveying in ethnographic writing: in written ethnography is embodied *storying*, and storying involves using particular literary devices (common to fictional works) such as metaphor, alliteration, anecdotes, and connotation. What made this method attractive to me were the possibilities it augured for expressing research using a narrative, storytelling approach.

Ethnography's orientation to working *with* people rather than treating them as objects of research (Wolcott, 1999:61-63) appealed to me, as did the way of being within the settings where receptiveness to looking, seeing, and responding reflexively was called for rather than obligation to a set of research procedures. At a practical level I needed to maintain a day job in order to fund my doctoral studies. Whilst my ethics and governance approvals for my research project allowed me to conduct fieldwork over 12 months, including an option to apply for extra time, employment commitments did not allow for one single long, uninterrupted duration of time in situ in the two settings. Later in this chapter in a section on the terms for conducting ethnographic fieldwork I offer some thoughts about the possible implications of undertaking ethnography in this time-segmented way, and I consider the factors which may be involved in spending time in situ in health and care settings.

Narrative and ethnographic work in the field, some of which was influential in my initial decisions about methodology whilst other work I came across during and after fieldwork, has included: chapters from Mol and colleagues' *Care in Practice* (2010); *Ethnographies of Diagnostic Work* (Buscher et al, 2009), particularly the

strands about tacit dimensions of work, and the chapter on Marte Meo; and Chatterji's ethnographic case study (1998) of a man with Alzheimer's Disease at the point at which he was institutionalised into a care home which is a narrative structured around a problematisation of the notion of 'voice' as it relates to people with dementia. I revisited Pauline Morris' sociological study, "Put Away" (1969), which I had read first in the mid-1990s in the context of studying for a vocational bachelor's degree to work with people with learning disabilities. The narrative - although not a self-claimed ethnography - is a powerful rendering of the languishing of people in long-stay 'mental handicap' hospitals during the 1960s, and the devaluation implicit in routines of care, the physical environment of the hospital, lack of personal possessions, and lack of personal agency.

The qualities of ethnography that I have been particularly drawn to may be summarised as: the *being there* in situ that provides possibilities for looking and seeing, then recording, reflecting and making sense; alongside the crafting of a narrative that imparts one's own sensemaking, but which also allows the reader, with their "own background and experiences" (Golden-Biddle and Locke, 1993) to engage with the text and advance their own understanding.

Formalities and Realities: Seeking research and ethical approvals

I had previous experience of the formalities of seeking and obtaining NHS research and ethical approval and knew that the processes were weighty and very time consuming.

At the stage of preparing applications for peer review, research governance, and ethical approval I was mindful also of how I might go about representing ethnographic work (specifically) in the terms of the approvals systems.

At the preparation stage I did not know how the ethics and governance for the social care component of my research project would be dealt with. It transpired that this was and is a grey area: even in instances where an NHS Research Ethics Committee (REC) reviews and grants approval for a combined health and social care project, local Research and Development (R&D) governance approvals and monitoring relates only to NHS fieldwork sites. Furthermore, it is outside of the remit of NHS RECs to comment on ethical issues relating to non-NHS sites such as local authorities.

The ordering of the processes, as I understood, was firstly an application for peer review of the project to Keele; then a mapping over of any relevant information from the peer review form to the online ethics application; ethical review by an NHS REC and, subject to obtaining ethical approval, the granting of research governance approvals from the R&D department at the NHS trust where I would be conducting my work. Alongside this I would be applying for local governance approvals from the local authority for the social care site. How the ethics approvals for the NHS related to the social care ethics approvals I did not know. Between early August and early September 2013 I submitted my peer review application to Keele, and the requisite Research Governance Framework (RGF) form to the local authority. In early October 2013 the local authority approved my proposed research project at the day-care and respite service (Oak Hall). In mid-November 2013 I finally obtained peer review approval after various delays relating to the review process and the requirement to make minor amendments. With local authority approvals granted I sought clarification from the Research and Governance lead at the university about whether I may now commence fieldwork at the local authority site. Taking this option would have meant submitting an application to Keele University ethics committee to review the social care component. The view from Keele seemed to be that the single, streamlined NHS REC process 'trumped' any other possible ethics review avenues open to me. My frustrations were related to my feelings that ethical issues my study raised specific to the social care setting should be dealt with in the context of social care ethical review.

In early January 2014 I emailed the regional manager for the Health Research Authority NRES putting to him my questions about the social care aspect of my project. He responded:

"I just need to clarify that NHS REC review is not normally required for research involving NHS or social care staff recruited as research participants by virtue of their professional role. Although if you intend to include service users then ethical review will be required. However, from the information provided it is entirely possible that your application would benefit from review by the National Social Care Research Ethics Committee - <http://www.screc.org.uk/>. SCREC can review studies taking place in NHS

settings with NHS patients where the approach uses social science or qualitative methods, provided that the research does not involve any change in treatment or clinical practice, so it may be worth contacting them to see if your application is more suitable for review by them." (Email: 02/01/14)

Given that I was using a social sciences methodology, SCREC sounded an appropriate route to follow. However, mindful of how close I was to completing my application to NHS REC I didn't want to unwittingly create more delays. I was also concerned that applying through a non-NHS process might be seen as less legitimate by the R&D department at Two Shires Trust, and that this may in turn compromise the positive relationship I had been trying to nurture with that team. As a researcher I would have preferred to follow the SCREC route, but pragmatically the 'right' decision was to continue the application for NHS REC approvals.

My initial online submission to the central hub overseeing RECs was rejected (for the reason of being "not valid"). Whilst the rejection was frustrating at the time, the narrative behind the "not valid" reason is particularly interesting and somewhat concerning when one considers the range of types of research study which may wish to recruit people with dementia. In the initial set of 'screening' questions on the form I had responded "no" to the question:

"Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?"

There are implications relating to this question on two counts. The definition of "intrusive research" provided on the form is: "any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information". The implication is that holding personal information about an individual - such as name and address - is no less intrusive than taking and using a tissue sample from an individual. The anomaly of not differentiating between levels of intrusion has been highlighted by Crabtree (2013: 361) who notes that "The reference to 'intrusive' research may equally relate to randomised controlled trials or qualitative studies of patients".

The other point is about capacity. In the statutory principles relating to the Mental Capacity Act (2005) principle 1 states: "A person must be assumed to have capacity unless it is established that he lacks capacity.' (section1(2))"

The Mental Capacity Act (2005) Code of Practice: Chapter 4.4 enlarges on and further clarifies this principle by indicating that assessing capacity must be established not according to the person's ability to make decisions generally, but according to the person's ability to make a particular decision at the time when required. The question on the form *implies* that it can be known in advance by a researcher that at least some participants will lack capacity to consent to what they are being asked to consent to, and at the time when the consent is being sought. To all intent and purpose the question is asking researchers who are involving participants from certain groups that may be deemed 'vulnerable' to make the assumption that those participants 'generally' lack capacity.

The response from the REC manager about my application was that I had given conflicting responses in relation to the questions about capacity/non-capacity of participants (i.e. people with dementia). There was a specialist REC that could approve studies involving people who lacked capacity, I was advised, to which I would need to submit a revised application form which would require a new batch of signatures.

February 2014 was the earliest that my application could be reviewed by a specialist REC. Two weeks after attending the REC meeting at which my project was discussed and questions posed to me by committee members, I was notified that my application had been given a 'provisional opinion'. This meant that there were aspects of the application which I would need to address and revise before a final opinion could be given. The REC's concerns mainly related to ethical issues at the social care setting which, as I knew from email correspondence with the R&D team, fell outside of RECs remit to comment on. The issues raised were:

- The consent process was viewed as insufficiently rigorous. It was suggested that a member of the clinical care team should approach individuals to determine capacity. If the individual lacked capacity the same member of the care team should approach the person's carer.
- Consent should be taken prior to the day of observation.

- Observations in a group setting where not all participants had consented to being observed was viewed as an issue, and the committee were recommending that everyone in the group should have consented or the researcher should not observe that day.

I sought an opinion about capacity from the medical director at the trust where I work, who is also a consultant psychiatrist with people with dementia. She advised that capacity is always topic specific. For example, a person with dementia may not have the ability to make decisions about their finances but would be capable of expressing their wishes or agreement for a here and now situation such as taking medication.

I also re-read the Mental Capacity Act's (2005) Code of Practice which concurred with my original thinking - that it was appropriate to seek consent from people with dementia within the setting and at the point in time directly relating to the reason for which they were being asked to consent. Thus:

"[A]n assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not on their ability to make decisions in general." (Mental Capacity Act (2005) Code of Practice: Chapter 4.4)

I could not see how the REC's proposals could work. The suggestion that the 'care team' should assess capacity, rather than the researcher, overlooked the fact that members of the care team were potential participants for my research project. In effect this would mean that one group of participants (staff) would be assessing capacity of another group of participants (people with dementia). Had this even been feasible it would create additional burdens for an already busy staff team. The assumption appeared to have been made that members of the care team would see the determining of capacity as theirs to make; a point I disagreed with. Furthermore, making judgements about capacity might rightly be questioned by social care staff on the premise that this was a big ask of a staff group who were not particularly well paid. My view was that, as a PhD researcher, I was responsible for weighing up whether an individual understood what I was asking in terms of consent.

My revised consent strategy was duly submitted to the committee. My project was given ethics approval in mid-April 2014 (IRAS project ID: 140652).

This turned out not to be quite the end of the approvals process: extending observations to cover home visits with the Older People's Community Mental Health Team required a further submission in the form of a substantial amendment. This was submitted to the REC in September 2014 and was approved.

A critical consideration of research approvals for research in health and care

The feelings of unease I had about making my research project 'fit' a prescribed process of application and review which felt restrictive and constraining have been articulated by other researchers who have questioned whether the paradigmatic assumptions that permeate NHS Research Ethics Committees (RECs) are appropriate for reviewing non-clinical research that uses social sciences methods. (e.g. Dingwall, 2008; Burr and Reynolds, 2010; Parker et al, 2011; Pollock, 2012; Crabtree, 2013; Stevenson et al, 2015)

The international trend towards tightening of ethical scrutiny for research projects is proclaimed as an "uncontested social good" (Crabtree, 2013: 359), and the extra layers of regulatory requirements for the conducting of research seem to represent a notching up of administrative obligations. However, it remains unknown whether meeting these requirements makes an actual difference to the ethical practice of researchers not only in terms of conduct in the field, but also at the planning and development stages where choices are made about methodology, method, and research design.

The process of seeking ethical approvals is essentially administrative and on the whole is conducted through online systems. For me it felt strange that - having crafted the materials of one's own PhD research project - this was then 'pushed' through an administrative system. I felt that this created a disconnect between the researcher and their work - a point that was reinforced during the REC meeting where I talked through my proposed research project and was asked questions about my work. Questions from the committee included those that touched on hefty theoretical and philosophical matters, such as "how tacit knowledge could

be transferred, if useful, to others", and "what an ethnographic study is". There was also a question about 'immersion' relating to ethnographic research specifically: "what the process for becoming embedded was." On the one hand I felt as though these questions were important ones to ask. On the other I felt frustrated that I was in a situation which was not amenable to appreciation of discourse around the question focus but was actually about process and 'processing' my application in the terms of a regulatory framework: essentially, deciding whether the proposed research posed risks to any of the participants. The weighty regulation and sometimes impenetrable processes that have developed around the ethics of research in the UK hark back to the circumstances of unregulated scientific activity by Nazi doctors during World War II, and the subsequent principles of 'permissible medical experiments' (1949) set out in the Nuremberg Code of 1947. Ethical principles for research later became enshrined in the Declaration of Helsinki (1964) which is intended to provide guidance to physicians and others conducting medical research involving human subjects. Specific types of research referred to in the Declaration are biomedical research, clinical research, and non-therapeutic biomedical research involving human subjects. (World Medical Association/WMA, 1964). In the UK, researchers (including PhD candidates) must obtain ethical approval for their work if they are intending to conduct research with participants who are identified on the basis of:

"their past or present use of services (adult and children's healthcare within the NHS and adult social care) for which the UK health departments are responsible (including services provided under contract with the private or voluntary sectors) including participants recruited through these services as healthy controls".

(<http://www.hra-decisiontools.org.uk/ethics/engset1.html>: accessed 14/06/16)

Such wide criteria make it likely that any research interested in aspects of health and/or social care will need to be subjected to ethical and research approvals. Depending on the type of research and whether it involves participants who are deemed as vulnerable related to attributes such as age, mental or physical health, or disability, researchers must follow the appropriate approvals route. In the case

of my research project - as already noted - the (blanket) assumption of lack of capacity of people with dementia meant that I was routed to a specialist REC which reviews projects that are assessed as involving participants lacking capacity. For any such project researchers are expected to make themselves familiar with the principles and provisions relating to research within the Mental Capacity Act, 2005. Anyone, including a researcher, who makes decisions involving people lacking capacity has a legal duty to have regard to the statutory Code of Practice that accompanies the Act. Researchers must also demonstrate in their ethics application how they will comply with the Data Protection Act (1998). That is, how the project will ensure safe storage, handling and protection of data about, and given by, research participants. As a researcher I recognised the importance of compliance with the legal and regulatory framework but, as I saw it, this was my 'duty of care' to my study participants.

The REC form question provoked my own reflections on the term "vulnerable". The assumption of 'vulnerability' made about certain groups of people in the context of their potential participation has, as Crabtree (2013: 366) suggests, "enormous ramifications attached in terms of research participation".

In relation to individuals with dementia one consequence of the 'vulnerable' label is that it provides no differentiation such as *who* is vulnerable, *in what circumstances*, or *when*. Any blanket application of a term to a group of people discourages approaching and thinking about each person as an individual. This seems to be in contrast with the tone of the Mental Capacity Act 2005 which does clearly emphasise that people who may fall within the provisions of the act are *individuals* who should be supported to reach their own decisions wherever this is possible. The juxtaposing of "vulnerability" with "consent" in the REC form question feels profoundly troubling - a symptom of a reductivist system that may (albeit unwittingly) prejudice how RECs deal with reviewing research projects which intend to involve participants deemed to have vulnerabilities. Boden et al (2009: 742) point out that the construct of 'vulnerability' is not easily classified nor are there objective classification schemes that may be applied. Being categorised as vulnerable can lead to being excluded from participation in research, thus the label of vulnerability can "be deeply silencing." (Boden et al, 2009:742)

The sound-bite that sums up my experience of taking a research project through the NHS ethics and governance regulatory system is "resistance is futile" (The Borg, Star Trek), but any resistance I felt to the requirements of a system was tempered by the idea that there was an ultimate purpose and goal. Being willing to play by the rules of the game resulted in being granted permissions to enter the spaces of worlds to which one would not normally be admitted, other than by virtue of working in that world, or being a patient or service user, or having a significant personal relationship to that person. Reaching the point of being able to start fieldwork with participants who have been labelled 'vulnerable' means that all the boxes have been ticked in terms of gaining the required approvals and, in those terms, it is certainly no mean feat. But reaching the start point might also be viewed as hugely meaningful in terms of the chances that become available to gain access to the narratives of people who use services. The need for the narratives of service users to be heard is considered by Crabtree (2013:374):

"Narratives that have emerged from obscurity through the struggles of service user movements have normally been regarded as emancipatory. However, within the discourses and ideology of many REC guidelines and procedures, similar attempts to elicit service user accounts may be deemed intrinsically harmful to participants."

It is the messiness and untidiness of social sciences research (in particular) that is perhaps most problematic for regulatory systems such as those for research ethics and governance approvals to deal with. Pollock (2012) and Burr and Reynolds (2010) raise the point that amongst qualitative research approaches the perceived 'messiness' of ethnography can amplify the notion in NHS RECs that it is riskier than other qualitative methodologies. For social science researchers wishing to conduct ethnography amongst persons defined as 'vulnerable' the barriers may be particularly significant.

Terms and methodological considerations for undertaking ethnographic fieldwork in statutory dementia services

In this section the particular terms for undertaking ethnographic fieldwork in the two services are considered.

I reflect on sensitisation to underlying structural issues related to services for people in older age, and consider being in situ engaging with people with certain types of frailties associated with older age, dementia, and caregiving.

I give thought to researcher positionality to project and to participants, and the methodological issues that are surfaced. I end with a consideration of 'time' introducing perspectives on time in ethnography from Dalsgaard (2013), Pink and Morgan (2013), Jeffrey and Troman (2004), and Wolcott (1987).

Whilst young onset dementia affects a substantial number of people in the UK with estimates of approximately 40,000 people under the age of 65 living with dementia, dementia is most prevalent amongst people aged over 65 affecting approximately 850,000 people. (Prince et al, 2014) From these figures it would be expected that people seen by memory services or using other dementia services would be predominantly of older age (65 plus), and that spousal carers might typically occupy similar age brackets. For undertaking research in situ within health and care dementia services it is necessary to become sensitised to particular positions on ageing and critiques of these. Two approaches to theoretically framing ageing which I have found helpful are Grenier et al's (2017) ideas about the marking out of boundaries of health and illness in later life through institutional and organisational practices, and "intersectionality and interlocking oppressions" from Hulko (2009). Debate and policy about later life, Grenier et al (2017) suggest, is framed from one of two perspectives: either successful 'active ageing' in late life, or failed or 'frail' ageing characterised by physical and/or cognitive frailties requiring care. (Grenier et al, 2017:318-319) Reflections sparked by these ideas about ageing for my own research project I briefly highlight here, and in my case study chapters (4 and 5) I provide further insights based on observations in the field.

Thinking about Grenier et al's (2017) framing of late life, increasing age is known to be the biggest risk factor for dementia. (<https://www.dementiastatistics.org/>) In terms of my fieldwork I would thus have expected to encounter people who developed dementia at different ages, including people who became cognitively frail in their 80s and 90s but up until that point had enjoyed a healthy active late life. Another consideration is aspects of individual identity (both of a person with

dementia and a carer) such as gender and class which, Hulko (2009) posits, are intersectional with dementia. For my research project, although I may be unable to draw confident conclusions from experiences in the field regarding how these aspects play out during interactions between practitioners, people with dementia and carers, my attunement to the conceptual framework of intersectionality and to ideas from Grenier et al (2017) about how practice shapes and perpetuates particular discourses about dementia enables me to reflexively consider this in the field. Through being in situ I am also able to consider how other factors - accumulating alongside cognitive frailty - might create conditions of precarity for the person and their carer, such as fragility of care arrangements, comorbidities, and behaviours that create risks.

As a PhD candidate I was approaching the fieldwork settings with my own personal history which included already acquired knowledge and experiences related to people with dementia, gained from previous employment. Regarding ethnography specifically, entering the field with pre-existing knowledge that is deemed relevant to the project sets up a particular researcher-to-project positionality. Knoblauch (2005:3) uses the term “members’ knowledge” to refer to having considerable tacit and explicit background knowledge of a field of study. Prior knowledge is considered problematic in terms of the potential effects of what the researcher already knows: for example, how does this play out in the researcher’s interactions with participants; during sensemaking in the field; and during analysis. Whilst it may not be possible to resolve the fact of having prior knowledge, how it is handled and accounted for reflexively becomes an important consideration.

In terms of my own positioning in relation to ‘outsider’ and ‘insider’ research Giazitzoglu and Payne’s (2018) discussion on this topic is particularly helpful. The key distinction made between outsider and insider research is that the former is carried out by ethnographers with limited prior knowledge of the research site and its members, and the latter by ethnographers who operate, to different degrees, within their own group, or in a group the ethnographer gains membership to, based on shared or closely similar social and cultural identity typically arising from previous experiences. (Giazitzoglu and Payne, 2018:1150)

For 'outsiders' key challenges centre around gaining physical, not to mention social entry to a research site, and the sensitivity to members' culture which may be lacking. Yet, "outsiders bring anthropological distance, and may be more alert to taken-for-granted features of the setting." (Giazitzoglu and Payne, 2018:1150). Crabtree (2013) describes the ethical approvals journeys of three doctoral students conducting ethnographic research projects in health-based institutional settings involving 'vulnerable' participants. One of the researchers had formerly been a nurse, and this insider-experience seemed to privilege her in terms of the relative ease she had in gaining access to the fieldwork site. Another researcher was an academic with 'outsider' status in respect to the NHS:

"I've no health care background at all so I had difficulty getting NHS ethical approval. My ethnography was based in a hospital study and the ethics committee . . . were uncomfortable with me being on the wards the whole time. So I could only go when I had a special interview or meeting, which I had prearranged." ('Hannah'. People with dementia, hospital setting, England, 2008, in Crabtree, 2013:370)

During both the research ethics and governance approvals processes and when I sought local permissions from the organisations with jurisdiction over the respective fieldwork sites, the information I was required to give announced my association to the NHS as an employee. To participants in the fieldwork settings I 'announced' myself as a researcher, but generally only if my background came up in conversation did I divulge that I had prior knowledge relevant to my field of study. A particular example where my prior knowledge collided with my fieldwork provides insights about which reflexive points can be articulated. The context for this example was my historical acquaintance with a man with learning disabilities who I subsequently encountered in one of the fieldwork settings. I had prior knowledge of him as an individual, we having both sat as committee members with an independent advocacy organisation. I also had prior knowledge of the field having previously worked with people with learning disabilities as a non-clinical practitioner, and I was sensitised to debates about historical oppression of people with learning disabilities. I enlarge upon prior knowledge as

a reflexive point in chapter 5 towards the end of the section entitled 'memory of the past and thoughts of the future'.

A further reflection on my positioning in relation to people with dementia, staff and carers concerns the question of how the requirements for conducting research in health and care settings (i.e. ethical and governance review and the researcher's subsequent compliance) shape or perhaps even 'prescribe' positionality. I have previously referred to the question of whether paradigmatic assumptions that permeate NHS Research Ethics Committees (RECs) are appropriate for reviewing non-clinical research that uses social sciences methods. Even just reflecting on the subtle difference in emphasis between the term 'participant' –the term specified in IRAS on the REC form for describing involvement in a research project - and 'informant' (typically used in ethnographic research), it becomes apparent how certain language might then shape subsequent aspects of being in the field. 'Participant consent' seems out of step in an ethnographic study. If, for example, 'informant' was substituted for 'participant' the term 'consent' would seemingly become strange: asking a person to give consent *to inform* lacks sense. In terms of my position as a researcher to people involved, the term participant might connote otherness: *my* research project that *others* participate in.

Moving these reflections into the notion of participant 'consent', in the terms of the REC form it was required that I ensured that consent was "voluntary and fully informed". (NHS REC Form A30-1.) Pollock (2012) has suggested that the ethical and governance review framework reduces the process of gaining informed consent into a "'rational-technical' procedure" entailing the involvement of persons idealised as fully informed and autonomous, and has advocated the idea of cultivating "'ethical mindfulness' on the part of individual researchers". (Pollock, 2012:3)

My own concerns about the participation of people with dementia centred around on what basis would I 'know' whether people gave consent that was informed and, if consent involved particular cognitive abilities, what was the meaning of consent in relation to individuals living with dementia? I could not see how it was possible to be completely sure about levels of 'informed-ness' and, regarding the people with dementia I encountered, there were significant questions about their

autonomy (regarding Pollock's point). For example, it was uncomfortable to think about people with memory problems in terms of the 'voluntariness' or not of their attendance at a memory appointment or day-care.

Further thoughts regarding informed consent relate to getting to know individuals with dementia and establishing rapport within the particular settings of fieldwork. At the memory service although the practitioners were a constant, the episodic nature of attending clinic for a memory appointment meant that I had only one encounter with each person with memory problems (and respective family member or carer). The one-off, bounded nature of appointment-time becomes problematic if one is trying to establish rapport with a person attending their appointment. It is also true that aspects of how appointments are structured – in terms of purpose and the interventions for unpacking the memory problem – provide no real 'space' or permissions for the researcher to develop rapport with appointment attendees. At the day-care and respite service setting practitioners, similarly, were a constant. Patterns of day-care attendance by individuals varied: some people attended day-care only during a stay in respite care; some people attended day-care because they happened to be staying in the respite service during assessment; some people attended day-care on regular 'set' days; and others were attending in order to try it out and find out whether it would be a satisfactory arrangement for themselves and their carers. Being ill, holidaying, or entering permanent care were reasons for non-attendance. Overall it was impossible to predict who would be there on days when I was there. Nonetheless, there were some people who did seem to mostly attend on their scheduled day(s) and this allowed me to spend time, engage in activities with, and talk with about ten people – with whom rapport was established. A further comment is that I became aware of potential limitations concerning rapport that were connected with a characteristic of dementia – that of 'forgetting'. The basis for, or content of, rapport established between a researcher and a person with dementia at one point in time may be forgotten by the person with dementia, and the threads of this may need to be re-established at each separate time of engagement between the researcher and the person. In both memory service and care settings establishing rapport may also be the basis for practitioners to carry out health or care interventions where the trust and confidence of the person with dementia

needs to be gained. Getting to 'know' an individual is likely to be a more realistic intent in a care setting (where there are possibilities for time spent together) than in the space of a memory appointment, where time duration tends to be relatively short and task or intervention focused.

In terms of protecting the identities of participants, I stated how I would address this issue on the participant information and consent sheets. I provided assurances of anonymisation of field-notes through removal of personal information such as the person's name, service name and location, and similarly anonymising quotations from participants used in the thesis. Regarding anonymisation of names, I opted not to use an individual letter followed by a blank (e.g. Mrs. H_____) but instead to use pseudonyms. I felt that using a blank name would have stripped out identity, whereas a pseudonym maintained a sense of persona. Selecting pseudonyms for participants was informed by norms in practice at the two service settings. In the memory service people with memory problems and carers were addressed by practitioners formally using Ms, Mrs or Mr. I emulated this by replacing real surnames with pseudonym surnames, except for daughters, sons or partners of the person with dementia where I replaced first names with pseudonyms. Since practitioners in the memory service mostly introduced themselves to people attending appointments using their first names I mirrored this by using first name pseudonyms, except for the consultant psychiatrist where I used 'Dr' followed by a family name pseudonym. In the social care setting individuals with dementia were addressed by practitioners using their first name (or less commonly their title followed by their family name), and people with dementia and carers used practitioners' first names. I adopted the same approach and used pseudonym first names, except in the case of a mother and father carer who I referred to as Mr and Mrs (and a pseudonym).

Absolute protection of identities of participants cannot be guaranteed or claimed in a research project such as this one which depends on narrative description and the possibility that in describing particular aspects of an individual the person might become recognisable to someone reading the thesis. I was very conscious of how language biases may creep into descriptions of situations and people and

was very careful during making field-notes to avoid representing something observed or heard with either a negative or a positive 'slant'.

I now turn to the matter of 'time' in a methodological sense in relation to my research project. I draw on perspectives from scholars concerning "time modes" (Jeffrey and Troman, 2004) in ethnography, and consider these in relation to my own project where I did not have one single long, uninterrupted period of time in fieldwork.

Wolcott's chapter 'On Ethnographic Intent' (1987) sets out one position on what ethnography is not. Wolcott offers a set of key statements, with corresponding caveats. His essential point is that the presence of individual ingredients of ethnography do not in-and-of-themselves make an ethnography or assure that the final creation will be ethnographic. The individual ingredients Wolcott refers to are 'field technique', 'good description', 'gaining and maintaining rapport with subjects', and 'length of time in the field'. Wolcott (1987:37) considers time in fieldwork as one of a number of 'necessary but not sufficient' ingredients of ethnography. He suggests that factors such as the individual researcher's skill, sensitivity, problem, and setting - as well as circumstances for pursuing fieldwork - are contingencies that inform optimum periods of fieldwork. Addressing this to my own fieldwork, on one hand the question was - what constituted sufficient time for achieving immersion and what duration of time would mean I could claim my work as ethnography? On the other hand the question was - if my work revealed deficiencies in duration of time what other modes of time might be helpful for re-framing the terms for my ethnographic fieldwork?

Knoblauch (2005) notes that the image of ethnography has been shaped by the actualities of long-term field studies common to anthropology, but that this image of ethnography is, in contemporary times, being reconsidered. One form that has emerged is "focused ethnography" - ethnographic work which focuses on small elements of one's own society and restricts itself to certain aspects of fields. It is characterised by relatively short-term field visits, with shorter time in data-collection substituted for by intensity of data-collection. (Knoblauch, 2005:1-8) Examples of eight ethnographic research projects in healthcare which have described themselves in the terms of focused ethnography are given in

Higginbottom et al (2013). Details of projects' time duration in the field are not provided, but data collection and analysis descriptions indicate the scope of each project inferring the duration of time in the field. For example, a study by Smallwood (2009) is described. Smallwood set out to explore, describe and interpret the roles of nurses in the culture of a cardiac assessment team, and this involved 7 semi-structured interviews, 5 participant observation sessions, and reflective field journals.

Pink and Morgan's (2013) exploration of short-term theoretically informed ethnography highlights a number of points about time. Research context and specific discipline, it is argued, are involved in characterising and shaping a particular ethnographic project. In healthcare contexts ethnography may involve intensive and short excursions into people's lives during which the researcher delves into questions that seek to "reveal what matters to those people in the context of what the researcher is seeking to find out". (Pink and Morgan, 2013:352) Theoretical engagement through a very focused dialog between research and theory is a particular feature of this mode (Pink and Morgan, 2013:352-3), and the authors suggest that this mode of short-term ethnography is very suited to interests in the nonrepresentational:

"the unspoken, unsaid, not seen, but sensory, tacit and known elements of everyday life".

Given that there is no actual 'standard' for duration of time in the field an ideal length of time in the field, Jeffrey and Troman (2004:536) suggest, is difficult to establish. Furthermore, Walker's (1986) thoughts (cited by Jeffrey and Troman, 2004: 538) – "ethnographic projects are never finished, only left, with their accounts considered provisional and tentative" – provide a different framing of the question of time: more as a question of how far has one got with one's own research question given one's own duration in the field. Jeffrey and Troman (2004:538-546) offer the concept of "ethnographic time modes" which they specify as 'compressed' (a short period of intense ethnographic research where the field site is inhabited by the researcher almost permanently for anything from a few days to a month); 'recurrent' (temporal phases such as the inspection of a statutory body, or regular points in chronological time, are sampled with a focus on ascertaining similarities and differences over time); and 'selective

intermittent' (specific rich contexts are selected and the frequency of time spent in the field is flexible and intermittent yet occurs over a sustained period of time). For my research project perhaps the most helpfully illuminating perspective on time in relation to ethnographic fieldwork is from Dalsgaard (2013). Dalsgaard highlights that 'the field' has typically been demarked in terms of spatial properties and defined by geographical distance. However, opening up to temporal-oriented thinking about the field generates other ideas about how the field is constituted:

“Defining a ‘site’ simply as a set of social relationships makes it as much temporal as spatial (see Okely 2007:360), and indeed, when replacing the longitudinal holistic study with question-based and time-limited projects, there seems to be an emergence of more and more ‘sites’, where it is primarily their temporality that is the defining characteristic that separates the selected site from that which it is not.” (Dalsgaard, 2013:214)

Thinking about my own project where fieldwork was not a long, single, unbroken duration of time, Dalsgaard's thoughts open up possibilities for differently emphasising time. Rather than thinking about my 'fieldwork' in terms of the timespan of my presence (Dalsgaard, 2013:217) and/or absence in which 'duration' is emphasised, I start to think about my fieldwork in terms of Dalsgaard's idea of "multi-temporality" of the field. This involves framing fieldwork as multi-temporal practice, "stretched between perspectives of time as duration (the experience of how the field is emerging) and time as dimension (the chronology of cumulative events that comprise it)". (Dalsgaard, 2013:222) How might such a framing of 'sites' as both multi-temporal and spatially-defined affect or inform a researcher's ethnographic practice? This brings to the fore the matters of engaging with the field conceptualised as spatial, and engaging with the field conceptualised as multi-temporal: the interplay between, on the one hand physically *being there* in the settings of fieldwork and, on the other, engaging with multi-temporality (e.g. temporalities of individuals and practice).

Thinking again of the ethnographic time modes set out by Jeffrey and Troman (2004), these become helpful for describing the temporal framing or temporal 'terms' for a specific research project. In terms of duration in the field, the time

mode that I would say characterised my fieldwork is 'selective intermittent' (Jeffrey and Troman, 2004:538-546). Undertaking ethnographic fieldwork within these terms does provoke the important question of what would be considered 'sufficient' time in the field to conduct ethnography and establish rapport with participants. For my research project, a long unbroken time duration in fieldwork would not necessarily have resolved the particular issue of rapport as there were other factors involved which were particular to the settings. The frequency of individuals' appointments with the memory service and the differing reasons and circumstances surrounding whether particular individuals attended day-care determined who I came into contact with and how frequently. These were factors that fundamentally shaped the options available to me for spending time with individuals and developing rapport.

Reflections on undertaking research in the settings and approaching the writing of the thesis

I provide some brief reflexive comments here about undertaking research in a memory service and a day-care and respite service, reflecting specifically on blending in or standing out.

Initially, being at the CSD Centre – the building where the memory service team was based - felt uncomfortable. I hung around in the team office, probably appearing to others as though I was doing very little in terms of research related activity. I felt oddly positioned in relation to the activities around me: practitioners on the phone to patients or other health and social care colleagues, recording information on the computer system, discussing a patient with another team member or arriving or leaving from or to a patient visit. My state of just 'being' –while noticing events in the office and entering into conversations with people - felt conspicuous in the context of the active 'doing' which was occurring around me. I felt less awkward in the care setting (Oak Hall), maybe because early on I began interacting with individuals with dementia which positioned me similarly to any other visitor to that setting. In the memory service once I began observational work in appointments and during home visits I felt that I was viewed by practitioners, clients and carers as a 'student' who happened to be doing a PhD. The wife of a man with dementia being seen in clinic asked me about

my PhD – where I was studying and how was I getting on, but this was the only occasion where attention was given to my PhD specifically. At Oak Hall, even though features of the setting made it easy for me to fade into its day-to-day normality, certain aspects would quite suddenly identify my role and position as different to that of others in the setting. For example, I was asked on a few occasions by individuals with dementia - who assumed I was a member of staff - if I would assist them to the toilet. Even though I always announced myself as a PhD researcher by wearing an ID badge, and I did not wear a uniform as direct care staff did, I sometimes needed to provide further explanation. Not having a swipe card meant I had no independent access into or out of locked areas of the Oak Hall building. This drew attention to a difference between staff and me, but also gave the ‘appearance’ of me sharing with people with dementia a lack of access. In fact, all I had to do was ask to be let through the locked door. I understood the rationale for locked doors but felt uncomfortable about the power imbalances surfaced in this – essentially that autonomy and agency was situated with staff, myself, other visitors: anyone who was not a person with dementia.

Making a difference is probably an overly optimistic hope for what a PhD might achieve, but more within reach in my particular case is, perhaps, to produce what Stoller (2007) calls "memorable ethnography". "Memorable ethnography" is memorable because it conveys to its readers a grappling by ethnographers and their characters -

"with the things most fundamentally human - love and loss, fear and courage, fate and compassion - deep issues that connect readers to the people they encounter in ethnographic texts." (Stoller, 2007:180-181)

The idea of an ethnography as an assembling together which, through skilful presenting of the juxtapositions of the items assembled, has an effect on readers is picked up by Willis and Trondman (2000). They describe the production of "'Ah ha'" effects "where evocative expression through data hits the experience, body and emotions of the reader". 'Ah ha' effects extend beyond any initial responses made by a reader, outwards, so that they "fuse old experiences with new ones, thus opening up readers' minds towards new horizons". (Willis and Trondman,

2000:12). Ethnographic texts, essentially, must "convince" (Golden-Biddle and Locke, 1993:595; 598-612), a process which concerns the persuasiveness of the narrative in terms of "authenticity" (the idea that the researcher 'was there' and conveys genuineness to the experience); "plausibility" (the ethnographic text rings true for the reader in terms of familiarity and relevance but is at the same time distinctive and innovative); and "criticality" (that the text disrupts and reframes the taken for granted, or the assumptive notions that the reader holds). Significant too are writing practices themselves in terms of the presenting of the narrative and the readability of the text to the reader. Ethnographic and narrative work that had struck a chord with me was mostly work that linked in some way to my own background and experiences. One cannot disentangle oneself from past experiences and knowledge, and this is self-evident. Golden-Biddle and Locke (199: 596) suggest that readers are "steeped in their own personal and intellectual contexts [and] engage and interpret the text by relating their reading to these contexts".

In preparing for and doing ethnography, and then writing it, 'time' took on a huge significance. Just the aspect of the judging of 'timing' for entering the field can be a critical factor (as I was to find out when one of my research settings was threatened with closure soon after entering the field), but also the beat of time which seems to quicken in the last stretch of the seven years allotted for undertaking a PhD part-time, concertinaing time. For engaging with temporality during doing and writing ethnography Dawson (2014:131) proposes a three-strand framework:

"Temporal awareness, that refers to a broadening of our understanding and sensitivity to time issues, for example, in recognizing that competing conceptions of time can co-exist; temporal practices, that relate to the research skills (practices) developed in doing the research, for example, in holding on to contradictory conceptions of time in the pragmatics of conducting fieldwork and in the analysis of competing data; and temporal merging, a concept used to capture the interweaving of time conceptions as well as the way temporality can be accommodated in the write-up of research material."

Furthermore, the polyphony of stories (about which one is constructing a sensemaking narrative) are themselves all engaged with time, from the participants' stories to the researcher's story. From my perspective writing ethnography involved holding different storylines and recognising the interweave with time: stories represent accumulations of human experience over time (looking backwards) and stories extend out into an future which is as yet unknown. In my writing I did not try to represent one definitive story, but I attempted instead to express my understanding about a unifying assemblage that provided linkages between the stories.

Chapter 4: case study of an NHS site

Preamble: scope of fieldwork

The Older Persons' Community Mental Health Team (OPCMHT) is a multi-disciplinary team based in the CSD Centre in the town of Northweston. The function of the team is to provide mental health care to older people experiencing mental health issues, including people with dementia. A specialist memory service is provided by the team offering assessment of memory, diagnosis, treatment and, if required, referral or signposting onto other services. The OPCMHT works under the auspices of the Two Shires NHS Foundation Trust. The trust provides inpatient and community mental health services for adults and children, Learning Disability and Drug and Alcohol services across 95 sites within two counties, and neighbouring areas. It also provides community based physical health care services in its west area, and a range of specialist services within a neighbouring city and four large towns.

Research fieldwork was conducted in the OPCMHT over a thirteen month period commencing in May 2014. During the course of fieldwork three staff members left the team, but at the point of entry into the fieldwork setting the team comprised a team leader; four members of medical staff; four administrative staff members; three specialist roles consisting of an Advanced Practitioner in Dementia, a Nursing Home Liaison Nurse, and two Memory Review Nurse Practitioners; four community mental health nurses; one assistant practitioner; one clinical support worker; two social workers, and two occupational therapists. The fieldwork involved observing patient/practitioner appointments in clinic, usually with a carer or family member present; home visits (approved via submission of a substantial amendment for this aspect of fieldwork by the REC on 1 July 2014: Ref. 14/NW/0090); a course session of the Wellbeing College where I observed carers; and observations at one team allocation meeting. In addition I conducted semi-structured interviews with two of the clinicians whose clinics or home visits I had previously observed.

Detailed summary of fieldwork

The fieldwork involved in situ observations of a total of 54 individuals, of whom 16 were people with memory problems, 15 were practitioners from the OPCMHT,

and 23 were carers or family members. The settings for observations were the CSD Centre (i.e. clinic rooms, the team meeting room, the team office, and a seminar room) and the homes of individuals referred to the memory service. Observations during prescheduled clinic appointments with a practitioner at the CSD Centre were attended by the person with memory problems and, in most cases, a spouse/partner or other family member. Between May and December 2014 thirteen such clinic appointments were observed, where the individual was being seen by either Laura Newton (Advanced Practitioner in Dementia) or Dr Ozha (Consultant Psychiatrist). For two of the appointments observed the individual with memory problems attended alone. In November 2014 fieldwork was extended to include observations during home visits. This required submitting a substantial amendment to the REC (approved on 1 July 2014: Ref. 14/NW/0090). Other observational work consisted of a team allocation meeting (September 2014) and a Wellbeing College seminar for carers (March 2015). About 15 hours were spent in informal activity including sitting in the team office; conversations with team members; liaison with the secretaries about clinic appointments that I could potentially observe; conversations with the administrators for the Wellbeing College; attendance at a Two Shires NHS Foundation Trust best practice event at which members of the team had a display stall about the service; and attendance at a meeting of the local Clinical Commissioning Group.

I interviewed two of the clinicians whose appointments with individuals with dementia I had already observed (Advanced Practitioner in Dementia and Community Psychiatric Nurse). I was unable to secure an interview with the Consultant Psychiatrist whose clinics I had observed, despite attempts made to do so.

Alongside fieldwork in the NHS setting I was required to provide regular updates by email to the Two Shires NHS Foundation Trust R&D department on recruitment, and to complete a yearly audit. I was also required to demonstrate that my project met formal research and information governance requirements (i.e. participant consent, recruitment, and maintaining a site folder). Compliance was monitored through a formal site monitoring visit from the R&D department's site monitor.

In total about 45 hours was spent doing observations, interviews, and attending meetings. This did not include either travel time to the sites of fieldwork or administrative aspects of fieldwork.

The observational work is presented in chronological order, and data from the two interviews with practitioners is pulled into the narrative and is used for elaborating on and explaining certain aspects of practice.

Setting the scene

It is common for the first face-to-face meeting between the individual with suspected memory problems and one of the team's registered practitioners to take place in a clinic setting. For the person, and often their carer too, this is a significant moment during which assessments of cognitive functioning are completed, from which indications and evidence of the presence of memory problems are relayed to and discussed with the person. Further tests may be requested, such as brain or MRI scans, but already there is a strong sense that the stage is set for a diagnosis of memory problems of some sort. A diagnosis of dementia may not be life threatening but it is almost certainly life-changing for the individual concerned.

The doing and the knowing: the work of the Advanced Practitioner in Dementia

I start by providing an account of the scope of the work of Laura Newton - the only Advanced Practitioner in Dementia in the team and a qualified RMN (Registered Mental Nurse) by background. This first section is primarily developed from interview data, supplemented by notes from observations, and from notes I made after conversations with Laura. My conversations with Laura were brief and occasional, only occurring when Laura had time to talk between her appointments, and consequently I have few notes from conversations. My decision to present some of the interview data at this early stage was made on the basis that the comprehensive account Laura gave during interview detailed aspects of Laura's professional background, her role, and the team context - which was information that might only be *inferred* during an observation of an

appointment. For example, observations of appointments on their own were not sufficient to enable me to comprehend the team's process of referral.

Laura runs a clinic in which she sees up to eleven patients per week. Patients are often accompanied by a family member, commonly their spouse or partner, or daughter or son. In the context of the appointment setting there is much happening in the interactions between the people involved: subtleties of communication such as a hesitation, emotional timbre, eye contact, facial expressions, and laughter.

Laura described specifics of her role in terms of referrals coming into the team:

"It's my role to do the bulk of new memory referrals so primarily from GP practices, practically all of the referrals are from GPs, sometimes from liaison psychiatry and occasionally from social services, but the bulk are from GPs. And what we do is we triage the memory referrals and if they seem to be reasonably straightforward, not too complex, then I will tend to do them. If, for example, they are younger people with memory problems, people with co-existing mental health problems, so a history of schizophrenia, that kind of thing, or where one of their main problems seems to be perhaps that the patient's depressed and has memory problems, then they will tend to go to a consultant, but other than that I will do the bulk of the memory referrals."

(Laura, interview)

Laura gave a start-to-finish summary of her role with patients - the process that applied to the majority of the patients she saw:

"So I will assess the patient either in their home or in memory clinic, usually send them off for more tests if I think there is a likelihood of dementia and then I'll see the patient again with the results of those tests and deliver a diagnosis. And then initiate medication - if that's indicated for the patient - and then I will see them usually after about three months to follow up, to make sure they're OK on their medication, reasonably stable, no side effects, and just check they've got all the services they need in place and then I'll pass them over to the memory nurse reviewers." (Laura, interview)

The vast majority of patients seen by Laura were referred from a General Practitioner (GP) with concerns that an individual had dementia-type memory problems. In most cases it was confirmed in the memory service that the individual had either dementia or mild cognitive impairment (MCI). The relatively uncommon instances of inappropriate referral included women experiencing memory problems associated with menopause, people with acquired brain injury, or memory problems that were associated with heavy drinking - these referrals often being of younger people, sometimes as young as twenties or thirties. The prevalence of young onset dementia (under the age of 65) albeit relatively rare is also difficult to spot, and thus any referral - regardless of age - needed to be investigated. As Laura explained, with these referrals the team preferred those people to go to Neurology first for in-depth screening and scans but: "we will see people with memory problems for whatever reason." The misconstruing of the nature of the service was considered one possible reason for the sometimes inappropriate referrals:

"I think that's because we call it a memory service as opposed to a dementia service." (Laura, interview)

Nonetheless, in a small minority of cases - Laura estimated two or three people in a year - it became apparent that these individuals who had been referred into the team did have early onset dementia.

Some referrals that Laura picked up were of people with memory problems that were unspecifiable. The term 'watchful waiting' is commonly used in healthcare to refer to the process of keeping an eye on a potentially emergent health problem whilst not actively intervening with any treatment. Those people for whom it was not possible to make a diagnosis of dementia Laura kept on her caseload so that she could monitor them:

"I suppose where it gets a little more complicated is some people when you see them have what's called a mild cognitive impairment, so you'll think it's more than just an age-related memory problem but you wouldn't feel confident to diagnose dementia. So then I will tend to see those patients again after six months and just keep an eye on what their memory's doing." (Laura, interview)

There were some people Laura saw with whom her role needed to stretch out to address not only their memory problems but also other dimensions of life where risks and complexities would pop up:

"And the other thing that can be more complicated is if somebody comes and actually they're not all that straightforward, when you get them in clinic they are, perhaps, depressed or they have other risk factors or there are safeguarding issues, that kind of thing. So quite often even though they look on paper as though they're reasonably stable and just need memory assessment, sometimes when they come to clinic we do actually have to get lots of other services involved with them and then I'll tend to keep those patients on for longer." (Laura, interview)

Not everyone referred into the memory service was always amenable to support. Laura described how she sometimes needed to negotiate with individuals in relation to additional support, utilising the rapport she had established with a person as the basis for then acting as a sort of support 'broker' between the individual and other members of the team. She gave one example of this:

"The other thing that I'm thinking about doing a little more often is working more closely with the Occupational Therapists and the reason for that is that quite often the patients who are most in need of some help and input at home - and I'm particularly thinking of a couple of patients that I have that are living in quite distressing conditions - let's say, their houses are in quite a neglected state and they're in quite a neglected state and they are absolutely adamant that they don't want services in. And I have to try and respect that but at the same time I'm wondering, because they've let me in quite happily, if I was doing joint visits with Occupational Therapists, maybe some of those patients would agree to see somebody that is actually already there and have some input from them. So I genuinely want to help these couple of patients that I'm thinking about but I have to be mindful and respectful of the fact that at the moment they're saying they don't want social services' input or don't want any more referrals." (Laura, interview)

Laura was undoubtedly a clinician of considerable experience and standing within the team, with her level of expertise reflected in the scope and responsibility that

her role carried. The acquisition of knowledge and skill for nursing practice that Benner (1982) describes is one way of comprehending the progression from novice to expert. Laura eloquently described becoming an Advanced Practitioner:

"I suppose many years ago when I was first training as an Advanced Practitioner and spent time with Consultants looking at how they assessed patients with dementia, what I was, I suppose, trying to do is build my own way of how I was going to adequately assess somebody so that at the end of an hour's assessment I could come up with some kind of impression and know whether I was going to refer for tests or a review or discharge or whatever. And I started looking at how I could write down what they were saying, how I could capture what the essence of what all these different consultants were doing and what was important. And I suppose from that - although I don't have anything written down - I have a very routine, set way of working when I'm assessing patients so I will kind of follow a medical model in terms of looking at presenting complaint, physical health issues, past medical history, physical health check, looking at current medication, doing that in a very routine way, but also in asking the same sort of questions in a fairly routine way."(Laura, interview)

Laura had a defined role within the team as advanced practitioner in dementia, but working to that role was not the whole story. Rather, the role was hewn and fashioned by Laura, given a characterisation by her based on her own experiences, acquired knowledge, and particular interests.

Appointment structure

In this section I describe from my observations of Laura's appointments their structure and format.

On the ground floor of the CSD Centre there were a number of clinicians' offices, which often doubled up as clinic rooms, and it was in one of these rooms that I sat in on Laura Newton's appointments. Appointments were not 'formulaic', but I observed a loose structure in terms of content and process, described by Laura in interview as "a routine, a set way of working". From Laura's perspective the focus

was the assessment of memory, but there was a prelude, a leading into this, a necessary setting of the scene before the topic of memory was broached. All appointments began informally, with introductions and maybe a brief exchange on something topical such as the weather. The formal part of proceedings usually opened with Laura outlining the reasons for the appointment. If this was the first time the person was being seen, the contents of the referral letter (usually this came from the individual's GP) would be summarised. The next part - in some senses the most delicate - was where memory was asked about explicitly. At this juncture a partner, family member or carer was often also asked for her/his perspective about the individual's memory. Laura's questions were usually couched in terms of any noticeable changes to the person's health and memory. A gathering-of-information section followed, which included questions about recent or historical physical and mental health, and current medication. There was also a brief physical examination, most often consisting of taking blood pressure, pulse, and sometimes requesting that the person demonstrate their mobility and agility by performing a movement such as raising an arm or leg. Laura's questions, along with the physical examination, were the means for probing for signs that may indicate the person had some form of memory problem. What generally followed was a formal assessment of memory. For people being seen by Laura for the first time the full Mini-Mental State Examination (MMSE) was used, whereas for a review appointment Laura might use the short form of the MMSE. After the test Laura relayed her conclusions back to the individual and outlined further actions, which might include asking whether the person would be willing to have an EEG or a scan. The person and their accompanier were given an opportunity to ask questions at this point. The final part of the appointment was concerned with the social context for the assessment of memory. This involved Laura seeking clarification from the person and their accompanier about any support they were receiving, and the offering of relevant information such as how memory was affected by the specific type of dementia, potential side effects of medication, practical information (e.g. how prescription ordering works; what a scan would involve should the person be referred for one), and in some cases signposting the person to relevant sources of support. Addressing the social context of being assessed for and diagnosed with

dementia is considered a critical part of the assessment process, without which the testing of memory can be experienced as threatening and anxiety provoking to individuals with memory problems (Cheston and Bender, 1999).

Having set the scene for this chapter by introducing the team, the fieldwork setting, Laura herself (advanced practitioner in dementia) whose appointments form a large part of the practice I observed, and the appointment structure I now commence with my account of observations of appointments beginning with three clusters of appointments between Laura and people with memory problems. Then, two of Dr Ozha's appointments; a Wellbeing College seminar for carers; and lastly two home visits with a community psychiatric nurse. This chapter concludes with a gathering of insights that have accumulated and how these define or shape the fitting together of the three concepts of tacit knowledge, practice and time.

Observations of Laura's appointments: the first clusters

My first observations were of four appointments over the space of a morning, the first being with a Mrs Maddox who was accompanied by her husband. This lady was newly referred by the GP who had concerns about Mrs Maddox' short-term memory. Laura used the letter from the GP as the basis for opening up a conversation about memory: what had Mrs Maddox noticed about her memory? A story emerged of Mrs Maddox noticing problems with her memory over the past year and, when Laura continued to gently probe into how this affected her everyday life, it seemed that this line of questioning provoked anxiety:

Mrs Maddox speaking: "I've seen people a lot worse. I never want to go like that." [...] "I just wanted to be normal. Are there a lot of people who go like this?" (Fieldnote 24/6/14)

Mr Maddox rallied to his wife's aid, seemingly attempting to soften the magnitude of the topic of the conversation by his suggestion that problems with her memory were intermittent rather than constant:

"It's been going on, little things, for a number of years. I think it's gone a little bit worse, but sometimes it just seems normal" (Fieldnote 24/6/14)

The word "normal" as used by both Mrs and Mr Maddox seemed to situate dementia as not normal, or as representing a moving away from normal. From Mr Maddox' perspective his wife's memory seemed normal *sometimes*, as though the problem of dementia was intermittent.

This exchange between the Maddox' and Laura surfaces the idea that an individual's memory problems may initially appear as occasional forgetfulness that fades in and out of prominence, seemingly nothing to be concerned about. However, this sense changes when the individual is first exposed to external scrutiny: perhaps it is during a routine check-up with the GP that memory problems become apparent.

Mr Maddox expressed that he was intervening with greater frequency to assist his wife in everyday activities of living. He seemed to normalise this assistance, referring to the sharing of activities and jobs around the home. Yet, he had also taken practical measures suggestive of someone preparing for a future problem of unknown proportions. He had made sure their Will was up-to-date and had put in place measures to try to maintain a safe home:

"We've tried to cover everything. We have the alarm system. We have a meter for any gas leaks". (Fieldnote 24/06/14)

In the appointment Mrs Maddox was encouraged to focus on her memory through Laura's request that she give attention to how her memory had been recently. This temporal framing of memory which was inherent in Laura's questions is interesting in terms of how this was responded to by Mrs and Mr Maddox. In her response to Laura Mrs Maddox placed her memory problem as emerging over the past year, whilst her husband said that "little things" had been occurring over a number of years. In Mrs Maddox' words there is also a juxtaposition between the other people she has previously seen with deteriorating memory and her own lived experience of memory problems *now*. Her words expressed a sense of apprehension about the possibility that her memory would deteriorate, already having seen the evidence from other people that memory problems usually get worse rather than better over time.

When I met Mrs Maddox it was at a point when she was continuing to engage in the activities she had been involved in, probably all her adult life. What was

changing now was that her husband was assisting her and even taking over some of these tasks:

Mr Maddox: "I blame myself really. I think I do a little bit too much for her. At times she feels normal. In the house we share duties, make it a joint event".

(Fieldnote: 24/06/14)

The situation of Mrs and Mr Maddox appeared to be characterised by change: as Mrs Maddox' memory worsened and affected her everyday life Mr Maddox adjusted to this by stepping in and filling in the gaps in tasks and routines that Mrs Maddox could no longer manage herself.

Laura carefully broached her view about the nature of the problems Mrs Maddox was experiencing - not using the word dementia but phrasing the problem as: "I do think that your short-term memory isn't so good". She then followed this with assurances that there would be further tests done, which seemed to provide some feeling of relief to Mr Maddox who commented that now "at least" they were in the system. The normality of life that the Mr and Mrs Maddox used to enjoy seemed to be retreating characterised by Mr Maddox moving into a carer role, and both looking at a future coping with the effects of dementia.

After the appointment with Mrs Maddox a lady called Mrs Bourne (accompanied by her husband) arrived. She was here to see Laura for a follow up review from a previous appointment. Since her last appointment she had attended the hospital for a CAT scan (computerised axial tomography) and an ECG (Electrocardiogram). Laura read through the CAT scan results and then interpreted, drawing attention to it being "quite good news", "a good scan" because there was whole brain shrinkage rather than selective, and there was no cerebral infarction which would have been indicative of a stroke or mini stroke. Nor was there evidence of any ischemic changes to the brain detected on the scan which Laura described as unusual, but also good. The scan did not provide sufficient grounds for a diagnosis of dementia, though Alzheimer's disease could not be ruled out entirely. Laura's appointment routine, her set way of doing things, did not in practice ever seem to translate into a prescribed or scripted approach in her questions to people with dementia and their family members and carers. During this

appointment she asked Mrs Bourne and her husband a question that initially appeared to me to be un-crafted and simplistic: "What is really troublesome?" Speculating further about this question and thinking about it in the context of other appointments subsequently observed in the course of fieldwork I concluded that there was a family of questions like this, all open ended and, I guessed, archetypal in the sense of having a concentrated purpose of trying to get to the nub of how a person is being affected by their memory problems. I imagined also that the use of questions like the one asked emerged from years of practicing in the field and being exposed to many different situations involving individuals with dementia. This accumulation of practice, I imagined, ultimately led to a knowing of what one was seeing (diagnosing) but also, alongside, a *knowing how* to ask the right questions of individuals and carers, to tap into their resources of experiential knowing.

Thinking along the lines of accumulated practice, from sitting in during Laura's appointments I gained an impression of practice being multi-faceted. Alongside certain observable expressions and performances of clinical knowledge (e.g. clinical procedures and explanations of medication) there were also the unseen processes of thought and making judgements about the individual's memory difficulties. Laura's conclusions were subsequently verbally articulated to the person in the clinic room. Even the *manner* in which conclusions and information were conveyed to the individual might be considered a facet of practice.

Mrs Bourne, Laura concluded, probably had MCI and the approach would be to watch and wait. The reality of this for Mrs Bourne was that she would be invited back for a review by Laura in six months' time and any problems that arose in the meantime should be directed to the GP. The care pathway for people seen by memory services in Northweton and its surrounds could be described as being designed around dementia exclusively in that - aside from assessment - the pathway was not geared for people with MCI. Given that there is credible evidence that suggests that MCI is a risk factor for developing dementia this waiting without intervention approach provided to people with early signs of memory problems but no formal diagnosis of dementia, seemed rather bleak.

The third person to arrive for an appointment was Mr Burton who attended unaccompanied. My immediate impression was of an independent and unimpaired man, although this was not his first appointment with Laura indicating that memory problems had already been identified. The conversation began with discussing medication. Mr Burton described how he was having dizzy spells, nausea, and was feeling light headed. Laura checked his blood pressure and pulse, relaying to him that his pulse had slowed a little, but that this can be an effect of particular medications. Mr Burton described his memory problems in terms of not remembering, and forgetting:

"I'm fine....it's just the memory, you know. It doesn't seem to be any worse, but it hasn't got any better." (Fieldnote 24/06/14)

And later on in the appointment:

"An example of my memory... I looked at the letter before coming in, and I couldn't remember your name." (Fieldnote 24/06/14)

Laura expressed concern about risks in everyday life, and asked Mr Burton about how he was managing with things such as remembering to lock the door at night or when the house was unoccupied. Mr Burton was forgetting to lock doors. But, in spite of a degree of impairment he seemed to be getting on with his everyday life: managing to hold down a cleaning job as well as delivering leaflets for a local charity, and he and his wife had put their house on the market. My impression of Mr Burton was that alongside the sense of just getting on with life as usual there were unexpected moments of forgetfulness which strayed into his daily routines causing some disruption, but not yet creating a serious problem for him. Laura advised him that she would arrange for him to be seen by one of the nurses from the team in three months' time - a "handing over" - indicating that there would be no further appointments with Laura for the time being. Mr Burton was at the stage of his memory problems being relatively mild, but he nonetheless had a cognitive impairment - an identified risk for progression to some form of dementia. Interruptions to daily life arising from momentary forgetfulness that anyone may experience from time to time are generally speaking unrelated to dementia. The notion of lapses in memory does represent a point of interest since temporarily forgetting is such a widely experienced phenomena that it might even

be considered 'normal' to forget. Fuchs (2016: 9) has given attention to this, noting that in everyday life confusion may arise and it may take some time "to remember where I am, what time of day it is, or even who I am". In Mr Burton's case it was not that forgetfulness was inconsequential. Indeed, there were implications of forgetting such as Mr Burton overlooking an important action which might have led to exposure to a risk.

When Mr Burton forgot to lock the door at night this was probably not a huge issue because he lived with his wife and he could rely on her to check that the door was locked. Going out in the day and forgetting to lock the door, bearing in mind that his wife was not at home during the day, *was* a problem. Practically, Mr Burton could not be relied upon to definitely lock the door, nor was it certain that the question would come to him implicitly - 'have I locked the door?' Mr Burton was aware and knew he was forgetting things, and in the appointment Laura's questions seemed to be directed towards establishing what sort of impact his memory problems were having on his everyday life.

Mr Burton's situation raises the question of the nature of the juxtaposition between a person's level of impairment and the risks they are exposed to. Does a more significant memory impairment always mean greater exposure to risk? Laura's illustrations given during interview suggested that the juxtaposition of impairment with risk factors was generally unpredictable. There were some people who looked "on paper" as though they were reasonably stable, but when they were seen in clinic it turned out that there were quite significant risk factors (e.g. issues related to safeguarding) that required a multi-agency response. Laura listed some of the risk factors she routinely asked patients about: whether the person was still driving; was s/he forgetting to switch off the cooker; or forgetting to lock doors. 'No' answers to such questions usually indicated that the person was reasonably stable -

..."but for other people the risk factors are the biggest reason why they're presenting with their memory difficulties, so you may need to spend an awful lot more time if somebody's leaving the house at night and getting lost or forgetting to take all their medication or taking too much medication. So things like risk factors sometimes you can deal with it really quite quickly,

other times it's the main issue for a patient's presentation." (Laura, interview)

The potential incongruence between level of impairment and exposure to risk was further elaborated on by Laura:

"We have people who are really quite impaired living alone at home and we have people who are only minimally impaired but are having to be moved into residential settings because of their risk factors." [...] "So we can have somebody who's quite impaired but is actually perfectly happy sitting at home all day long just having carers come in two or three times a day to make sure that they've got things to eat, and they'll sit and watch TV quite comfortably and won't ever do anything else. Sometimes people with minimal impairment will be going out, losing their money, not being particularly safe on the roads, still feel perfectly capable to manage their lives but actually - because of their lack of awareness of some of the risk issues - are quite vulnerable." (Laura, interview)

Given these examples from Laura, and the specific example from Mr Burton's situation, questions arise concerning the delicate topic of *when*. That is, when is the point that the exposure to risk tips the balance and it becomes necessary to intervene? Laura seemed to have judged Mr Burton to be stable because her intention now was to hand over to one of her nurse colleagues who would review him in due course, but at the same time there was an acknowledgement that there was at least one risk factor that persisted - forgetting to lock the door.

The final observation of the morning was of Laura's appointment with Mr Wooler, who was accompanied by his wife. The conversation initially concentrated on the recent retest of Mr Wooler's driving through the Driver Vehicle Licensing Authority (DVLA). Mr Wooler had recently received a four-page letter from the DVLA notifying him that he had failed the test and the reasons why. In spite of this news Mr Wooler seemed upbeat: "You don't forget about driving"; whilst his wife had the view that not driving would save them money, with no road tax, MOT or vehicle insurance to pay. Mrs Wooler proceeded to provide Laura with an

update on Mr Wooler's physical health. He had been a possible candidate for surgery to sort out a vein blockage in his legs, but the operation was considered too risky, a state of affairs that Laura was already *au fait* with as it was recorded in his notes. The conversation moved on with Laura tactfully asking about any other changes, to which both Mr Wooler and his wife responded by saying that his memory had improved. The short form of the memory test which Laura then administered did not show evidence of memory deterioration. Mr Wooler was taking medication for his memory problems - Donepezil, which is in the family of cholinesterase inhibitor drugs often prescribed for people with Alzheimer's disease and some other dementias. These drugs work by boosting the level of a chemical in the brain that seems to help memory, and can result in improved cognitive function. However, one not uncommon side effect which must be monitored by a healthcare professional is that a person's pulse and heart rate may be slowed. A blood pressure and pulse check carried out by Laura revealed that his pulse had slowed. Laura reassured Mr Wooler telling him that although his pulse was "a bit on the slow side [it] has always been a bit slow. No harm". But nonetheless she would write to the GP to ask whether the other medications Mr Wooler was on might be reduced, and in time Laura may need to reduce the Donepezil dosage.

Neither Mr nor Mrs Wooler seemed particularly perturbed by the situation they were in- that of living with dementia. It seemed that for the moment at least that Mr Wooler's memory problems were not impinging on their lives to any great extent. In fact, Mr Wooler talked about how he had been working on building a dolls' house "from memory" over the past seven years, and was currently wallpapering it. Even in the face of what appeared to be a major issue facing Mr Wooler - the vein blockages in his legs - this couple were remarkably upbeat and, it seemed, had great confidence in Laura and her management of Mr Wooler's treatment:

Mr Wooler to Laura: "I'll just keep doing what you say and I can't go wrong then." (Fieldnote: 24/06/14)

The second cluster of appointments I observed was a week later, with the first person to be seen - a Mrs Ladley - newly referred by the GP and accompanied by

her daughter. The letter from the GP to Laura stated that both Mrs Ladley and her daughter were concerned about Mrs Ladley's memory. Laura began by addressing Mrs Ladley, opening with a question that seemed simple and unremarkable but having profound implications:

Laura: "Do you think you have a problem with your memory?"

Mrs Ladley: "Yes. I was a bit heady, and can't remember..." [tails off]

Laura: "Do you think it's worse than your friends' memories?"

Mrs Ladley: "I play bridge - it [the ability to remember] depends who you are with"

Laura: "Are you aware you are forgetting conversations with people?"

Mrs Ladley: "It creeps up on you...I try to write everything down". (Fieldnote: 1/7/14)

As the conversation progressed it became apparent that there were discrepancies between Mrs Ladley's account and that of her daughter:

Daughter: "She can't remember conversations that we've had. She can't remember family news. I have to write things down for her. She hasn't played Bridge for six months". (Fieldnote: 1/7/14)

These were frank words, voiced to Laura, but with Mrs Ladley present and party to the conversation. Mrs Ladley had become "she". There was frustration in Mrs Ladley's daughter's voice. She was faced with a changed and changing situation, one which was now starting to impinge on her own reality. She was taking up the reins and filling in the gaps where Mrs Ladley was beginning to struggle, compensating for her mum's memory difficulties, giving reminders and writing things down. The strain of this seemed apparent in Mrs Ladley's daughter's expressions of exasperation with her mum, and distilled in her words:

"It's hard when you're doing it *all*." (Fieldnote: 1/7/14)

Laura asked Mrs Ladley's daughter how long she thought the problem had been going on for. "About seven years?" was the response, followed by an explanation that the start of the problems coincided with a stroke that Mrs Ladley had in 2007. Mrs Ladley's daughter presented a narrative of events in chronological time: the

stroke in 2007, and her mum not having played Bridge for six months. Mrs Ladley herself had a clear view of the far past and recounted childhood experiences of school. This memory, it seemed, was within her power to recall:

Mrs Ladley: "I can remember certain things like that, quite easily."

(Fieldnote: 1/7/14)

Her short-term memory, though, was vague. Mrs Ladley remembered that a cleaner was coming in, but the discrepancy between hers and her daughter's recollections about the level of support and who was providing it was evident. Another 'correction' of events from her daughter followed:

"I'm going in nearly every day." (Fieldnote: 1/7/14)

These parallel narratives of mum and daughter suggest divergences - each account indicating a view of placements of events in time - and perhaps indicative of two differing temporal experiences. The clinician, Laura, seemed to act as a sort of moderator to these two temporal accounts. Laura, undoubtedly, had seen such gaps between patient and carer accounts on many occasions before.

The situation of Mrs Ladley may be seen as one where memory problems impinged on normal going about one's daily life - the normal routines of life that are set in time and, to a certain extent, ordered by time (e.g. waking, sleeping, mealtimes). Liaschenko, in Thorne and Hayes (1997: 28), expressed this idea of going about daily life as the "routines of lived experience". If these are disturbed or interrupted by disease, injury or disaster Liaschenko (citing Charmaz, 1991) notes that "our subjective sense is that our lives, and not merely patterns of clock time, are affected". The fact that Mrs Ladley's daughter was going in every day to check on and assist her mum - yet Mrs Ladley's version of her own life (playing Bridge, and doing what she had always done) was very different - suggested that memory problems were creating ongoing disruption to the normal experience and routines of life.

The living arrangements for Mrs Ladley were becoming ever more precarious and fragile. She had fallen in her garden, and she had tripped over in her bedroom resulting in two black eyes. There was some doubt about whether she was remembering to eat - even though her daughter cooked and plated dinners for her

it was not certain that she was always eating these, and whether she was managing to independently prepare something for her tea was also questionable. There was an occasion when Mrs Ladley had left the gas on, and she did not always remember to lock the doors at night. There were also concerns expressed by Mrs Ladley and her daughter about the medication she was taking, particularly statins prescribed for cholesterol. Both wanted the statins to be stopped, or reduced. For Laura the statins were less of a worry: her view was that Mrs Ladley was on the right level of medication and getting this changed would be a matter for Mrs Ladley and her daughter to consult with the GP. What concerned Laura most was that Mrs Ladley might have further falls. For the time being the fall risk and other risks that had been spoken about during the appointment were essentially being 'absorbed' by Mrs Ladley's daughter. But, there was some slightly better news in relation to Mrs Ladley's memory function. The results from the short form of the memory test Laura conducted were notable enough for her to comment. On the drawing exercise Mrs Ladley had done well:

"The drawing is really quite good. This is surprising" (Fieldnote: 1/7/14)

Laura felt surprised perhaps because Mrs Ladley's performance was not what Laura had expected given the descriptions from Mrs Ladley's daughter about her level of impairment. Maybe Laura was erring towards the daughter's account being more credible than Mrs Ladley's, and the good drawing represented something of a disturbance to the daughter's narrative.

Towards the end of the appointment Mrs Ladley's daughter asked what help was available. When Laura answered she perhaps had in mind the risk of falls that had surfaced during the conversation earlier. Referral to an Occupational Therapist, various meal delivery options and, possibly, the need for a care package were Laura's thoughts. Asking for help, as Mrs Ladley's daughter was doing, is perhaps one indication that one's own resources to manage are now either insufficient, exhausted, or both. Some attention has been given to the significance of the *when* of carers asking for help, for example by Newbronner et al (2013) who reported on a study of the experiences of the journey of care by family carers of people with dementia. The findings highlighted that caring for someone with dementia was characterised by being a "long-term and changing experience" in contrast to the

characterisation of typical encounters with health and social care practitioners being "short term and episodic". (Newbrunner et al, 2013:70) These encounters with service providers and other professionals were viewed as potentially critical in terms of often being the points in time when carers' needs for help, advice and information would be most acute. If professionals either failed to recognise carers' needs when there was the opportunity to do so during contact, or were poorly equipped to advise and support, this ran the risk of care-giving breaking down and the knock on effects of this such as impact on physical or mental health. Laura's concerns about Mrs Ladley falling, and the tangible offers of help that she put to Mrs Ladley's daughter, signified that she did recognise that there was potential for the care relationship between Mrs Ladley's daughter and her mum to break down. The likely consequences of a breakdown in this family care relationship were not voiced but undoubtedly Mrs Ladley's daughter had at least an inkling that this might push her into a situation where permanent long-term care would have to be considered.

The next person Laura was to see - a Mrs Eadie - did not show up, although I did meet this lady a fortnight later at a rescheduled appointment. Laura's response to the 'no show' was to phone Mrs Eadie at home. Mr Eadie answered and explained that his wife was out shopping. It seemed as though she had not received the appointment letter, or that she had forgotten. There was now an unexpected space before the next appointment which Laura used for reviewing notes and catching up with phone-calls. I sat and waited, conscious of how busy Laura was, and that even when it seemed there was a moment available to her to reflect on clinical work there were always more pressing matters that she needed to attend to in relation to clinic and other appointments.

The next scheduled appointment that day was with Mrs Osborne who arrived with her daughter. Mrs Osborne was here for a review appointment, and Laura began by asking whether there were any changes in her health or her memory.

"Occasionally, you know, you worry you've said the wrong thing". (Fieldnote: 1/7/14)

Mrs Osborne appeared to be quite passive, barely speaking during the appointment, her daughter instead providing most of the responses to Laura's questions. As the appointment progressed a narrative emerged about Mrs Osborne's weight loss and the possible reasons for this. Her daughter was concerned because although there were meals being delivered to her mum and paid carers were there at lunchtime to ensure that the meals were offered, Mrs Osborne was refusing these, saying that she was not hungry. Laura questioned why the carers weren't monitoring food consumption, and asked Mrs Osborne directly whether she knew why this was happening. Laura was interested in whether the 'not eating' problem had been worse since Mrs Osborne had started on prescribed medication, since it was known that the particular medication she was on could reduce appetite. Mrs Osborne's daughter corroborated Laura's theory - yes, her mum's appetite had diminished since she had started on the medication. For Laura the eating difficulty required a collective solution: "How can we get over these problems with food?" Might a solution be for carers to spend more time with Mrs Osborne, cook her a meal, and eat with her? Laura was putting forward this suggestion without knowing the full details of the domiciliary care arrangements that had been put in place. For example, it may well have been the case that, - from the domiciliary care agency's perspective - time constraints were an issue. Time constraints for care visits have received much attention in national news in recent years, the problems associated with time typified in the idea of the fifteen minute care visit. Some local authorities continue to commission these very short care visits (Moriarty et al, 2014: 85), often unsatisfactory for addressing the complexities of needs related to dementia, and unsatisfactory not only from the individual's perspective (not getting their needs met) but also from the perspective of family carers who are putting their trust in the care being provided. Short visits, in Mrs Osborne's case, would have prohibited care staff from going beyond the basics of heating a meal and putting it in front of her.

It was not just Mrs Osborne's daughter and Laura who were concerned about this. A member of staff from a local housing association was visiting Mrs Osborne regularly, and had also expressed concerns about her not eating. It was particularly important for Mrs Osborne to have regular meals - she had diabetes.

Furthermore, her daughter said there were occasions when Mrs Osborne had put her medication in ornaments, so had not taken it, and this posed a risk in relation to the continued successful management of her diabetes.

There were other risks too. Mrs Osborne had an alarm which she wore on a lanyard, but when she fell recently she was not wearing the alarm. Her wandering out on the streets was worrisome to her daughter: "Is she forgetting where she is going?"

Mrs Osborne's perspective was very much less dramatic: she was simply walking to the paper shop every day to buy a daily newspaper. The facts were that she was able to remember both where the shop was *and* the name of the newspaper she purchased. Laura's administration of the short form of the memory test revealed little deterioration in Mrs Osborne's memory. Putting in extra support to Mrs Osborne at mealtimes certainly looked like a way of resolving the eating problem, but the longer visits that would facilitate this were contingent on care agency staff availability and resources. Although potential solutions were defined by Laura she could not really influence the outcome, and it would be left to Mrs Osborne's family to negotiate a solution directly with the social services care manager and the home care agency.

Taking stock of the appointments

In these first two clusters amounting to six observations of appointments there are some points that begin to build up from aspects that seem interesting and may also act as connectors between different 'cases'. Points of note are the nature of the impact of dementia; accumulations of practice and what this may mean in the context of the appointment setting; and the delicate balance that seems to exist in the weighing of diverse risks, risks that are often consequential to increased forgetfulness but sometimes arising when other needs of the individual are only being partially met.

The accounts provided by patients and carers seem to indicate a rather complex interweave between lived memory problem experience and the impact that memory problems are having on individuals and carers, respectively.

Discrepancies in accounts given by individuals and by carers of their experience of dementia were evident, which raises questions about how memory problems are

recognised, acknowledged (or not), and impactful. For example - how might a view that dementia is not "normal" (as in the case of Mrs Maddox) be consequential in terms of how an individual and their carer cope as memory problems progress? The second point concerns practice in the clinic appointment setting. In these six appointments there were observable aspects of practice that could be articulated in the form of a notated commentary (e.g. describing administration of the memory test). However, what remains hidden, that these outward expressions of doing do not reveal, are the over-time accumulations of experience and types of knowledge, and how these are combined or configured uniquely to each appointment. This is illustrated in the aspect of Laura asked questions of patients and carers. For me as an outsider a question can be heard (observed) and understood in terms of the nature of its enquiry, but its meaning in terms of the 'why that phrasing', 'why asked at that particular moment', 'why asked in a particular tone of voice' are known only to the person who asks it. The point of interest is that observable aspects of practices are like the visible outer layer of something, but all that is involved in the formation of a practice is like its inner layers - indiscernible, undetectable.

Another noteworthy point is about the risks that arise when a set of conditions changes. Even though the transition from 'normal' forgetfulness associated with ageing to problematic or abnormal forgetfulness may be very gradual, and may involve passing through distinct phases such as mild cognitive impairment (MCI) as was the case for Mrs Bourne, there comes a point when 'forgetting' starts to have consequences. A clinician's mental checklist alerts her to risks which she can then probe further to ascertain whether action should be taken, and the urgency (or not) required to address risk. Risks are not necessarily always to do with forgetfulness. For example, Mr Wooler's risks were about the state of his physical health as much as his memory. The risks around a slow pulse and heart rate caused by the Donepezil medication had to be weighed against the benefit of the medication. There was also his physical health to be considered. With Mrs Osborne, similarly, the situation of not eating was risky for management of her diabetes, and for Mrs Ladley there were risks around falling, and what seemed to be a risk that the care relationship with her daughter was beginning to break down.

Observations of another cluster of appointments

A fortnight later I attended the CSD Centre to observe another cluster of four morning appointments with Laura. The first person was a Mr Powell, attending for a review appointment and accompanied by his son and his son's partner. Prior to the appointment there was time to have a brief conversation with Laura who told me that Mr Powell had an alcohol problem, but that he had not yet acknowledged or accepted that he had memory problems.

From my first encounter with Mr Powell I noticed straight away the smell of alcohol on his breath. His alcohol consumption was broached very carefully by Laura, who wanted to know how much he was drinking, and whether he was driving after drinking. Mr Powell said he had two pints of beer a day and sometimes whisky as well, but that he did not drive after drinking. These probing questions about this very sensitive topic of alcohol were not just about making sense of the type of memory problems Mr Powell was experiencing. Questions were also a way for Laura to elicit information that would help her to decide if she would need to take actions related to her duty of care as a clinician in this instance. So, although Mr Powell's daughter had apparently contacted the DVLA about his memory problems it was entirely possible that Mr Powell was continuing to drive. A priority for Laura was to ascertain whether Mr Powell was telling the truth regarding driving whilst under the influence of alcohol. This was a topic that Mr Powell's son was silent about, and he seemed nonplussed about his dad's memory problems and their interweave with alcohol consumption, perhaps because as yet underlying risks had not surfaced into critical problems:

Mr Powell's son: "My dad has his moments but nine times out of ten everything seems to be ok". (Fieldnote: 14/7/14)

The relevance of Mr Powell's alcohol consumption to his memory problems became apparent when Laura explained that his memory issues were related to vascular issues. Heavy consumption of alcohol has been shown to be a contributory factor to illness, and there is consistent evidence to show that there is an association between heavy drinking and/or abstinence and cognitive decline (Lafortune et al, 2016). It could also be said that drinking, smoking, eating, and exercise behaviours are a matter for individuals to decide about rather than for

governments or even family members. In Mr Powell's case his decision to drink had been brought into the space of a health service setting, and was now recorded in patient notes, no longer a private matter. Laura advised, if possible, to cut down on alcohol. Then, in what seemed to be an empathic gesture, she drew attention to herself and acknowledged that she was "overweight" and that she felt "hypocritical" (Fieldnote: 14/7/14) in advising Mr Powell to change his behaviour. This felt like a very human moment, an expression of trying to dissolve or blur the edges of the distinct roles of patient recipient and clinician expert. The triangle of driving, memory problems, and (what seemed to be) heavy drinking was of particular concern, and the risks in the scenario Laura elaborated to me after Mr Powell and his son and partner had left. Without the evidence that Mr Powell was driving whilst under the influence of alcohol there was little that Laura could do, other than advising the family to inform the DVLA.

The next person to be seen by Laura was a Mr Ron Seymour whose brother, Doug, accompanied him. This was a review appointment. Doug, the main carer, managed most aspects of Ron's life and spoke on his behalf. As well as caring for his brother Doug was also supporting their sister who had arthritis. All three lived in the same house; none of them had ever married. There was acknowledgement of Doug's essential role within this family unit:

Laura: "You're the gel that's holding everything together".

Doug: "I'm the one that's keeping it going".

(Fieldnote 14/7/14)

Over the past nine months there had been some changes in Ron's capacity and he could no longer manage his own medication, nor understand or deal with money. Doug had picked up the reins and now supervised Ron, making sure that he was taking his medication correctly, and all essential tasks such as cooking and budgeting were also now undertaken by Doug. Ron's involvement in his own affairs seemed to be diminishing - limited to jobs such as helping Doug in the garden, and this gave the appearance that Ron was retreating into the background where he was the 'cared for'. This arrangement whereby Doug was *lynchpin* clearly worked in terms of keeping everything ticking over. Nonetheless, the two

brothers were elderly and their sister clearly had some health issues, and there was no obvious back-up plan should Doug no longer be able to care for his brother. Although establishing the nature of the clinical needs of the person and monitoring any changes in mental and physical health might be described as core aspects of Laura's role, I noted that Laura used the time in the appointment to check out practical issues such as social care needs, safety at home, Power of Attorney arrangements, and carer wellbeing. In the instance of Mr Seymour there was active enquiring by Laura about how the two brothers were managing, and whether extra help was needed in the home. The information volunteered by Doug about Ron's diminishing independence provided potential clues to his current status in terms of memory. The memory test was the tool available for assessing memory, but was not used on this occasion because Ron had scored very low on the test at his last appointment (as Laura later explained to me after the brothers had left).

Doug's narrative captured his brother's declining independence and his transition through states of increasing impairment towards greater reliance on Doug.

Laura's role was that of a clinician involved in the care and treatment for Ron. Her standing as a professional did mean she could wield at least some influence in terms of mobilising resources that would bolster up support to Doug in his caring role. There was also a more personal aspect to her role in this situation, which was linked to particular knowledge Laura had been made privy to, which was that Ron, Doug and their sister had made a 'pact' to care for their parents and then for each other when their parents died. This pact was now being put into action by Doug as he took on a caring role towards his brother and his sister.

The Seymour's situation was a changing one, and it could not be known if or, more likely, *when* an event might occur that would 'tip' the fragile arrangements of family care into an entirely different scenario where, perhaps, formal care arrangements would be needed. Laura knew that the current care arrangements for Ron were almost entirely contingent on Doug's ability to continue to provide support - a situation which Laura would undoubtedly have seen replicated in other families she had met during her years in practice. From this practice experience Laura would have seen how situations panned out, and the sorts of factors that pre-empted a breakdown in care arrangements. This sort of

knowledge might be described as both practical and experiential: the ability to estimate - 'if this, then that' and 'when this, then that'.

Knowing what she did know about the Seymour's situation was probably a factor in how she then proceeded to not only advise but to actually *insist* that Doug should telephone *her* if any problems arose. Ordinarily Laura would have handed over to Pat (a specialist nurse in the team) but Pat was leaving - a cause for concern for Laura as the post Pat was leaving had not been advertised as yet, leaving Laura in a holding position with patients such as Ron.

The last appointment was with a Mrs Eadie, a lady who had been seen by one of Laura's colleagues at home and subsequently been referred to Laura with "slight" memory problems. This was a rescheduled appointment from a fortnight earlier when Mrs Eadie had failed to attend the original appointment. Laura was unsure whether she would turn up for this one, but she arrived on time having been dropped off by her husband, who arranged to pick her up after the appointment. Mrs Eadie came across as a very intelligent and independent person, appearing to distance herself somewhat from the notion that she may have memory difficulties. Laura started by recapping about the most recent memory test that Mrs Eadie had undergone, referring to one of the tasks of completing a half drawn picture.

Mrs Eadie responded with:

"It's automatic, it's not something you remember. You've seen it before."

(Fieldnote: 14/07/14)

Mrs Eadie's words caused me to wonder if she was thinking about the tests and that people have no control over their automatic responses to these sorts of tests. For example, if an automatic response turned out to be 'wrong' this would draw attention to the possibility that there was a problem. Mrs Eadie knew that she had a memory problem, and voiced this. Laura's response was to confirm what *her* role was: "My job is to sort out mild memory problems from more severe ones". This led to Laura asking Mrs Eadie a question which was of a type which suggested that Laura was taking a softly, softly approach - offering self-determination:

"What would you like us to do about your memory difficulties? We could send you for a scan, then look at possible medication?"(Fieldnote: 14/07/14)

The conversation continued with Mrs Eadie - seeming to pre-empt the possibility that Laura would suggest she start on medication - talking at length about her previous bad experiences of taking medication in relation to major surgery, and for hypertension. The conversation progressed and yielded further insights into the context for Mrs Eadie's thinking: her daughter had mental health issues and a diagnosis of Multiple Sclerosis, for which she was taking medication. It seemed that Mrs Eadie's own difficulties with memory were being eclipsed by her daughter's needs as well as by Mrs Eadie's anxieties about her daughter. Laura gently continued with the tack of passing 'ownership' of the memory issue back to Mrs Eadie:

"Let's talk about your memory. What would you like to do? Do you want to be discharged and just carry on as you are?"(Fieldnote: 14/07/14)

This, it seemed, gave Mrs Eadie permission to say what she wanted, which was to be discharged from memory services. She started to talk about her friend's husband with dementia, saying that he was now in care, and then: "I'm not like that at all." This differentiation between her own memory difficulties (currently mild) and those of her friend's husband (considerable enough for him to be admitted into long-term care) conveyed a sense of her distancing herself from dementia. It echoed the way in which Mrs Maddox, the first patient whose appointment I observed, had seemed to push the possibility of dementia away. The process of being referred back to Laura by asking the GP was explained to Mrs Eadie, and her obvious reluctance to consider trying out medication was a further reason for her to be discharged. However, at this point Laura offered Mrs Eadie an ECG brain scan, something which she agreed to. An information leaflet about the scan was given to Mrs Eadie, along with verbal indications about the timescale in which this would take place. Mrs Eadie left, and Laura spoke to me about her thoughts:

"I think she *does* have Alzheimer's disease, so I'm quite happy for her to come back". (Fieldnote: 14/07/14)

The interaction between Laura and Mrs Eadie illustrated well the enormity of being faced with the prospect of a significant memory impairment, and how a clinician tried to facilitate a patient to take the first steps (agreeing to a scan) towards finding out the nature of the problem and possible lines of treatment. Laura's hypothesis that Mrs Eadie had Alzheimer's disease was not voiced during the appointment because Laura had made a judgement that Mrs Eadie was the sort of person who needed to see for herself the evidence to support or refute this. The skilful coaxing of Mrs Eadie to have a scan demonstrated knowledge in action; the bridging of the gap between what is known (or at least strongly suspected) and setting a process in motion towards confirmation of what is known and appropriately addressing the problem.

Just over a week later I was at the CSD Centre again, to observe two morning appointments. The first was with Mrs Bell whose daughter-in-law Anne accompanied her. Having explained the format of the appointment, Laura then introduced the matter of memory. Mrs Bell felt that her memory was about right for someone of her age. Laura's opening question was typically understated, but I had realised from early on during my observations that her questioning was designed to reach the nub of the issue at hand:

Laura: "Do you lose track of a conversation, of what you were about to say?"
(Fieldnote: 22/7/14)

Laura continued with gently asking probing questions of Mrs Bell, allowing her daughter-in-law to interject. Anne's account of her mother-in-law suggested that over the past eighteen months there had been a gradual deterioration in short term memory. Mrs Bell was apparently unable to remember birthdays or appointments, and more worryingly she was forgetting how much medication to take and when, which had led to an incident in which she overdosed on co-codamol, taking a whole day's dose in just a couple of hours. The conversation moved on to some questions about physical health and then a physical health check. This began with checking blood pressure, and then pulse. Laura explained that she would listen carefully to Mrs Bell's pulse and so things would go quiet whilst she did so. A pulse cannot literally be 'heard', but it can be perceived.

Taking a pulse requires the clinician to touch the wrist of the person; taking a blood pressure reading involved Laura using a piece of equipment - which bridged the gap between the clinician's physical body and the patient's body, connecting the two together. Involved in these two clinical procedures is perception via the senses: touch, seeing, and hearing, the purpose being to assess the body, to check that blood pressure and pulse are within the norm of what would be expected. Polanyi (1967; 1961) described the perceiving of something as a projecting from within a person to the outside, and that the projection was similar in cases when people used tools and probes to perceive.

After blood pressure and pulse had been taken there were some different questions about medication and then her family and how she was managing currently. Mrs Bell was very clear and quite adamant on some pieces of information. She knew she had a brother and could remember his name; remembered her sons' names; recounted details of her youth and how she had worked as a domestic at the local hospital; and knew that she was having some help from her sons in managing day to day finances. Laura had sight of the full list of prescribed medications for Mrs Bell, but Mrs Bell was sure that she was taking only one tablet per day which was for her blood pressure. Mrs Bell's daughter in law seemed unconvinced that the medication was going untaken because it was known to her that Mrs Bell's son Eddie was organising the medication for her. Mrs Bell's certainty about the medication that she was taking was rather puzzling - what if it *was* the case that she was only taking one tablet for blood pressure? The question of who decides whether an account of a person with dementia is credible, and whether expectations about capability to give an accurate account need to be adjusted over time raises the issue of agency in people with dementia, and this seemed pertinent to Mrs Bell. In the short form memory test that Laura then conducted with Mrs Bell these questions seemed to be amplified further. There is a part of the test where the person is read three words, and a few moments later is asked to try to recall the three words. Mrs Bell was unable to do so:

"I should have been able to remember - it was only five minutes ago".

(Fieldnote: 22/7/14)

Clearly, the memory test is designed to test for memory problems, and implicit in this is the revealing of deficits. I surmised that this set up a rather peculiar tension, which I made a note about:

"I have a feeling that Mrs B wants to get it right. She wants to please Laura. Do these two things equate with each other?" (Fieldnote: 22/7/14)

The experience of having one's memory assessed - however kind and caring the clinician - would be difficult to conceive in any way other than as anxiety-provoking. Mrs Bell's defence of herself, as a person who could provide an accurate account, was revealed in her expressing herself adamantly about the medication she was taking. Rather poignantly, it seemed to me, was how this self-account now seemed overruled by the exposing of her difficulties through the memory test.

Following Mrs Bell, Laura was seeing a Mrs Noyce with her daughter Elaine. Mrs Noyce had recently had two scans: a CT scan which showed that she had had a very minor heart attack, and a brain scan which revealed there was some atrophy to the brain, a generalised shrinkage that was more than would be expected for someone of her age. Laura explained that this was indicative of mild Alzheimer's disease, but that there was some good news in that there was no evidence of stroke.

With Mrs Noyce there was discussion in relation to her physical health and history. The fact that Mrs Noyce had had one of her kidneys removed meant there were certain considerations in relation to prescribing medication to help with her memory. Laura introduced the possibility that Donepezil could be prescribed, and explained that this helped to maintain a person's memory as it is currently, usually for four to five years. Mrs Noyce agreed to this and Laura wrote out the prescription, also giving details about possible side effects, to make an appointment with Laura if these were severe, and described to Elaine how the prescription ordering worked. Laura seemed to want to particularly press home to Mrs Noyce the importance of taking the medication, saying to her that she should try to stick with the medication even if the tablets caused nausea because this would usually settle down.

Laura: "Your job is to take the tablets; your daughter's is to order them."
(Fieldnote: 22/7/14)

Mrs Noyce's daughter Elaine used to work as a ward clerk at the local hospital and had recognised Laura through this connection. She also had contacts with Keele University and was clearly familiar with local health systems, a likely advantage in relation to helping her mum navigate through the system. Checking with Mrs Noyce whether there was anything further she could help with, and reassuring her that she or her daughter should contact Laura if there were any problems, the appointment came to an end and the two women left the clinic room.

My observations of Laura's appointments resumed in late autumn 2014 with three home visits. The first of these was with Laura and one of the team's occupational therapists, Karen, to meet a lady called Ms Evans who lived alone. Ms Evans had been seen by Laura in clinic six months ago, and she had been having fairly regular appointments with Karen. Ms Evans had a package of care consisting of two domiciliary visits per week from a home care agency, a pendant alarm for emergencies, and Karen had referred her to a befriending service run by the local branch of the Alzheimer's Society, and to Age UK which had completed an Attendance Allowance application (Higher Rate) on Ms Evans' behalf. A 'hot meals' service had been offered to Ms Evans but not taken up. Ms Evans was managing everyday life adequately by following reminders on her calendar, using a tablet dispenser for medication, and having support from the home care agency to attend hospital and other appointments. However, Laura was concerned about her overall vulnerability in relation both to her isolation, and the progression of dementia: a recent brain scan showed that there was slight shrinkage to the brain, but also a Meningioma - a slow growing, usually benign, brain tumour associated with symptoms of dementia, as well as other impairments including tremor, unsteadiness, seizures, headaches and behaviour change. Ms Evans explained that she had had a fall hurting the right side of her head and was having twinges of pain.

Laura did some basic health checks of blood pressure and pulse, confirming that her BP was a bit high but not too bad. Then she broached the subject of Ms Evans' current circumstances:

Laura: "Speaking very frankly [Ms Evans], you are very committed to staying here, in the home you know and love?"

Ms Evans: "I don't go out now. I've been to the gate and along a bit. I'm afraid of tripping". (Fieldnote: 25/11/14)

This exchange represented Laura's concern as well as her professional duty of care, as she now knew that Ms Evans had a Meningioma, was having problems with memory, and had had a fall in a two storey house where her bedroom was on the first floor. Ms Evans' response confirmed the fear she had of falling, but was also a reassurance to Laura and Karen that she was mainly staying indoors which she perceived as a low risk environment. There was no mention of family involvement, but Ms Evans had a next door neighbour, Alan, who had Enduring Power of Attorney for her, and helped out by visiting her and generally keeping an eye out for her. Karen viewed the main risk for Ms Evans as there being nobody on hand to help if she fell or became unwell, but that this was being addressed by an alarm system for any emergencies and the two domiciliary visits per week for ongoing monitoring and support.

Laura brought the conversation back to medication, and asked if they could talk about medication for memory problems. She could prescribe medication if Ms Evans wanted to try, although it was not certain that medication would help. Ms Evans wanted to know if the medication would interact with other tablets she was taking, and would the medication be taken separately to her other tablets. She clearly knew the questions to ask as well as seeing that the medication would maybe help with her memory problems:

"I would like to try something, with being on my own". [...] I think anything's worth trying. It goes blank. Even normal things get forgotten." (Fieldnote: 25/11/14)

Laura would write the new prescription and contact the pharmacy directly, and there would be a general keeping an eye on things entailing one of the support workers from the team popping in to see how Ms Evans was getting on.

Without the involvement of next of kin (there did not appear to be immediate or extended family involved, and Ms Evans described herself as being on her own) Ms Evans' continuing independence largely relied on her own strength of will, of wanting to continue to live in her own home rather than going into permanent care. The accumulation of different factors in Ms Evans' situation (Meningioma, dementia, the circumstances of living alone and without family involvement), and how she coped with these pressures whilst trying to preserve a sense of independence seem to signal fragilities in her life situation at this point. Being in late age and living alone with dementia is suggestive of a different reality to being in late age and living alone whilst continuing to be active and healthy.

Portacolone et al (2018:2) highlight that the impact of cognitive impairment on abilities to manage domestic matters and to navigate service systems is likely to intensify the precarity of living alone in old age.

Regarding all the other people with dementia whose appointments I observed, even though several people lived alone, in those cases there was still at least one family member involved - a brother, daughter, son, or daughter-in-law. For people with dementia who don't have family, or whose families are simply not involved, there are not the same possibilities for the knowledge or knowing of family members about the person to be brought to bear. In the case of Ron Seymour for example, his brother (and carer) Doug was a witness not only to the subtle memory changes that occurred over time affecting Ron's capacity to manage, but he also *knew* his brother and could provide a narrative to professionals of who Ron was. In the interaction between Ms Evans and Laura and Karen, there was an acknowledgement of and respect expressed by Laura that Ms Evans loved her home and wanted to remain there, but all that was available to build up a picture of *who* she was as an individual were fragments of knowledge gathered about her only since the time she had begun to have memory problems and been referred to the team. If a person with dementia is unable to provide a narrative about her/himself, and there is not a family member or advocate to do so, this would seem to be a risky situation for the person. One risk that may arise

is being at the mercy of the state to provide support and care, and this seemed to be the situation that Ms Evans was in, with her package of care and support being provided by public, private and voluntary sector agencies. Another risk, which seems a more serious one, is related to loss of personal identity. Without any family members to provide a knowledgeable account of who the person is, keeping the person's identity intact - especially as s/he continues to be affected by dementia through the passage of time - presents a problem. This second risk may be traced to ways of understanding what a human self is, and particularly how the self is perceived under the medical gaze in the context of healthcare where the biomedical view is dominant. In terms of nursing practice Liaschenko (1997:25) suggests that a nurse's construction of meaning of what a *person* is, is interrelated with the type or types of knowledge a nurse is bringing into the encounter with an individual. If a person is classified as a 'case' the knowledge that is brought to bear is "limited to objectified physiological and psychological data, and the relationship between person and nurse focuses on the functioning and monitoring of physical and psychological processes." (Liaschenko, 1997:25). Liaschenko goes on to link personal agency to the bringing about of a meaningful life, and in this context she offers a perspective on what knowledge of a person *is*:

"partly a knowledge of how that person lives, as well as what she or he lives for." (Liaschenko, 1997:27)

Svanstrom and Sundler (2015) suggest that the lived experience of people with dementia who live alone is a neglected area of research. Their study of the phenomenon of living alone with dementia whilst having a manifest care need revealed a number of interesting findings. In relation to my own reflections on the living situations of participants who came into contact with local NHS memory services, Svanstrom and Sundler's (2015) study illustrates from the accounts of people with dementia a fragmentation of identity:

"It seems as if the person with dementia gradually loses their memory of themselves and their former life when the home does not act as a demand for attention or a spur to action anymore. Ordinary life becomes increasingly more like a quiet background and life seems to become slow". [...] "Vague memories of what were once meaningful for the person with dementia, such

as memories of a partner, work or events in their youth, seem to be all that remain of their identity. These memories can be stirred in interaction with other people and become very vivid even though they are distant in time." (Svanstrom and Sundler, 2015:150)

In acknowledging Ms Evans' strong wish to stay in her own home Laura was affirming that she had personal agency and, implicit in this, that Ms Evans was free to exercise this. For Ms Evans perhaps the threat to identity would become apparent if she was unable to remain in her own home and had to enter permanent care. For people who live alone and without family involvement it is difficult to imagine a way of continuation and safeguarding of the story of a person's life - her past experiences, talents, connections with other people, personality and characteristics - as she moves from home into care.

The second home visit I was due to observe was with a ninety two year old lady. When Laura and I arrived at the house there was nobody in, and we were unable to proceed with the visit.

In early December 2014 I did my final observation of Laura's appointments - a home visit with Laura to a Mrs Perkins who appeared to be quite physically unwell as well as having memory problems. Her husband, also her main carer, answered the door to Laura and me. During the visit it was mainly Mr Perkins who provided the narrative of how things were while Mrs Perkins spoke infrequently. I suspected this was related to her seeming to be quite breathless, and the struggle she seemed to have with articulating much beyond yes and no answers to Laura's questions. Mrs and Mr Perkins were clearly a close couple, and it appeared to me that Mr Perkins loved his wife and was content to care for her, in spite of the challenges of doing so. Laura wanted to find out how things were and, as the conversation progressed, it became clear that Mrs and Mr Perkins had differing opinions about the difficulties within their current situation. Mrs Perkins said that she wasn't sleeping well but that she generally felt fine. Mr Perkins' view was that she always said this but the way he saw it was that she wasn't fine - she could do very little for herself, her sleeping was disturbed, and all the symptoms Laura had foretold would appear had now appeared. Laura

checked Mrs Perkins' blood pressure, a process which Mrs Perkins found uncomfortable, although her blood pressure reading was normal. The memory test was conducted and afterwards Laura explained that Mrs Perkins' score had gone down from 10 to 6, but this was par for the course. Mr Perkins seemed to view the visit as an opportunity for him to voice his concerns about the situation, and from Laura's responses it was plainly obvious that things were becoming very difficult:

Mr Perkins: "Everything falls down and collapses when I'm ill." [...] "I was off colour the other week... I had a bad turn in Smiths at the Post Office.... I went all wobbly. That's when things break down - when I'm ill." (Fieldnote: 9/12/14)

Laura did a quick check of the notes and confirmed that Mrs Perkins was getting all of the entitlements that she should be getting. She asked whether extra help was needed, and whether Mr Perkins was feeling "depressed at all?" Then, who was doing the cooking? To which Mrs Perkins pointed to her husband and both of them laughed, after which Mr Perkins said "I do everything". Although Mr Perkins said that he didn't have any particular concerns about risk to his wife, the ongoing care arrangement was clearly solely dependent on his ability to continue to be the carer. Information about a local voluntary sector organisation that provided a sitting service was offered by Laura, who then voiced her concerns:

Laura: "One of my concerns is if you become unwell."

Mr Perkins: "That is my concern too."

Laura: "Would family rally round?"

Mr Perkins: "They have no idea how she is...they don't grasp it".

(Fieldnote: 9/12/14)

In this situation Laura's priority was for Mrs Perkins, as the patient. Once it had been ascertained that Mrs Perkins was not exposed to risk Laura's concerns turned to Mr Perkins. Like Doug Seymour who was lynchpin in the care arrangements for his brother, Mr Perkins was similarly essential to his wife's care, and in these terms Mr Perkins' needs were inseparable from those of his wife.

Thinking across these thirteen situations of individuals who had been seen by Laura in clinic or at home, the intersections between different characteristics of a situation may be drawn out and considered using the lens of 'precarity'. Here, attention is drawn to intersections between (for example) living with dementia, types of care arrangements and contingencies, physical health status, carer gender and carer relationship to the person with dementia. The question of keeping a watchful eye on the person with dementia and, in some instances, monitoring domiciliary care arrangements was highlighted in the situations of Mrs Ladley, Mrs Osborne, Mrs Maddox, and Mr Powell. The family member or carer was keeping a watch on the individual to either a greater extent – as in the case of Mr Maddox who adopted high vigilance and monitoring of risks – or a lesser extent – as in the case of Mr Powell whose combination of drinking and driving was underplayed by his son. With Mrs Ladley there was a sense that her situation was 'being held up' by her daughter and that these familial resources were close to being exhausted, with a corresponding possibility that familial caregiving could break down completely. The situations of Ron Seymour and Mrs Perkins can be characterised by the sense of their respective familial carers being the lynchpins of care, but this is precarious because everything depends on one person whose own situation might change in some way which may move the carer into precarity. As Mr Perkins observed:

“Everything falls down and collapses when I’m ill. [...] That’s when things break down – when I’m ill.”

The situation of another person seen by Laura – Mr Wooler - was characterised by precarity because of a physical health issue for which he could not have surgery. Remaining in satisfactory health became essential because the restorative surgical procedure was not an option for Mr Wooler.

A further comment concerns unarticulated assumptions that may be made by practitioners regarding gender in relation to familial caregiving. Viewed through the paradigm of intersectionality (e.g. Grenier et al, 2017; Hulko, 2009) interlocking oppressions within caregiving in dementia become highlighted relating to membership of defined social groups - e.g. being a woman carer and the intersectionality between this and caring for someone who is in late age and has dementia. The disproportionate impact of dementia on women has been

clearly described in the report 'Women and Dementia: a global research review' (Erol et al, 2015) which highlights that more women than men live with dementia and around two thirds of primary caregivers for people with dementia are women. (Erol et al, 2015: 5,23). It is likely that this reality is perpetuated in practice in terms of the assumptions that may be made by practitioners about women taking on care responsibilities for a relative with dementia.

Observations of memory appointments with Dr Ozha, a Consultant Psychiatrist

I observed two appointments in clinics of one of the consultant psychiatrists, Dr Ozha, at the CSD Centre. These were in early October 2014 and early December 2014, respectively.

The first appointment observed was with Ms Baker, who looked only to be in her 50s, accompanied by her partner Damien. People under the age of 60 with suspected dementia are always seen by a consultant psychiatrist from the team, as I had become aware of during Laura's interview. Dr Ozha reminded Ms Baker of when he had last seen her, and that this was a follow up appointment relating to concerns raised about her memory following a memory test she had undergone at home. More positively, results from the brain scan showed that things were "fine, and nothing to worry about". The conversation then moved on to how Ms Baker had been over the last few months, were there any problems with taking medication, could she provide any examples of her memory getting worse, and how much help had she needed in recent months. Ms Baker described how she had been worse over the course of the last few months, struggling with her fibromyalgia, and staying in bed because of it. Her partner Damien filled in some of the gaps where Ms Baker was clearly struggling to answer. He explained that she would forget straight away, and this was really noticeable during conversation. Ms Baker said she liked Damien to be around because she had fits. Dr Ozha asked her about her bowels and bladder and she explained that she was struggling to get upstairs to the bathroom toilet in time. Both the seizures and not getting to the toilet in time were clearly distressing events for her and Dr Ozha gave reassurance and, whereas at the start of the appointment he had frequently looked at his notes, he now gave and continued to give good eye contact. Ms Baker

rarely went out now - which I imagined was related to the threat of seizures, the pain from the fibromyalgia, and fear of what may happen if she needed the toilet. Advice for managing fibromyalgia by doing some light exercise had already been given, and Dr Ozha gave some encouragement to stick with the advice, underlining that by giving the heart a needed workout this would also give the brain a workout. The theme of exercise continued with Dr Ozha introducing the idea of exercise on prescription: "Small things you do will help you". Dr Ozha's approach was to encourage Ms Baker to do what she could for herself, and it seemed as though he was affirming Ms Baker's agency. Ms Baker was concerned that the fact that she had had a lot of injuries to her head and had these contributed to her memory problems? Dr Ozha explained that head injuries did increase the risk of memory problems, and that seizures and medication were also contributory to risk. Maintaining good eye contact with Ms Baker he gave further reassurance not to worry about the brain scan; and that being stressed and uptight during the memory test would affect the score. These two pieces of information I then realised were a preamble to Dr Ozha giving his diagnosis:

Dr Ozha: "Clinically, I would say you have a mild form of dementia".

Ms Baker: "That's not very nice, telling me that! Won't it go worse?"

Dr Ozha (maintaining good eye contact):

"Memory problems don't necessarily deteriorate quickly...it can be years. People develop their own strategies." (Fieldnote: 2/10/14)

Beyond this diagnosis Dr Ozha didn't know what type of dementia it was, and the important thing was that Ms Baker shouldn't let it interfere with her life. It was vital to keep up with hobbies - Ms Baker mentioned that she enjoyed knitting. Ms Baker was clearly shocked by the diagnosis and Dr Ozha then seemed to adapt to her response by using a gentler approach and modified language, describing the diagnosis as: "It is a mild form of memory problems". He suggested that the brain scan may need to be repeated further down the line.

Dr Ozha asked about support: did Ms Baker need any more help or support at home? Her partner Damien was experiencing bouts of depression, but he was getting help through a local voluntary sector support group. He was the main carer for Ms Baker, and this was acknowledged by both she and Dr Ozha.

Ms Baker: "He does a good job. I don't know what I would do without him."

Dr Ozha: "We need to tap into these sources of support. We do underestimate things like talking to people, meeting people, and how they can help. We are primed to think in terms of medication. Talking to other people in groups - these things will help." (Fieldnote: 2/10/14)

Implicit in Dr Ozha's words was an expression of how the effects of dementia extended into all aspects of a person's life, and thus the biomedical perspective of dementia was only a partial view; the acknowledgement that medication alone did not help a person to get on with their life, and that psychosocial support was equally if not more important. Medication might help Ms Baker, and Dr Ozha said that he was thinking that Donepezil may be useful to try, but that there were both risks and benefits in taking medication and that he would be happy to put this on hold for the moment. For Ms Baker what was happening to her physical body was a concern: she was putting on weight and she did not like this. Dr Ozha responded to this by saying that the body needs to expend a certain amount of energy but as a person aged this meant that not as many calories were required.

Ms Baker: "When I get down and depressed the first thing I go for is chocolate."

Dr Ozha: "It is ok having a plan, but you need to stick to the plan for the rest of your life". (Fieldnote: 2/10/14)

Dr Ozha saw where things were going with Ms Baker - her overall physical health, the effect of the seizures, and the fibromyalgia, all of which predisposed her to weight gain, and how all of these factors can conspire against good health. Dr Ozha had the view that it was essential for Ms Baker to optimise her health and slow deterioration by following a plan of health maintenance. Dr Ozha would refer her back to her GP - and then the question posed to Ms Baker: "shall we meet again in a few months' time?" Asking Ms Baker to see him a few months hence was a way of monitoring how she was getting on. Dr Ozha thought that it would be necessary and beneficial to see Ms Baker again, and from Ms Baker and her partner's perspective it was a short enough time away to give reassurance that

they were not being abandoned by the professional who had expert knowledge about memory problems and the impact these had on Ms Baker's life.

In early December 2014 I attended the CSD Centre to observe Dr Ozha's appointment with a Mr Seward, who was accompanied by his wife and his daughter Kay. Mr Seward had recently been seen by Dr Candler, and was also being visited at home by Suzanne, another member of the team. As Mr Seward began to talk it was evident that he was experiencing some very distressing symptoms of mental health, which Dr Ozha was aware of. Mr Seward was seeing snakes, people in the house, people down the toilet, cameras outside, a man with a moustache and, his daughter added: "and furry creatures".

Dr Ozha (to Mrs Seward and Kay): "Does it upset him?"

Mr Seward: "Terrible it is".

Dr Ozha (to Mr Seward): "You *do* get upset by it? Do you think it is real, or the brain playing tricks? Are those images very sharp, are they very clear?"

Mr Seward: "They are in a pipe. They come up through the carpet."

Dr Ozha: "Do you talk to them? Do you ignore them?"

Mr Seward: "I tell them to bugger off!" <laughs> (Fieldnote: 11/12/14)

The conversation then turned to medication and Dr Ozha asked Mrs Seward about medication. Mr Seward had been prescribed risperidone, a drug that could help people with dementia experiencing psychotic symptoms such as delusions and hallucinations. Dr Ozha told the family that results from Mr Seward's blood tests showed that his lithium levels were normal, and then proceeded to talk the family through the diagnosis and what could be done to help with the hallucinations. Mr Seward was diagnosed with Lewy Bodies dementia, a type of dementia that Mr Seward's daughter Kay already had collected information about and now said: "It sounds exactly like my dad". She had also read up on antipsychotic medication, that it could make worse the symptoms of Lewy Bodies dementia. Dr Ozha was in agreement and explained in more detail the symptoms presentation, and that from today Mr Seward should stop taking risperidone and begin with a different medication that was not an antipsychotic. It was logical to stay clear of risperidone, but if it became necessary a different antipsychotic could be

prescribed. Mr Seward would also be referred for a second brain scan and an Electroencephalography (EEG). As a clearer picture emerged about the diagnosis, symptoms, and treatment options that would be pursued the family appeared reassured. The frightening nature of the hallucinations was fully recognised by Dr Ozha who explained that these were caused by chemical imbalances in the brain. He advised on some practical measures that could be taken to moderate the effects of these negative symptoms, suggesting making sure that there was adequate lighting.

Dr Ozha (to Mr Seward): "Is there any other alternative that you can think of?" (Fieldnote: 11/12/14)

This question was really asking whether Mr Seward was able to take on board a different explanation of the hallucinations; could he see that they were not 'real'? This seemed too much of a stretch for Mr Seward who clearly felt convinced that what he was seeing was real. As the appointment drew to a close Dr Ozha gave further reassurance to the family, and checked how Mrs Seward was coping. Kay interjected that her dad was struggling with walking. A referral would be put through to the occupational therapist for this. The final action was Dr Ozha writing the prescription for the new medication and handing it to Kay. In spite of Mr Seward's situation being one which involved highly distressing and ongoing symptoms, in this 25 minute appointment the exercising of knowledge from the respective repertoires of Mr Seward, his daughter and wife, and Dr Ozha, seemed to combine together and bring about a resolution for that moment in time. There was no absolute solution to Mr Seward's difficulties but with the symptoms very clearly described by Mr Seward and his daughter a plan could then be devised by Dr Ozha, checked with the family for its acceptability, and then put in place. Addressing difficult to manage symptoms of dementia to render them more manageable, although only a temporary solution, does push the ultimate inevitability of the end point of a trajectory of dementia away and further into the future. Reaching points of agreement through sharing knowledge and through negotiation - as was the case in looking at and finding a better way to manage Mr Seward's symptoms - would seem to be a cause for the individual with dementia and their family to have some hope.

Observation of a seminar for carers run through the Wellbeing College

The Wellbeing College was the overarching banner under which was bundled all courses related to recovery in mental health. Out of the programme of courses was one course specifically designed for carers of people with dementia which was led by the senior occupational therapist Judith and co-facilitated by a former carer. The course ran over four sessions, and I observed session three:

"Understanding and living well with dementia".

The session began with welcoming a mixed group of carers and people with dementia. Refreshments were available and there was a nice atmosphere of people talking and interacting. About fifteen minutes into the session Judith introduced the plan of how the session would work which was that the group would 'split' into two and there would be a seminar in one room and a physical activity session in the other. The expectation, although not voiced, was that carers would separate from the person with dementia they cared for and go into the seminar group, whilst people with dementia would remain in the same room and participate in the activities session. This separation seemed relatively smooth and people who had been to either of the two previous sessions would have known that this is how the sessions were run.

I joined the carer seminar in which there were five female carers and three male carers participating, plus the two facilitators. The session was introduced as being about understanding the different ways that dementia can affect a person's life at home. The 'tone' for the session was set by Judith's opening words to carers:

"All the knowledge I have pales in comparison to the knowledge and experience you have as carers. I have the theory and professional knowledge". (Fieldnote: 11/3/15)

In Judith's words was the acknowledgement that there were different repertoires of knowledge - knowledge which arises from lived experience, theoretical knowledge, and professional knowledge. In Polanyian terms all knowledge is fundamentally tacit (Polanyi, 1961: 467). The idea that carers are armed not with "professional" knowledge but with a different repertoire of experiential knowledge is an interesting one, and in the discussions within this seminar contrasts, as well as overlaps, between spheres of knowledge emerged. Judith

talked through some of the resources available that carers might see as relevant and of interest - books on prescription, Alzheimer's Society information sheets, and national policies and resources. Judith probed a little deeper, asking carers what they *hoped* would be in national policies. The question clearly interested the carers and drew some enlivened responses.

The first comment was - "joined up care for both the sufferer and the carer." This viewpoint snowballed into an exchange of responses and views about GP practices specifically:

Carer: "I would hope they would bring GPs on board more, and they would show more interest."

Carer: "We have a heart nurse at our surgery, but we don't have a dementia nurse."

Judith (responding to first carer): "They are generalists - hopefully they know how to refer."

Carer: "It is carers who *know*. GPs understand this, and will straight away write a referral to the specialist service."

Carer: "At our practice we have '*I am a Carer*'. You get the GP to sign it and it opens all the doors."

Carer: "There's no 'line': today you're you, and tomorrow you're a carer. There's no card you can carry." (Fieldnotes [selected]: 11/3/15)

This exchange of comments and views crystallises some essential characteristics of the lived experience of carers. Here it is indicated that carers are those who *know*: they know that something is not right about their partner, husband, mum, dad, sibling. GPs acknowledge this knowing as an expertise of carers that derives from intimate knowing. But, these comments also provide a poignant sense that as dementia is confirmed as a likely diagnosis in the person with suspected memory problems, the person who cares - a husband, wife or daughter - silently steps over a line into a new identity of a carer.

A slide was put up by Judith with a quote from Tom Kitwood: "Once you have met one patient with dementia you have met one patient with dementia." This framed a group exercise which followed which was to list as many ways (as could be

thought of) that dementia could affect a person's daily life. Carers chipped in with suggestions from their own experiences:

"safety - the gas cooker"; "loss of interest" (in things the person used to enjoy); "putting things away in different places than where they belong"; "passivity"; "loss of independence"; "problem solving ability"; "the financial side - things they used to do financially, and now they can't do them...and losing money as well".

Some of these comments provoked knowing laughter from carers, and Judith commented that all of this was very serious but sometimes all you can do is laugh; humour could diffuse a situation.

Carers highlighted some of the strategies they had adopted for improving communication with the person they cared for:

Carer: "It's reducing choices, isn't it." I ask my wife to put her "black shoes on" or "walking boots". This was the carer's way of specifying the task".

(Fieldnote: 11/3/15)

The co-facilitator of the seminar, a former carer, then drew carers' attention to the book "Contented Dementia", from which she quoted the author's three commandments:

- Don't ask questions;
- Learn from the *person* what they can do;
- Always agree, and walk into another room if necessary.

Here, another way of approaching knowledge was offered: a co-producing of knowledge, but also an approach that reflects acknowledgement of the individual agency of the person with dementia.

The seminar seemed to provide some positive time out for carers, during which they could share their expertise with other carers and gather some new insights and knowledge from carers and the facilitators. The "two groups" approach seemed satisfactory to carers, and perhaps the person with dementia knowing that their carer was nearby (in the adjacent room) and vice versa was a helpful way of structuring the sessions.

Home visits with Keith Chapman, a community psychiatric nurse

Accompanying Keith on two consecutive home visits to the home of Mr Merfyn Jenkins represented my last contacts with patients connected to the memory service. Out of all the observational work involving patients receiving a service through the memory team Merfyn was the only person I saw more than once. This came about because of luck and timing: Keith happened to be doing two home visits to Merfyn with only a month in between them, and both coincided with times when I was available.

The visits to Merfyn felt qualitatively different to the other home visits which had all been with Laura, maybe partly because Keith had a different role to that of Laura's and a different personal style, but also perhaps because of the engagement with Merfyn being focused around an activity that was a particular passion for Merfyn and was an activity that he excelled in. The accounts of the two home visits that follow are of a man with dementia who was able to preserve an entire skill-set, fully absorb himself in his hobby which, it seemed to me, allowed him to temporarily put aside his own sadness about the recent loss of his wife.

First visit to Merfyn Jenkins

I had already met Keith during my fieldwork visits to the CSD Centre, and he had said he would be happy for me to accompany him on some scheduled home visits. We had arranged that I would attend a home visit at Mr Merfyn Jenkins' home at 2pm on March 11th 2015. I arrived and waited on the pavement near to the house for about fifteen minutes, but there was no sign of Keith. As I waited, Merfyn - who would have been expecting Keith to arrive - came out of his house and invited me in. In the house Merfyn tried to explain to me that Keith had contacted his daughter to relay a message that the visit was cancelled. Merfyn seemed very sure that this was the case, and I could see that his account was consistent with there being no sign of Keith. I made my goodbyes, promising that I would speak with Keith and find out when the appointment was going to be rescheduled. Once back at the car I realised that Keith had left a voicemail message saying that he had to cancel the visit at the last minute in order to cover the duty rota for the team.

The visit to Merfyn was promptly rescheduled by Keith, and a week later I arrived for the second time at Merfyn's home. He greeted Keith and me in Welsh and, once inside his home I realised that his Welsh roots were of great importance to him. Keith had, on several previous occasions, been shown Merfyn's collection of photographs and prints of a bay in North Wales. Now, as a first time visitor, it was my turn to be shown the pictures. There were also photographs of his wife who within the past twelve months had died. Merfyn still felt this loss. His wife's bedroom he had kept as it was before she died - the bed made up and her personal items still in the room. Just prior to the game of snooker Merfyn showed Keith and I his wife's room, and I imagined Keith had been shown the room on previous occasions.

Merfyn said to Keith that he was looking forward to having a game of snooker with him; playing snooker was for Merfyn a great source of pleasure and he seemed to view it as the focus for the interaction with Keith. Upstairs Merfyn had a large room that he had converted into a snooker room, complete with a full sized table, a set of cues, scoring board, table light, and various certificates and trophies that indicated that Merfyn had been a serious player in his time. As the game between Merfyn and Keith commenced it was noticeable how good Merfyn was at explaining the rules of the game and the values of the individual balls, and that he also seemed instinctively to know in what order to pot the balls, knew exactly the scoring system, and at moments during the game offered advice to Keith on the best positioning for taking a particular shot. Merfyn was comfortable in the role of expert snooker player, and it was obvious that he was very knowledgeable of the game. However, this ease was disturbed by his awareness that memory problems were starting to creep up on him.

Merfyn: "That's one thing I'm not doing as good - I miss things".

Keith: "Do you wear glasses?"

"I notice that Merfyn then goes over to the cupboard, takes his glasses and puts them on". (Fieldnote: 17/3/15)

The game continued with Merfyn noting that the game was at the stage where all the red balls were in the pockets and "we're both onto the colours".

Keith (to Merfyn): "Have you mastered any tricks over the years?"

Merfyn: "I don't think so". [...] "I've noticed already that *you* are a good player." (Fieldnote: 17/3/15)

Merfyn's words suggested hesitation and doubt, and a sense that he felt unable to talk confidently about his own past achievements in snooker, even though to me it seemed clear that he had retained much of the silent, tacit knowledge required to play (and win) a game. Yet, the next moment he was explaining that he had a game of snooker with a friend the previous night and that he had potted the balls "one by one, and they were hard ones". (Fieldnote: 17/3/15) The game with Keith ended, and Merfyn had won. He then instructed Keith on potting the remaining balls up, and himself re-arranged and reset the scoring board.

Through activities that a person with dementia does over time, and repeatedly, it is often the case that changes in the person's abilities become noticeable. Merfyn had an awareness of change over time: he was aware that he would "miss things". In the snooker game he had forgotten to put his glasses on, although not forgotten where his glasses were. There was doubt and uncertainty creeping in which coloured his appraisals of his own achievements - even his previous achievements in snooker, of which there was visible and tangible evidence in the various trophies and awards on display in the snooker room.

During an interview with Keith three months later he described what the signs were of doing a good job day to day. A key goal was to establish the confidence of people with dementia, and a sure sign of this was:

"...that people let you back in their house" [...] "If they answer the phone to you, if they agree to another visit, then you're doing something right." (Keith, interview: 4/6/15)

The initial developing of a rapport with the person was extended into support and interventions:

"And following that, I guess it's just perception and how reactive they are to the different therapies and interventions that you might put forward, whether they complete them, whether they engage in that process or not. Because it's easy to go in with a leaflet and a piece of paper and a direction and say, 'Here, do this!' but if you don't put all of the colour around it as well

and the relationship, the rapport, the therapeutic alliance that goes with it, then it can get lost and people don't place any value on it, so they're less likely to do what you're asking them to do. " (Keith, interview:4/6/15)

This implies that a relationship involving getting to 'know' the person is key both because this is the basis for a therapeutic alliance and it is likely to be valued by the person, inferring too that this approach is valuing *of* the person. Keith playing snooker - on every occasion that Merfyn wished it - could be viewed as an expression of entering the world of Merfyn. Keith's approach also expressed a recognition of individual agency, particularly in the sense that snooker was a specific area where Merfyn's unique skills and sense of self were enacted. This chimes with Liaschenko's discussion of knowledge in nursing practice to affirm individual agency:

"Knowledge of a person is partly a knowledge of how that person lives, as well as what she or he lives for."(Liaschenko, 1997:27, citing Charmaz, 1991)

Second visit to Merfyn Jenkins

I met Keith at Merfyn's home and we were greeted and invited into the house. We sat in the dining room and Merfyn recounted to us how, since Keith's last visit, he had been to the cemetery to his wife's grave, and that a memorial was now in situ containing a photograph of his wife and with a holder for flowers. And set into the memorial were two stones from Cemaes Bay on Anglesey, a place depicted in many of Merfyn's paintings and which clearly had been an important place for him and his wife. Merfyn went into the kitchen whilst Keith and I remained sitting. With Merfyn out of earshot Keith said to me that this was "quite positive", because usually Merfyn would have become upset by now, talking about the loss of his wife.

When Merfyn re-entered the room Keith broached with him the subject of the carers who used to come in. Merfyn hadn't wanted to continue with the service and it had been stopped. Keith was raising the subject now because he wanted to check with Merfyn whether the current arrangement of his daughter calling in each day was working satisfactorily. Merfyn reassured Keith that all was well and showed him the notebook which his daughter kept updated with entries detailing

recent activity. Keith continued to ask how things were generally with Merfyn - was he managing to sort out meals for himself, was he managing his medication? Merfyn described meal arrangements as "a mix of Tesco and Megan [his daughter] bringing meals". But, he was having trouble with sleeping, he said.

At this point Merfyn seemed to struggle to express himself, and it appeared to be a big effort for him to maintain the conversation with Keith. The difficulty was resolved by Merfyn thinking that he needed to call Megan, and initiating a phone-call to her. He was checking with her what time she would be calling in today.

Having the time of Megan's visit clear seemed to reassure Merfyn who then suggested to Keith that they have a game of snooker. Upstairs Merfyn showed us more pictures of Anglesey, some of them in the spare bedroom. This was the room that we had been shown when we previously visited - the room that Merfyn's wife slept in prior to her death, and that had been kept in the same way since her death. Merfyn kissed the pillow, talking as though to his wife. He told us that he visited his wife's room and always cried.

Soon a game of snooker was underway between Merfyn and Keith. In the relaxed atmosphere of the game Keith casually revisited Merfyn's earlier comment about having problems with sleeping: how was he managing sleep and not sleeping, and did he find it easier to sleep at night if he was active and busy during the day?

Whether or not he did a lot in the day Merfyn noticed no difference to his sleep.

Watching Merfyn play snooker - having earlier seen him struggle with finding the words when in conversation with Keith - he seemed more comfortable and more articulate in this role of playing. As the game progressed Merfyn occasionally interjected with hints and tips about techniques, directing his comments to Keith. Again, making the most of the easy and relaxed situation Keith asked Merfyn whether he wore glasses. Merfyn said that he did, but couldn't find them, to which Keith responded:

"I was wondering if that was why your playing is a bit off today". (Fieldnote: 21/4/15)

Merfyn then potted the next ball, seemingly a retort to Keith's comment about the glasses. Keith potted the brown ball (in error) and it was put back on the table by Merfyn, who then potted another ball. Taking a different cue and a stand from the

rack Merfyn tried another shot. He didn't get the one he attempted but then returned the cue he had just used and picked up the previously used cue. With this he took a very tricky shot, managing to hit the red ball, and at the next go he potted the red. Following on with another tricky shot he was less successful - missing the shot and accidentally potting the white and the black. Seemingly in full command of the game he stated to Keith the value of the ball that Keith should try for, and offered instruction on exactly where he should aim the shot. Watching this interaction between the two men I was struck by Keith's approach:

"There is a sense in Keith's approach of recognising Merfyn as the expert, a veteran. A sort of deference, or at least respect". (Fieldnote:21/4/15)

Keith won the game, possibly a confirmation that Merfyn hadn't been quite on his usual form. Merfyn instructed Keith on how to tidy the balls away - a further display of his expertise and his command over the playing of snooker on his 'home ground'. He was also a good loser - evident in how he complimented Keith on his style and for winning the game.

Keith and I left Merfyn's home, Merfyn giving me a hug goodbye - just a gesture of his appreciation of the visit, and the company it provided. It seemed to me that on both visits the snooker game was the real 'therapy', during which Merfyn relaxed, stepped into the role of expert and was perhaps more amenable to respond to questions or talk about himself than he would have been in a more typical style of home visit.

Concluding thoughts

In this chapter I have surfaced a number of ways in which knowledge might be characterised in a memory service: the idea of repertoires of knowledge and how individuals' current knowledge repertoire seems to reference the past (both illustrated in articulations of individual histories and insights about memory problems, and in the knowledge of clinicians which has been accumulated through professional training and practice); and how these knowledge repertoires are brought to bear in the describing, explaining, assessing and diagnosing of memory problems.

To conclude this chapter I offer an articulation of how I see the linking together of the three concepts of tacit knowledge, practice and time.

Time is implicated in memory loss. It is indicated in aspects such as the rapidity of memory loss, and that memory might seem to be better on some days than others. Memory deterioration is gradual and occurs over time, yet there cannot be assumed to be a pattern or regular gradient to this deterioration, as with Mrs Maddox whose husband perceived her memory loss as intermittent. The effect of certain dementia drugs such as Donepezil is to maintain memory function on a plateau, seemingly giving people 'more time' in a maintained status of cognitive acuity.

Whilst cognitive function becomes more impaired over time, this increasing impairment is not, of itself, a reliable indicator of a parallel increase in risks. In the case of Mr Powell - a man who had not lost the ability to drive - unregulated alcohol consumption was nevertheless a factor that potentially rendered driving risky.

When individuals have their memories assessed, this might bring to mind thoughts of other people they know with memory problems. However, these thoughts might be uncomfortable as seemed to be the case for Mrs Eadie who voiced her thoughts about her friend's husband with memory problems: "I'm not like that at all." The main difference, perhaps, between Mrs Eadie and the husband of her friend was simply that she had lived for less time with memory problems than he had.

In trying to express how these insights might link together knowledge, time and practice, I start by drawing out the idea that at the point when individuals and carers have their initial appointment with Laura or Dr Ozha the situation is one of the individual having experiential knowledge of memory problems. Yet, at this stage the individual lacks an explanation of the nature of the problem, a 'name' that defines it, and knowledge of what will happen with the problem as time passes.

The clinician's knowledge is crucial not just for establishing what the problem is, but also for anticipating the various scenarios that could unfold for the individual, and for commanding a sequence of next steps (e.g. referring the person for a scan,

or signposting to support in applying for attendance allowance). Given that the clinician has encountered people previously whose cases resemble those of the person being seen now, it is probable that this knowledge is helping the clinician to understand *this* person. For example, in the case of Ms Evans Laura's clinical knowledge meant that she was familiar with the effects of a benign but growing Meningioma and the risks associated with this. Yet, perhaps because she grasped that what mattered to Ms Evans was to continue to live at home, Laura respected and did not try to dissuade Ms Evans in her wish to remain at home.

Detailed predictions of how dementia will affect how an individual's situation or how the person's future might unfold are likely to be unreliable simply because of the many variables in each instance of a person living with dementia. However, Benner (1982:127-128) has suggested that clinicians make "use of past, concrete experience as paradigms." What might be taken from this in relation to clinicians working in memory services is that knowledge from past practice experience may help to inform a current or emergent situation of a person with dementia.

How the interlinking between knowledge, time, and practice might be expressed is to say that a clinician brings to the memory appointment clinical knowledge of how memory problems affect individuals and how symptoms and risks may be managed and, because the clinician knows how dementia affects people, she can also advise on what considerations and preparations for the future might be helpful for people with dementia and carers. Time and practice are what have forged the knowledge of the clinician, whereas we might say that the individual's knowledge has been forged by lived experience of memory problems. A carer's knowledge spans time, but in a different manner to that of the clinician: a carer knows the person as they were before dementia and as they are now. In the appointment the clinician, person with memory problems and carer use knowledge from the past to bring to bear on the current situation, as well as on any future concerns.

Chapter 5. Case Study of a Social Care site

Preamble: the service context for fieldwork

Oak Hall is a local authority run two storey purpose-built facility for care, known as a Community Support Centre. Located in the town of Northweston, it hosts three services: an intermediate care service supporting people without dementia between hospital discharge to home or into permanent care, or from home into a permanent care home placement; a respite service for people with learning disabilities catering mainly for people living in the community whose care arrangements or general living situation has broken down in some way; and a respite and a day-care service for people diagnosed with dementia residing in Polshire area. It is this latter service for people with dementia that my case study is constructed around.

The facility where respite and day-care is provided is called the Minton Suite, but the service is known and referred to as 'Oak Hall' by carers, clients and staff. The staff team - as it was for the 13-month duration of my fieldwork - consisted of an operational manager, a deputy manager, four receptionists, an activity worker, and a team of care workers and senior care workers (known as 'seniors'). All staff are employees of Polshire council. When I commenced fieldwork in May 2014 a new manager had just started in post. This was to change four months later at the end of September when the manager left her post and a new manager started.

The scope and account of fieldwork

Research fieldwork was conducted at Oak Hall over a thirteen month period from May 2014 until June 2015. Mainly, my observational work focused on interactions between clients and care staff. The exceptions were two observations of staff meetings, namely a half-hour hand-over meeting and one three-hour management meeting. Observational work was supplemented by semi-structured interviews with five members of care staff, one of whom was the Activities Co-ordinator.

Unlike at the NHS memory service where my observations were almost exclusively 'one-offs' of individuals in memory appointments, at the social care service I had repeat contact with the same individuals with dementia (and in some cases their carers) over time. This reality of fieldwork afforded me the

opportunity with at least some of my participants to 'follow' some aspects of their lives. Conversations I had with individuals, and the interactions between individuals and staff that I observed, triggered in me insights about people's personal stories and experiences. I reflected on how people's stories have past, present and future dimensions, and how certain fragments of an individual's storyline may become surfaced during a conversation or are gleaned from seeing an individual demonstrating a competence during an activity (for example, calling for a game of bingo signals that the person has probably previously done this). Being party to the storylines of participants with dementia was one way through which I could get to know my participants.

When deciding how to write my account of fieldwork at Oak Hall I wanted to try both to conserve the notion of past, present, future experiences as interlinked across the entirety of a life, and to reflect the sense of multiple times spent with the same individuals. I thought that a chronological account of my fieldwork would probably prohibit the threading together of several lots of observations of one person from different points in time. To illustrate, I write about my first encounter with Stuart at Oak Hall, and immediately follow this with my visit to his parents' home, even though there were several weeks between these two events. My data is organised and elaborated on under conceptual headings (e.g. *Arriving and departing*).

Detailed summary of fieldwork

The fieldwork took place between May 6th 2014 and October 7th 2015. Fieldwork involved in situ observations involving a total of 27 individuals from whom signed consent had been obtained. Of these, ten were people with dementia – consent being provided by the person with dementia except in two cases where a caregiver gave consent as nominated consultee. Twelve of the individuals were frontline care staff and five were managers. Observations took place at Oak Hall in the day-care lounge, the adjacent kitchen, the two smaller lounges, and the team meeting room. Five members of the care staff team participated in individual semi-structured interviews.

Three public council meetings held in council buildings I attended in person, and one council meeting I viewed subsequently via the broadcast of the webcam.

I visited the home of the family carers of one person with dementia who at the time was staying at Oak Hall whilst being assessed, and I visited one person with dementia and their spouse in their own home.

Nine months into my fieldwork I presented some slides about my fieldwork and early thoughts about findings to a group of seven clients, four members of staff and two family carers. This was an informal session followed by a discussion. In total about 96 hours were spent in observation, interviews, home visits and attending meetings. This did not include travel time to the sites of fieldwork or administrative time.

Introduction to Oak Hall staff

My first visit to Oak Hall Community Support Centre (hereafter referred to as Oak Hall) was arranged during a phone conversation with the newly appointed manager, Cath. She suggested that attending the seniors' meeting would be a good way for meeting staff and introducing myself. 'Seniors' were staff who had responsibility for each shift or, in the case of day-care, the senior on duty who planned and led activities in the day-care room.

My thinking was to try to impart to this group of staff the research project, what the project entailed, and to answer any questions. The reality was somewhat different.

At the meeting on May 8th 2014 I spoke briefly about the proposed research study, including what my hopes were in terms of recruitment and involvement of staff and people with dementia:

"From the responses from staff to my introduction - no questions and something I interpreted as a sense of awkwardness - I felt that staff probably did not fully understand what I would be doing, but I was hoping this understanding would develop over time. In retrospect introducing the research was a necessary formality to go through but not something that I felt had helped people to understand the research project." (Fieldnote: 10/5/14)

A few months into my fieldwork - when I was regularly spending time in day-care, and staff and clients were used to seeing me - I adjusted these first impressions of

staff's responses to the project. Most staff seemed willing to keep an open mind about why I was there and what I was doing. As time went by there were instances where staff provided 'tip offs' and snippets of knowledge, such as a nurse who also worked at another care facility telling me about what she viewed as the very positive care philosophy there, and suggesting that it may be interesting for me to visit.

Another snippet of information had emerged from a conversation with Cath after the first seniors' meeting I attended. She had explained that it was a new experience for staff to have a researcher in situ at Oak Hall. I was unaware of what conversations, if any, had taken place between Cath and my original contact person, the Commissioning Manager for Children, Families and Adults. Cath was fairly new in post at Oak Hall, and I thought it unlikely that during that short time she would have been involved in decisions about a research project, but I just did not know. As a researcher I had an 'agenda' of objectives, the primary one being to successfully complete fieldwork. Fieldwork itself was contingent on having access to potential participants, obtaining consent, and being able to collect data. Furthermore, an aspect of being granted local research permissions to conduct research at Oak Hall was my agreement to produce an end of fieldwork report. Once in the field these various fieldwork activities required ongoing negotiation - finding out what would work in situ (e.g. how to approach potential participants) whilst being sensitive to and mindful of everyday constraints in this environment.

Introduction to the building, clients, and the service provided

The respite and day-care service is located in the Minton Suite - a wing that was added to the existing Oak Hall building in 2012 at a cost of £500,000. The wing provides twelve respite beds and twelve day care places for people with a diagnosis of dementia. It is named after "Minton Lodge", the council's former local centre of excellence for dementia care where seventeen assessment and respite places to people with dementia had been provided. Minton Lodge was sold by the council in 2010 and subsequently demolished in 2012, then replaced with a housing development. When the Minton Lodge service closed its respite and day-care facility was transferred to Oak Hall. The reprovisioned service fits the description of a specialist facility, as defined by Bamford et al (2009:30):

"Specialist Respite Facility: Provision of overnight respite, sometimes in conjunction with day care. Some facilities also provide residential/nursing care."

On my second visit to Oak Hall Cath gave me a tour of the building. I was shown the Day Care lounge and dining room - primarily for people with dementia - then the corridors where there were bedrooms, sluices, and another lounge. We went into a couple of the unoccupied bedrooms, used for respite breaks by people with dementia. I was struck by the manager's emphasis on the physical aspects of the building, particularly her highlighting of the state-of-the-art hoist tracker system in most of the bedrooms, which enabled staff to hoist a person easily between bedroom and en-suite bathroom. The mirrors in each bedroom were also pointed out and I was told that each mirror had wooden shutters that could be drawn across the mirror so that anyone distressed at seeing their reflection - perhaps not recognising who they saw - could keep the shutters drawn across. The corridor where all the bedrooms were was light and airy and had lots of windows, as well as some seating areas. Further on in my fieldwork I did see people with dementia using the seating areas.

I was shown a very attractive and well maintained landscaped garden which could be accessed from either of the two lounges and had a covered walkway so that people with dementia could go in the garden safely and walk a whole loop through and then back into either lounge and along the corridor back to the day-care lounge. I imagined that this was designed to engender in the person with dementia a sense that they were progressing from place to place, rather than merely walking round in a loop.

The respite part of the building was a place where people temporarily *lived* and it was here that there were the bedrooms, bathrooms and sluices.

"I did notice the smell of the physical building, generated (no doubt) from toilets, the sluice, just people's bodily stuff." (Fieldnote: 20.5.14)

The purpose of the Oak Hall building, its architectural features, and the 'feel' of it for me as a visitor-researcher is worth a brief reflection. In my earlier working life I had worked in care homes for people with dementia, visited people in care

homes, been into long-stay institutions, worked with people with learning disabilities after they had been resettled from long-stay hospitals, and read and heard first-hand accounts about life in an institution. My acclimatisation to Oak Hall had a very personal dimension in which past experiences sensitised me to the Oak Hall environment in particular ways. For example, the locked door between the day-care lounge and the rest of the building reminded me of a previous situation I had encountered in which people were told by staff that they could not leave. Robinson (2004) explains how the architectural features of a building and its equipment and furnishings 'cue' behaviours, expectations, and beliefs. There is potency to this cueing process because it engages subconscious aspects of ourselves such as our memory of other experiences and, furthermore, if we then enter the specific building we are likely to adopt particular behaviours that are normatively correct for that environment (Robinson, 2004:13). Wolf Wolfensberger (1969) coined the term the "language of architecture" to suggest that a building's architecture is infused with the attitudes and philosophies of the designers and those that guide and direct them. This idea he applied to the architecture of institutions to which people who are devalued, or are at risk of being devalued, have a direct association (for example, a medium secure mental health unit). To reduce the risk of negative associations relating to architectural forms and devalued persons, over-compensatory measures should be adopted in the creation of what Wolfensberger termed "supra-normative" environments containing value-enhancing features and excluding stigmatising ones:

[if] "a person or group is already devalued or at risk, processes and juxtapositions should not merely be statistically normative ones, but should even go further by being supra-normative in the sense of actually adding extra value projection to the person or group. For example [...] the interior of a residence for devalued people should be even a bit more attractive and clean than average homes". (Wolfensberger in Bednar, 1977:159)

In Oak Hall my first impressions of the material environment were coloured by noticing traces of institutional regimes. The entry and exit doors to the respite area and the day-care lounge were locked and only accessible with a swipe-card, which only staff had. Seats in the main day-care lounge were arranged in a large

circle, and the high-backed chairs looked as though they would be unwieldy to move and rearrange in a different way. Yet, such traces of institutional life were juxtaposed with other factors such as friendliness and kindness of staff, and the general look and feel of homeliness that staff had created.

As we walked around Cath introduced me to several people with dementia including one man who had been resident at Oak Hall for several months.

Decisions were pending about a suitable permanent care placement for him.

Much later on in my fieldwork I heard the term 'over-stayer' used by the leader of the council during a public meeting to describe people whose stay at community support centres exceeded the 'maximum' respite care period of 29 days. Stays of more than 29 days were deemed as "permanent care" which the council was not licensed to provide. I thought it was telling that I never heard this 'rule' mentioned by the manager or any of the staff at Oak Hall.

During the tour of the building I broached with Cath the delicate issue of clients' consent in relation to my research project. Her view was that many - possibly most - of the people with dementia using services at Oak Hall were unlikely to have capacity to consent. I felt unsure how to interpret her seemingly broad statement about capacity: whether the implication was that I should work from the basis of *not* assuming capacity and steer down the Nominated Consultee route. The assumption of capacity - unless there is evidence confirming lack of capacity - is made clear in the Mental Capacity Act (2005). The Act also acknowledges that capacity is subject to fluctuations, and is topic and time specific. Cath's comments, which may simply have been her way of alerting me to the basic challenges associated with obtaining consent from people with dementia, usefully provoked me to reflect on the possible variations and viewpoints about ethics. That is, how did practitioners address ethical issues arising in day-to-day practice (I thought it likely that this would be mainly along pragmatic lines), and were there any formal mechanisms for monitoring of ethical issues in frontline local authority services? And, importantly, what were the ethical issues of concern to people with dementia and carers? The concerns of carers and people with dementia did come to the fore in a rather unexpected way in July 2014: a local newspaper headlined that the council were considering closing the service to people with dementia at Oak Hall.

Recruitment and establishing myself as researcher in the field

In the first months of fieldwork between May and July 2014 I visited Oak Hall once a week, typically arriving around 09:30 and staying until lunch was served at around 12.15. On the few occasions I spent time at Oak Hall in afternoons I found it seemed not such a good time to engage individuals in conversation as people often fell asleep or appeared less energised.

My efforts were initially put into the practicalities of meeting and introducing myself to people with dementia, usually in the day-care lounge; and also in negotiating with the administrative and reception staff the most effective way to make contact with carers to inform them of the research project. It was suggested by the manager and the administrative staff that I provided participant information sheets and consent forms for inclusion in the Oak Hall welcome pack - posted out to all new clients. I agreed to this approach, which seemed promising, and by early July 2014 a trickle of signed consent forms began arriving at Oak Hall, mostly signed by carers rather than the person with dementia.

I was in regular contact with one of the members of the administrative team (Karen) by email. She became my main contact for getting information out to potential participants.

"I had received an email from Karen requesting more SAEs and consent forms. Decided that - on the basis that *carers* had signed the forms in both instances - the best, though not ideal, approach would be to give Oak Hall Consultee forms. My concerns about doing this are that it makes a huge assumption that people are unable to consent for themselves, and also I risk the chance that carers will not fully understand the 'consultee' form. Tricky really." [Fieldnote: 9/7/14]

These first fieldwork visits typically involved me sitting in the day-care room with people with dementia and staff, chatting with people, and joining in activities. I adopted a mind-set oriented towards noticing what was happening in the environment, the conversations and interactions taking place between people, care practices; and trying to pick up on clues to emergent 'story-lines'. Alongside my orientation towards becoming immersed I was aware that I needed to start to approach individuals with dementia to introduce my role and my research project

at Oak Hall. Every visit offered the possibility for recruiting a person with dementia or a staff member, and so I always carried with me a folder containing participant information sheets, consent forms and Nominated Consultee forms. I adopted a fairly stock way of introducing the research to people with dementia:

- Asking the individual if I may sit by them and introduce what I was doing at Oak Hall. If the person agreed, I described the research purpose as being to try to understand how staff used their knowledge to help and support people. I offered an information sheet to the person, and drew attention to the part about observing and what this meant (i.e. sitting in the room, looking, making notes). I then asked the person how they would feel about me doing some observations of them. If the person indicated being content, I then asked directly whether or not they were willing to give me permission to do so. This was the basis for introducing the consent form and requesting signed consent.

Directly recruiting people with dementia (rather than approaching a carer to be a Nominated Consultee) involved me making judgements about the person's comprehension of what it meant to give consent. I could not know in any definitive sense whether an individual had fully grasped what I was asking, but I approached people assuming their capacity. There were people who I did not approach directly: individuals who I could see still interacted with staff, and sometimes participated in activities, but whose verbalisations were single words or sounds from which it was impossible to know the meaning or what the person wished to impart. I drew on the knowledge of day-care staff about individuals and their life situations, and this coloured my thoughts about whether to approach a person or not. For example, I discovered from talking with Kate and Jan the general unhappiness of one man who did not want to be at Oak Hall and had to comply with specific dietary restrictions. Understandably this resulted in him being short tempered and usually reluctant to take part in any activities. Even though this man was quite articulate and would have been likely to understand and be able to provide consent, I did not want to put him in a situation where he might have felt another demand was being placed on him. Two individuals - Andrew and Stuart - I realised I would not be able to obtain informed consent

directly from and I approached their respective carers who agreed to be Nominated Consultees.

Three other individuals who I had spent time talking with and recognised it was very unlikely that they would be able to provide informed consent, had family involved. One of these individuals was dropped off at Oak Hall by her husband, who often appeared concerned and stressed. In theory the point at which a carer dropped off or collected the person was a good time to speak with them, but in reality this was probably one of the most stressful points of the day for carers. Dropping off and then leaving the person involved separation which was not necessarily what the person with dementia wanted, and carers undoubtedly knew this and had their own feelings about this to somehow manage. I decided it would be insensitive for me to use this moment to approach carers, unless an arrangement had been agreed in advance to meet with a carer at this point. My other options for approaching carers were: to offer an information sheet to carers to take with them when they dropped off the person with dementia (which I did in one instance but it did not open up an opportunity to follow up with the carer); to write to carers (in one case a carer I wrote to about being a Nominated Consultee did not respond to my letter, and in another case there were no contact details available for me to write to the son of a lady with dementia). The first person recruited into my research project was in early July 2014. The last person I recruited in February 2015 - a gentleman with dementia who I saw infrequently but always had a chat to when his respite stay coincided with one of my visits.

Arriving and departing: a practical representation

It was typical that at the point when I arrived at Oak Hall at around 9:30am I would see several clients already in the day-care lounge - usually people who were staying in respite care. Other people would be having breakfast in the dining area, visible from the main day-care lounge through an always open sliding door. Two or more members of staff, one a senior, were there preparing for that day's session and welcoming people with dementia as they arrived - generally transported in for the day by a family carer or sometimes by a taxi driver. In the lounge and dining area it was common to see five or six members of the care team

involved in various day-to-day activities such as assisting individuals with breakfast, chatting to people in the day-care lounge, reading through handover information, and writing notes. When a carer left the building after dropping off the individual with dementia it was usually to do something that was easier accomplished alone, such as shopping or going to the hairdresser's or bank. On arrival at Oak Hall people with dementia signed in at reception - maybe having a brief chat with the reception staff - then were shown through an opaque glass door into the day-care lounge, an area that was only accessible using the swipe card which all staff carried. The panelled glass wall between the day-care lounge and the corridor led to reception in one direction and in the other direction to the staffroom, manager's office and the kitchen. This partitioning wall had been draped with curtains so that any activity in the corridor could not be seen by clients who were in the day-care lounge, and the frosted glass of the locked door also prevented seeing in or seeing out. The basic premise of the door that was locked and therefore impossible to exit from (without a swipe card) was to reduce the risk of people with dementia absconding from the building. However, this didn't mean that people didn't try. Michael, a man who was always dropped off at day-care by his wife, must have realised that the day-care lounge door was the main entry and exit point and would often go up to the door, try to open it, try again, and then either give up or become frustrated and demand to leave. Often staff were able to distract him with the offer of a cup of tea, but occasionally there was a minor altercation in which Michael would protest, raise his voice, swear, and staff would respond by very firmly stating that he needed to stay here until his wife came to collect him later on.

Arrivals and departures took on particular meanings in the context of day-care and respite care at Oak Hall. There were arrival-departure events that were of very short duration, such as the individual with dementia and their carer arriving then the carer promptly leaving in order to minimise disruption or upset to the person. At a practical level moments of arrival were opportunities for carers to pass information about the person with dementia to care staff: relaying that an individual had a poor night's sleep, for example, signalled to care staff that the person may be tired and more likely to fall asleep during the day. Arrivals for respite care were more complex events, drawn out in time. They involved

bringing items the person needed for their stay such as clothing, toiletries, and medication, and usually there was a handover between carer and a staff member. Arrivals and departures of staff starting or ending their shift, or to attend the handover meetings at the beginnings and ends of shifts were everyday events. Perhaps less obvious, but equally interesting, were instances of *attempted* departure (as in the example of Michael) that remained uncompleted, prevented by the locked door. Other forms of departure included temporary halts or suspension in using the day or respite service, common in instances where a person was unwell, and stayed at home, or had been admitted to hospital. Entry into a nursing home was generally a sign that the person could no longer be managed at home, and represented not only a permanent cessation in using the services at Oak Hall, but also signalled the near certainty that the person would not return home. For a spouse or other family carer of an individual with dementia - even in cases of the individual eventually entering permanent care - there is a journey towards this for the carer and the individual which is gradual. In the general instances I have already described there was a sense in which dropping off the person with dementia for the day or for a weekend or longer respite break became a familiar pattern that perhaps enabled individual and carer to get used to periods of separation.

I was also party to the narratives of specific individuals whose impairments seemed to become more apparent over the duration of fieldwork. These were small fragments of information about individual journeys, through which I learned of particular events in a person's life from which change ensued that seemed to affect both the individual and their carer. Out of six people who I met during my fieldwork who all eventually moved into permanent care there were two people - Stuart and William (participants in this research)- whose lives I came to know about, mainly through meeting their carers and other family members. William, who I recruited into my research project within the first couple of months of starting fieldwork, is married to Cherry. She wrote to me early on in my fieldwork inviting me to visit her and William at their home, keen that I should meet William in his home environment. My first visit to their home was one evening in September 2014, during which I learned a little about their life

together and the changes that Cherry saw in William related to dementia. Over the following nine months there were about four occasions when my fieldwork visits to Oak Hall coincided with one of William's stays in respite care. Shortly after completion of fieldwork at Oak Hall I heard that William had fallen at home. I subsequently visited Cherry and heard from her how William had fallen late at night and despite considerable effort she found it impossible to get him up. The paramedics were called. As a result of the fall he was promptly admitted to a local residential care home, an interim placement whilst the options could be considered. This seemed like an inevitability. The precarity of the situation leading up to William's admission could be described in terms of Cherry's coping with all aspects of care for William who himself was becoming less mobile. Cherry had problems with her back, undoubtedly further aggravated by physically assisting William to the bathroom and bedroom which were upstairs. It had been Cherry's firm wish to continue to care for William at home, but this option now retreated following William's admission into interim care. The fall seemed to me to represent a defining moment of diminishing options. In fact, unless Cherry thought that she could manage William back at home, there was no choice other than entry into permanent care: a transition that seemed to symbolise a relinquishing of care responsibilities from a carer to a care home. At the time William fell there were no care home places available locally, therefore the place initially offered for William was some distance from their home. This was unsatisfactory and Cherry was insistent to the social worker that William should be somewhere close to her. By late 2015 William had moved into permanent care, where he remains, a mile from his original home. His departure from his home and entry into permanent care marked profoundly a separation between William and Cherry, perhaps unimagined by either of them even just a few years earlier. There was another type of departure that signified endings that were final and involved loss, such as people dying or the 'taking away' or removal of certain things permanently. During the time that I conducted fieldwork at Oak Hall none of the people I had met died, but I knew individuals - such as Michael - who lost faculties or whose faculties became irreversibly impaired through a particular health crisis.

As well as personal forms of loss there are losses and permanent 'takings away' that can affect people collectively. One such taking away occurred during my fieldwork stage. This was the closing and removing of the county's two council run day and respite services for people with dementia - Oak Hall and Long Edge - an important event for carers and people with dementia, and one which I give an account of at the end of chapter 5.

Memory of the past and thoughts of the future

Having a dementia-type memory problem is the essential eligibility criteria for an individual to use the services provided at Oak Hall, and so almost by definition 'memory' is significant.

Many of the activities that took place in the day-care lounge were structured around a memory frame of reference. Activities such as quizzes and crosswords taxed people's abilities to remember. Reminiscence activities involved objects from the past which individuals were gently encouraged to engage with for jogging memories of past experiences. For singing sessions songbooks were provided so people could follow the words and sing or hum the tune. Games such as bingo or skittles provided opportunities for people to exercise previously learned skills.

There were people I met at Oak Hall - Claire and Andrew for example - whose reduced verbal repertoire became noticeable when staff, or I, tried to engage them in conversation. Yet, people who seemingly struggled to converse could still surprise by uttering the correct answer to a quiz question at the right time, or knowing all the words to a song.

Out of all the people I met at Oak Hall it was Paul who maintained the abilities to articulate his thoughts about past, present and future with great clarity. It was within the first few weeks of fieldwork that Paul and I met. He was one of the youngest people with dementia I encountered at Oak Hall. Over the fieldwork period I felt that he was a 'constant' in that not only did our paths cross most weeks, but also that when they did Paul would often update me on the events he had witnessed, some funny, others sad, but all insightful of everyday life at Oak Hall. Paul did not sit with other clients in the circle of chairs arranged around the edges of the lounge, but instead sat at a table outside of the circle, near the main

door. Shortly before I first introduced myself to Paul I had heard from a member of staff what seemed to represent the consensus view that the reason he always sat at a table at the side of the room attending to activities he brought with him was because he had previously been a teacher. Paul's own account was qualitatively different, and served to highlight how he saw himself positioned currently in relation to his diagnosis of dementia. He described to me how he sat at the edge of the room looking in because:

[Paul]"wants to convey a slight 'distance', not from people but more from *the future* in terms of developing dementia himself." (Fieldnote - 9/7/14).

Paul had a diagnosis of Pick's Disease - a frontotemporal form of dementia. Up until near the end of my fieldwork at Oak Hall he was very aware of the likely trajectory of his dementia and how it would affect his needs and abilities over the next couple of years: the near future. However, all this was brought into question sometime during the last couple of months I was conducting fieldwork. A new picture had begun to unfold concerning Paul's future. From a conversation with his consultant psychiatrist Paul had found out that he was one of only a handful of people affected by Pick's Disease in whom the characteristics came together in an atypical way, involving less severe effects. This revised prognosis was presented to Paul by the health professionals involved in his care who were suggesting in fairly optimistic and confident terms that he should expect to be invited for a review in two years' time with no major deterioration anticipated within that timeframe. Paul and his wife were thus presented with a revised future, different to the one that they had started to prepare themselves for psychologically and in terms of practical measures they had begun to put in place. Paul was upbeat about this latest appraisal of a much slower decline, and laughingly told me that there was now a possibility that he may 'outlive' his wife. However, it was not all plain sailing just because of this less gloomy prognosis: the emergence of a new problem - that Paul's eyesight was affected by Pick's Disease - was quite a blow. The healthcare team had referred him to an eye specialist to see what could be done to optimise his vision, but I realised that the deterioration in Paul's eyesight concerned him.

Paul always brought with him a sketch pad and would draw pictures of scenes within Oak Hall including of clients, the lounge area, and the garden, explaining to me that nobody was allowed to take photographs within the building so drawing was his way of developing a record of his experiences at Oak Hall. I suspected that deteriorating eyesight would bring an end to his drawings, even though failing eyesight was perhaps the trade-off for a slower decline in cognitive capabilities.



Figure 1: Drawing by Paul: researcher (SM) taking fieldnotes in situ at Oak Hall, 22/04/15

Life expectancy of people living with dementia might be viewed as a temporal aspect of dementia. In frontotemporal type dementias - of which Pick's Disease is one - there is a specificity to projections about life expectancy. In terms of number of years the outlook can be gloomy. From the initial onset of symptoms of frontotemporal dementia life expectancy averages 6.6 - 9 years, but from the time of diagnosis life expectancy is only 3-4 years on average (Wilfong et al, 2016). The degree to which temporal expectations are known with certainty, Glaser and Strauss suggest, "becomes a crucial condition for the people involved" (Glaser and Strauss, 1971:34). The first that Paul knew about what was, essentially, a revised temporal framing to his diagnosis of Pick's Disease was during his conversation with the psychiatrist. Up until this point Paul's view about his future was

informed by and in accordance with the original assessment by the healthcare team. The further examinations and tests he had undergone had revealed new factors and new information that threw the original 'certainties' into disarray. In their theory of status passage Glaser and Strauss (1971) draw attention to how uncertain timings may be dealt with by those who have roles as legitimators for a passage. Legitimators are those individuals who have rightful authority, related (usually) to specialist knowledge about a particular passage. In uncertain situations one possibility is for legitimators to develop a "'wait and see' passage", permitting them "to work in a temporal vacuum" (Glaser and Strauss, 1971:37). Given what Paul had said about the expected delay in deterioration (the healthcare team's confidence that Paul would continue to maintain his current level of wellbeing at least for the next two years, and quite possibly beyond) it seemed that Paul would have *more* time before seeing any deterioration. This idea of the bestowing of time by legitimators has been termed "promised time" (Glaser and Strauss, 1971:37). In Paul's case, this was time that neither he nor his wife or family expected. The judgement by legitimators (in this case the healthcare team) that there will be more time has been suggested as crucial (Glaser and Strauss, 1971:37) because it means that the legitimator(s) have "a structural prerogative to create a timing for the passage by which others may (even should) then organize their behaviour for its duration".

In Paul's case this might well mean that his appointments with the consultant psychiatrist would be able to be planned further ahead into the future. There might be a relaxing of the intensity and frequency of checking the status of Pick's disease in light of a different picture of the future emerging. With expectations about *when* Paul would become more impaired now changed, the possibility that Paul may manage for longer living in his own home was now a real prospect. There were also grounds for hope that permanent care might not have to be considered, at least not in the near future. Perhaps the amount of day-care and respite care would need 'upping', or fine tuning of existing arrangements in some way to support a continuation of living at home.

The situation of Stuart - a man with Down syndrome who had begun to have significant memory problems - illustrates ideas about the significance of being

known by others when someone is no longer able to speak of one's own history. Stuart arrived at Oak Hall in August 2014, the plan being to assess his needs so that provision could be made for his ongoing care. Stuart had all but lost his ability to verbally communicate in a coherent way, and gaining a sense from *him* of what he knew about his recent past was unachievable. However, aspects of Stuart's story did become apparent through my own encounter with him and through his parents' account during my meeting with them.

When I encountered Stuart at Oak Hall in mid-August 2014 I immediately recognised him as somebody I knew from about 15 years previously when I was involved in a local advocacy organisation that supported people with learning disabilities:

"The biggest shock was seeing Stuart (I used to know him from Advocacy). Hadn't seen him for about 6 or 7 years. Asked Kate about the situation. Stuart is staying here for a couple of weeks in the Minton Suite. He has dementia. I remember him as very articulate and able to speak for himself, and quite 'exact' and particular. Quite different now." [Fieldnote: 19/8/14]

I had not anticipated seeing somebody from my own personal past in the course of my fieldwork, and meeting Stuart triggered in me an odd sensation of seeing a person I knew, but completely out of context. This was a moment when I felt I had fallen out of the 'role' of researcher and briefly struggled to maintain my composure. I had the feeling that Stuart was diminished in some way and that any possibility of again enjoying a two-way conversation with him was irretrievably lost. Stuart did not know me or recognise me. I was meeting him again now in my role as researcher, a Stuart who appeared changed. But because I knew him I was also dealing with my own personal feeling of shock at seeing him as he was now, and recalibrating in my head this new reality. I experienced my own 'jolt' and a disturbance to my personal temporality; the idea that on one day I had seen him as an animated and capable man and the next time I saw him he looked the same yet was barely recognisable as Stuart. I had the feeling of having missed a crucial section of the continuum of time during which he had stepped into having the experience of dementia.

Stuart was the only participant in my research project who I had previously had an acquaintance with, and with whom there was a before and an after encounter. His parents and sisters had a rich familial knowledge of Stuart, extending far back in time to his childhood. Mr and Mrs Harris, Stuart's parents, knew him probably better than anyone else, and had cared for him at home throughout his life until he was brought into Oak Hall. I met the Harris' at their home in September 2014, having contacted them to ask whether I might discuss with them the possibility of Stuart participating in my research project for which I would need agreement from a nominated consultee. Mrs Harris expressed happiness and relief that there was somebody who remembered Stuart as he had been before he developed memory problems. As I talked with the Harris' there were vividly recounted stories about him growing up, playing with his four sisters, family holidays to Scotland, and to France where Stuart used to read his selection from the menu in French to the waiters. Mrs Harris frequently referred to Stuart in the past tense, rather as though there was no possibility of reconciling these two different realities of her son - Stuart 'then' and Stuart 'now'. The situation of Stuart was atypical compared with other people with dementia I met at Oak Hall. Unlike the majority of people who participated in this research project Stuart's carer was not a partner, son, or daughter, but his parents. Carers are the primary witnesses to changes over time in the person they care for. They notice 'first times' - the first time a person is unable to perform a task which she or he was formerly able to manage with ease:

[Mrs Harris] "explained how Stuart had started to change subtly about two and a half to three years ago. Then there had been an acceleration. One day he had gone upstairs to shave and wash his hair and had come down with only part of his hair wet. [...] Now, Mrs Harris says, he doesn't recognise his sisters, or family members. She tells him 'I'm your mum', but he doesn't understand". (Fieldnote: 11/9/14 - during a visit to Stuart's parents at their home)

How Mrs Harris experienced this moment was personal and wrapped up in her history with Stuart, of being his mum. However, we might also say that the 'first time' does occur for every person who develops dementia. A first time may be

consciously realised by the individual (or not), or by a family member or partner (or not), but there has to be a first time. Beard and Fox (2008:1512) describe these moments as "a specific episode, or turning point", which may nudge the person towards seeking an appointment with a physician.

Mrs Harris' words allude to another aspect of carer experience - the reconciling of memories of how someone *was* and how someone is perceived to be now. Mr and Mrs Harris had shared their home with Stuart and therefore witnessed him becoming a person with dementia over a period of time, whereas my experience was of meeting him when he did not have any signs of dementia and then meeting him 15 years later by which time he was significantly impaired. The change in Stuart was experienced as something gradual and subtle by Mrs Harris; whereas my experience of the change in Stuart was that it had the appearance of being sudden because I had not been there to see changes in Stuart. All I saw was a before and after, and had experienced none of the interim time.

Thinking reflexively about how my own prior knowledge played out, I concluded that divulging to the Harris' information about my previous acquaintance with Stuart and the circumstances through which I had known him, provided something like a shared reference point: my recollections of Stuart as a person before he had dementia converged with the Harris' memories of him.

Furthermore, prior knowledge acquired through a vocational degree course meant that I was sensitised to the communal history of people with learning disabilities in the United Kingdom, and am knowledgeable about the Normalisation critique (Wolfensberger et al, 1972) and the aspirations of the service accomplishments (O'Brien, 1989). This prior knowledge filtered how I made sense of the interactions between staff and Stuart which I observed.

The lived experiences of people with dementia: responding to and making sense of individual expressions

At the point at which Stuart had come to Oak Hall to be assessed his ability to verbalise in a way that could be understood by people around him was so diminished that conversation tended to be focused around shared activities such as reading or, more accurately, looking through one of his favourite books. There

were two or three members of the care staff who were clearly fond of Stuart and made efforts to spend time with him and build a rapport. I noticed that Jan, a senior care worker, used humour with Stuart to encourage a response:

"Jan finds his 'Mr Big' book and looks at it with Stuart. 'Mr Big with his ball'. She goes through the pages, then says to him that they will play ball later. 'What do we do when someone scores a goal? We shout hurrah!' Stuart joins in on the 'hurrah!' I see a bit of the former spark of Stuart. Then Jan asks where the keyboard is, and goes and finds it, brings it to Stuart. Jan plays some of the keys and asks Stuart if he can do this. 'I can't play the piano - can you, Stuart?' Jan is really gentle and encouraging towards Stuart". (Fieldnote: 2/9/14)

I learned from staff that a decision had been made to prioritise Stuart's needs related to dementia over his needs related to being a person with a learning disability, so he was being assessed at the Minton Suite rather than at the respite service for people with learning disabilities, located in another part of the Oak Hall building. There were differences between how staff talked to and related to Stuart and how they related to other clients. One way of construing staff approaches to Stuart was that these ways of relating to him 'infantilised' him. Yet, I thought that their approaches were more likely motivated by a wish to connect with him and get to know him, and therefore be in the best position to assess his needs.

Nonetheless, words are the content of discourse, and it is useful to be mindful of the many examples in history where discourse has resulted in 'silencing' whole groups of people – for example, through removing people from their families and communities and placing them in institutions. A further point is that care work greatly relies on verbal communication between care staff and individuals.

Listening, finding out, negotiating, and even challenging may be involved. It was also apparent that Oak Hall staff working with people with dementia had little or no experience of working with people with learning disabilities, and so there was no reason to expect them to be knowledgeable in this field.

Stuart, as he was now, was unable to coherently verbalise his experiences of dementia, and *how* the experience was affecting him was essentially unfathomable

to the staff he had daily contact with. This was true of other clients at Oak Hall, many of whom were losing the ability to articulate verbally their lived experience. At Oak Hall people's behaviour, body language, gesture, facial expression, posture, skin pallor/flush provided important clues to care staff which could signal how an individual was at that moment in time (e.g. sad, happy, in pain, disoriented). Along similar lines, behaviour or demeanour could signal that something was about to change (e.g. a person becoming unwell, aggressive, upset). A behaviour I observed quite regularly was restlessness (of participants in my research study and non-participants) which was sometimes accompanied by disorientation. A common way that restlessness manifested itself was an individual asking staff where s/he was, or where was their partner, spouse, or family member. If a person's concerns were not allayed to their satisfaction s/he might then pace about, and might try the doors in an attempt to leave the building.

"A lady who I haven't met gets up and picks up a cushion from the seat next to her, then tries to open the (locked) door."(Fieldnote: 24/6/15)

"Jan asks Andrew whether he would like a drink and biscuits. Andrew says no, he doesn't want anything at the moment. Jan has clearly picked up on something because she then goes into the dining area (where Kate is on a one-to-one with a lady), and says to Kate that Andrew is getting restless. By this point Andrew has removed his blanket."(Fieldnote: 22/1/15)

These instances illustrated that individuals could be actively engaged in leaving - whether getting ready to leave the building, or setting off from one place with a particular intention to go elsewhere. These activities made perfect sense to them in the context of a lived experience at that moment in time. Fuchs (2006) has suggested that whenever a person is absorbed in what they are doing an "implicit mode of temporality is retrieved", but that:

..."this changes when a gap arises between need and satisfaction, desire and fulfilment, or plan and execution. Now the future appears as a "not yet" or "yet to come", experienced as the temporality of awaiting, striving, or longing for." (Fuchs, 2006:195)

For people whose sense of time is disturbed as a result of memory impairment, that disturbance or disorientation forms part of their lived experience, on the basis that they are interacting with the world as and how they perceive it. The instances described of people feeling that they want to leave seem to come close to what Fuchs (2006:196) refers to as "lived time", which he states:

..."may be regarded as a function of the lived body, opened up by its potentiality and capability." (Fuchs, 2006:196)

Even if an individual with dementia could be distracted from trying to leave the building, and then forgot that s/he was attempting to do so, this might still be regarded as an interruption to that individual's lived time, as well as a pushing away into the future any possibility of realisation of what that person wanted (i.e. their desire to leave the building remaining unfulfilled). This may suggest the possibility that there are facets of services such as policies, and perhaps some practices, that are in conflict with the lived time of a person with dementia. At Oak Hall having locked doors might be one such policy that conflicted with lived time, whereas the design of the garden - through which a person with dementia could walk in a continuous loop without being hindered by doors that were locked - did not obstruct or disturb this activity of moving from one place to another in lived time.

On a day to day basis how staff responded to the lived experience of people with dementia when it may have appeared baffling, and in the absence of an explanation offered by the person, becomes an important consideration; important for two interrelated reasons. Firstly, there was what might be termed a "diagnostic" (Buscher et al, 2010:193-207) element, whereby staff needed to try to accurately 'diagnose' what was going on for the individual with dementia at that moment in order to provide a response that reflected accordance with the individual's lived experience. Secondly, such moments might be seen as involving several elements: the individual's sense of lived time (temporality), the knowledge and knowing that is involved in making sense of that, and the practices within which the knowing or knowledge are then enacted. The simultaneous coming together of tacit knowledge with practices Polanyi referred to as a blend of "skilful doing and knowing". (Polanyi, 1961: 461). At Oak Hall I did observe

instances that I considered to be expressions of this blending of "skilful doing and knowing", and I also heard accounts during interviews of examples of skilful doing and knowing. In other interactions I observed between members of staff and people with dementia this blend of skilful doing and knowing seemed to be absent. These were occasions where I felt there was a jarring or disharmony between the lived world being expressed by an individual with dementia and the responses to the person from an external source, or from the conditions of the external environment. For example:

"During a game of skittles Michael appears unsure whether he should continue with knocking skittles over - he looks for reassurance from Jan (staff member)." (Fieldnote: 9/10/14)

Michael seemed to have forgotten parts of the sequence of playing skittles, and there were no verbal or other cues in his environment available to him at that moment that would prompt him to continue with his turn at skittles.

With Paul it was different. Because he came across as an eloquent and seemingly unimpaired man it was difficult to get a sense of how his cognitive impairment was impacting on his everyday life and his interactions with others, except when he said something unexpected or reacted in a surprising way. This *leaking out* of the person's inner world, their lived experience, was sometimes anticipated by staff if they knew the individual, but could by no means be guaranteed. I observed a situation which illustrated what seemed like a mismatch between an individual's lived experience and a member of staff's perception of that person's experience. In the lead up to Christmas 2014 clients were being involved in decorating cards and making decorations.

"Tina (staff) came over to where Paul was sitting and asked if he would draw a robin on two Xmas cards which Tina and three ladies in day-care were making. Paul agreed and did some practice versions on some green paper. He then drew a robin on each of the two cards. Then Tina came back over and asked Paul if he would do another robin for a further card. Paul responded: 'Don't push me to do any more, this is my limit'. Up until that point there had been friendly banter between Paul and Tina. Tina backed off at this point and went back to the ladies who were making cards. I heard

Diane (staff) say 'He has made his point'. Then Paul (who I was sitting by) recounted to me a previous situation, as follows: When Paul had first started coming in for a few days' respite stay he was, on one of these occasions, preparing to go home (bags packed, and so on), at which point Tina had come into his room and asked if he had had a bath or shower. Paul replied 'no', and Tina then said that he mustn't go home without having a bath or shower because if he did then she would get in trouble. Paul was adamant that he wasn't going to have a bath or shower, and recounted to me that 'I went home and I was in a right state'. He linked the bath scenario with the Xmas card situation just passed and said 'It was Paul do this. Paul, you must do that!' I concluded to myself that there can be a level of distress, or something like powerlessness, that can be provoked, it seemed." (Fieldnote: 19/11/14)

The manifestation of skilful doing and knowing seemed to be differentiated according to the individual with dementia who the staff member was interacting with. For example, the interaction already described between Jan and Stuart looking at Stuart's book, where Jan used her knowledge that there could be meaningful interaction with Stuart (who had very limited coherent verbal expression) via proxies such as his book, the keyboard, and so on. This was a situation where Jan was being empathic to Stuart's lived experience, and using this as a basis for trying to establish a relationship with him. In interactions between staff and Michael skilful doing and knowing revealed itself differently. Michael was able to verbally articulate, albeit in an unelaborated way, but often behaved in ways where it was difficult to fathom the underlying reason for the behaviour. On one occasion Michael had misappropriated a cutlery spoon:

"Michael has 'acquired' a spoon and staff adopt various approaches to getting it off him. None of these strategies is successful. Michael then offers to 'lend' me 'his' spoon when he notices that I don't have a spoon. Today Michael also thinks Bernadetta (an Italian lady) is his wife Yvonne. It is not until Bernadetta repeatedly tells him that she is not his wife that he is able to accept it, but actually he then goes and sits by Bernadetta. I think he must still imagine that Bernadetta is Yvonne". (Fieldnote: 28/10/14)

Staff did not pursue retrieving the spoon from Michael: it posed no particular risk to him or to others, and staff knew that when he went home his wife would find the right moment to remove it and return it to a member of staff at Oak Hall. Similarly, though staff recognised that Bernadetta was finding Michael's advances tiresome this situation could be managed by distracting Michael. Constantly telling Michael that Bernadetta was not his wife was unlikely to convince him that this was the case, just as telling him the spoon was not his was not going to change his belief that it was. On what grounds would it be considered *necessary* to comprehend why a person with dementia has taken a particular course of action is an interesting question, and provokes further thoughts about different ways of trying to understand individuals with dementia through their behaviours and outward gestures (e.g. the new understandings from using the Marte Meo approach, described in chapter 2, did appear to offer a positive contribution to care). Who shapes, constructs and decides what is included in such an account may be a further question to consider. A comment by Grenier et al (2017) provides a way of situating what cannot be known in the context of care services, where:

“the task is to value the lives, experiences and convictions of persons with dementia, even in circumstances where what is expressed seems foreign or ‘unknowable’.” (Grenier et al, 2017:320)

Staff members, particularly those who had spent considerable time with Michael, seemed to have a sense of what tactics worked best with him - not only in situations where Michael's lived experiences seemed out of synch with those of staff and other clients such as when he became fixated with wanting to leave the building, or was hiding food, but also the times when he was most amenable to interaction when staff would engage him in conversations and activities related to things that he liked or was good at. Bingo was one such activity:

Jan speaking: "Shall we have a game of bingo after? Get some of the other staff to help with marking the cards? And we'll ask Michael to call the numbers" [...] "Michael is a very competent caller. Starts with Michael reading number, then Jan repeats the number. Then Michael quite suddenly

takes on the role and loudly speaks the numbers, really getting into the role - 'legs eleven!' Paul speaking: "'Michael calls the numbers very steadily' [...]
Michael adjusts the numbers on the board so they are straight. Jan
comments: 'that's it, you put them right. You don't like them messy do you?!'
Michael laughs. They both laugh". (Fieldnote: 12/09/14)

Here, Michael's skills were deliberately made visible and positively affirmed by Jan who announced to the clients in the room that she would ask him to call the numbers, and then acknowledged positively an aspect of his *particular* style which was to straighten the number counters on the board. Underpinning Jan's practice in this instance was that she knew Michael, knew that at this point in time he had the skills and capabilities to call the numbers and that he enjoyed doing this. Skilful doing and knowing applied to another situation with Michael, one which I did not observe but which was recounted to me during one of my observation sessions by the senior care worker, Kate, who had oversight for the day-care sessions:

"Kate said that Michael 'had been in the wars'. He had a procedure carried out on his eye in hospital - something to do with a blocked vein behind his eye. The procedure was not successful, and the build-up of pressure behind his eye was causing headaches. As a result of this he went back to hospital to have laser treatment. This had to be repeated. When he was next in day-care (early October 2014) Kate had heard a noise and saw that Michael was shaking and had gone white, and had stopped breathing. The paramedics were immediately called". (Fieldnote: 9/10/14)

In this instance where Michael had suddenly become very unwell the bodily signals were very obvious and Kate was immediately alerted. This timely, responsive care was in part due to Kate *knowing* the events that had occurred beforehand, and this knowing was reliant on Michael's wife having previously relayed this information to staff. As Kate relayed more of the incident to me she looked over to where Michael was sitting pointing out to me that his colour had returned, and then drew him into the conversation saying to him that she was very pleased he looked so much better. But, Michael's wife had said he was more

confused, and Kate wondered whether the confusion would continue and become part of how life was for Michael. This situation highlighted the temporalities of Michael's physical health condition - the sudden onset of an eye problem which then became acute; and the interaction between *knowing* (Kate knowing something was seriously wrong) and the suddenness of the onset of a life threatening situation. Incidents such as this one might be described as having a particular and temporal rhythm: a rapid escalation of a health threat over such a short period of time might indicate that the event overtakes the speed at which it is possible to act. The speed of the event required swift intervention from those who were in a position to help, a response involving simultaneous doing and knowing. Gourlay (2004) has suggested that tacit knowledge is said to be essential for competent performance in concrete situations to enable individuals to deal with new situations, and to fill in the gaps in formal training.

Getting to know the person: practice from the position of knowing

At Oak Hall the majority of the individuals with dementia who I met had lost or were losing the ability to coherently verbally communicate and were reliant on staff to make sense of nonverbal signals and expression. This was highlighted in an interview with Kate (senior care worker) who described how knowing the individual was of critical importance for understanding when something was wrong:

"...you've got to take into account people's characters. Through their life, or how they've changed now, so it's patience really - getting to know people, that's the main one. Once you've got to know a person, if they can't communicate you sense, you get to sense... there's something wrong." [...] "I think if you get to know someone really well - we've had a couple - a gentleman who's just gone into full-time care. He didn't communicate at all, and he was a top accountant in his time, but the last month or so here - and I kept saying 'It's not right, there's something that's not right'." [...] "You just pick up. Because he used to sit and he used to watch, he used to do, he liked skittle games and that, but I don't know - he seemed to be more into himself. You know, he weren't looking around so much, and he used to clap and whistle...well, that stopped." [...] "There was a slight change, you know,

gradually, but the last month or so we had him, I said to Jan, my colleague, I said 'He's not right is he?' And she said 'No', but there was nothing we could actually put a finger on." [...] "...because sometimes when someone with dementia is not well, uhhm...it depends on the illness but sometimes it takes them down a notch, and it's a notch that they might not be able to get up from, so that can take them further into a dementia, it depends." (Interview with Kate: July 29, 2014)

This illustrates something of the subtlety or nuances of 'perception', a human sense which Polanyi viewed as being central to tacit knowledge. Perception as it applied in the situation that Kate described involved *getting a sense of*, and *picking something up* - impressions that are difficult to specify, a point that Polanyi articulated in his work *Knowing and Being* (1961). Both Kate and Jan *knew* that something was wrong but were unable to precisely pinpoint the something. There were other instances where people with dementia left staff in no doubt about their preferences, wishes or other concerns. An example of this was given during an interview with Lily, a care worker:

"The way an individual likes... say how they like to have a wash or they like a shower or a bath or they don't like that. We've had a lady in recently who doesn't like water at all, so obviously she still has to bathe but she doesn't want it near her face. So obviously when I found that out I had to relay that to me colleagues so they wouldn't have to go through that. Because I give her the flannel and she went hysterical because it was all wet and so obviously you pass that on to someone else to make sure all of the staff members know."
(Interview with Lily: 27/8/14)

Handing over information was one system which enabled staff to know *about* the person. One of the members of care staff, Esme, asked me whether I was aware of the handover reports system:

"Care staff carry the sheet around with them and use it as an 'aide memoire'...they often look at it just before they enter someone's room. The detail and narrative 'behind' the handover info is the client's individual file. Esme said some clients come with a 'This is Me' booklet. This is reliant on

carers/families to complete. Staff also do a 'pen picture' which seems to be a strengths based account - e.g. - 'Mrs X lets us know she is in pain by.....'. Esme showed me another A4 sheet/table. This is used for flagging up any issues of an individual". (Fieldnote: 23/3/15)

Client files, handover sheets, handover meetings and the 'This is Me' booklet all represented methods for capturing and codifying knowledge so that even before a member of staff got to know a person with dementia that member of staff could at least know about him or her.

I came across several instances of an individual being previously known to either a member of staff at Oak Hall or to a client, dating back to before s/he was diagnosed with dementia. One gentleman was the cousin of the wife of another client, James, and I heard James commented on changes he had noticed - one being that the man had lost a lot of weight. On another occasion a member of staff mentioned that she had lived next door to this gentleman and that when he first came to Oak Hall he recognised her, but not now, and signs of deterioration have become obvious. A friend of the father-in-law of one of the senior care workers had developed dementia and was in respite at Oak Hall:

"...he was a very good friend to my father-in-law and his dementia is more advanced and when I first saw him it really did upset me, because I knew him before. And his is more advanced and I did go home and I did get upset and then I thought, 'Come on, you know you've got to go back to work and you've got to get on with it,' but that really did upset me because he used to go round with my father-in-law and they were very good buddies. I just couldn't believe how advanced his had got and that really was upsetting. But now he's been back again and I was alright this time, but at first I thought, 'I can't cope with this,' but then I thought, 'Come on Jan, you can cope with anything.' And I felt a lot better since he's been in again, I wasn't upset, I just kept thinking that is the later stage of dementia." (Interview with Jan: Senior Care Worker 29/7/14)

One of the implications of having knowledge about dementia and working with people with dementia was that if a member of staff also encountered dementia

closer to home - affecting a loved one - the member of staff could not help but know the potential trajectory for their loved one. This represented a convergence between their private and their professional life and, for some members of staff, going home after their shift did not mean a complete break from caring responsibilities. Jan, who had accepted and adjusted to the fact that her father-in-law's friend was in the later stages of dementia, was also now adjusting to her father-in-law having fairly recently been diagnosed with dementia:

"And my father-in-law he's only got early stages of it. Some days I go and I can have a real good conversation with him and he's switched on, and then another day he just can't remember what happened, he doesn't remember doing things or whatever. And I used to take him up the town every other Saturday, but now he's decided he just doesn't want to go through that door and that is very challenging. And my husband as well, obviously because it's his dad, he can't understand it. I said to him, 'This is the early stage, he's going to get a lot worse than what he is now,' but he obviously doesn't work here so he doesn't really deal with that sort of thing and it is hard for my husband." (Interview with Jan: Senior Care Worker 29/7/14)

The here and now moment, and being in transition

At Oak Hall I noticed that staff appeared to make every effort to involve clients in the *here and now* moment, and seemingly suspended - or perhaps downplayed - the problematic nature of memory problems that caused temporal disorientation in individuals they were caring for. One tactic I observed might be described as 'compensatory', where a member of staff acted in some manner that filled in the gaps where a person lacked capability:

"I notice that Jan keeps swapping her songbook (putting it to the correct page for each song) with the gentleman (Andrew) next to her - to enable him to feel part of the singing - even though Jan comments that he has fallen asleep." (Fieldnote 23/3/15)

Jan's actions created the appearance that Andrew was on the correct page, which seemed like a compensatory action for any difficulty he may have had in finding the right page. It was also anticipatory - should Andrew have awoken during the

singing he would be in synch with everyone else in the room who had a song book and was joining in. Music - playing compact disks (CDs), singing along, dancing to music, and the occasional live music event - was given a central place in everyday activities at Oak Hall. Many of the CDs that were played had songbooks with them and these were passed around so that people could follow the words if they wished to. The inclusiveness of the music and singing sessions made it very easy for anyone to join in, so for clients who were new to Oak Hall these sessions seemed to offer a way of feeling part of what was happening at that moment:

"Singing is definitely good for involving people. Even clients who aren't singing (or who are dipping in and out of singing) are connecting with the music. I look at Claire who is moving her hand in time to 'Rock around the Clock'. I haven't seen her so engaged and interested in other previous activities". (Fieldnote: 23/3/15).

Sometimes both clients and staff got up to dance, and on several occasions a client or member of staff pulled me up to dance with them. Dancing and singing placed few cognitive demands on clients and I noticed that these were moments when people often looked animated. Songs needed to be familiar to clients in order for them to join in the singing, and this was illustrated on one occasion where Christine, a student from a local further education college on a short work experience placement at Oak Hall - was handing out song books to clients. Jan suggested to Christine that she changed the CD to one that had songs that people would know and would be able to sing along to:

"There is a moving moment when we sing 'My Way'. The singing by six women and two men just encapsulated a feeling for me - something about singing the words and connecting to the meaning - 'Regrets, I've had a few, but then again, too few to mention. I did what I had to do, and saw it through without exemption' ". (Fieldnote: 23/3/15)

This example of connecting to music is a far from spurious idea, and there are both emotional and temporal considerations in relation to music. Music itself is a unique example of a temporal object, something which Toombs (1990) discusses in her work on the temporality of illness where she cites Edmund Husserl's

(1964) phenomenological analysis of time. A tone or a melody is a temporal object which is temporally extended, yet experienced as wholes or unities (Toombs, 1990:228, citing Husserl, 1964). What is both noteworthy about experiencing a temporal object, and relevant to the example from fieldwork, is that:

"it is experienced not as a succession of discrete, isolatable, now points along a given time-line but rather as a continuum - a continuum which at once incorporates not only the present now-point but those now-points which are just-past, as well as anticipations of future now-points." [...] "...when I hear a melody, I hear it as *succeeding* the note just-past which I still retain in my present consciousness. Furthermore, in hearing the present note, I anticipate a future note which will follow it as the melody unfolds temporally".

(Toombs, 1990:228)

This is a subjective experience of duration, and in relation to the hearing of a melody this is considered as "the temporal 'living through' the melody, and the experiencing of the melody *as* extended in duration." (Toombs, 1990:229). The singing along to Frank Sinatra's 'My Way' by people with dementia was them being involved in doing something that connected them back to previous moments in time, but also everyone who was there in the room at that moment *knew* and anticipated what was coming in the chorus line 'I did it my way', and collectively joined in. Music has also been highlighted by Fuchs (2016) who described it as being the "carrier of affects par excellence, and is thus capable of awakening the affective dimension of body memory" (Fuchs, 2016:21), and by Busch et al (2001:3) who referred to the recognition of musical note as inarticulable tacit knowledge. Music as a connector between the here and now and a person's past experiences (such as an instance of a song or tune sparking a memory of a salient experience) does evoke the idea of moving between experiences, the notion of tacking back and forth.

This might also provide a starting point for making sense of different types of arrivals and departures to and from Oak Hall, and the *staying* or *remaining* that people with dementia were subject to in the space between arriving and departing. The concept of "transitional statuses" (Glaser and Strauss, 1971: 47-52)

might be applied to such instances, given that arriving, staying and leaving indicated an aspect of living with the reality of dementia, whether experienced first-hand or as a carer of a person with dementia. A person's attendance at Oak Hall drew attention to their status of having a diagnosis of dementia, yet away from Oak Hall many people enjoyed positive roles such as living in ordinary homes; being a grandparent, partner, father, mother; enjoying hobbies and interests; doing and being the same as other people. A scenario of how the status passage of a person may move back and forth from being prominent on one hand to fading into the background on the other according to the person's movement between home and places designated for expert help, is provided by Glaser and Strauss:

“Although some transitional statuses encumber only on a certain dimension of the passagee's existence, they may require that his total existence occur in a particular context. A mental patient may require therapy a few times a week; the rest of the time other aspects of his life are prominent, and his illness is subordinate. Thus, his illness passage is attended to only intermittently”. (Glaser and Strauss, 1971:47)

On a person's arrival (for day-care or a respite stay) staff would usually initiate conversation, drawing on their repertoire of knowledge about the individual, perhaps oiling the wheels of conversation by focusing on individual characteristics such as where the person lived or a particular hobby, or the person's grandchildren. The initial welcome was about helping people to feel comfortable:

"Obviously when you first come here it's not going to be familiar but the fact that it's comfortable helps them to relax and obviously the way that people are then welcomed to that environment, so it's all a matter of ... are they going to just say, 'Hello Mr Jones' or are they going to say 'Hello Fred'. It's hopefully building up a familiarity so, again, when they come in the door it's almost like oh, it's just another place where you go in and meet friends, like going to an over-fifties club or whatever." (Interview with Activities Co-ordinator: January 2015)

Establishing a sense of continuity for the person meant the staff building some threads within the experience that were repeated each time the person attended day-care, and thus imparting to the person some sense of familiarity with the people and environment of Oak Hall. These important threads included having knowledge of, and knowing the person and acting on this by, for example, a person's personal preferences being incorporated into care regardless of which member of staff was providing the care; the same group of staff providing care to the person over time; and people with dementia receiving care in an environment that was the same from one time to the next. *Knowing* the person, and then providing care from that perspective was a core positive bias at Oak Hall indicated in conversations between staff and noticeable in action and interactions between staff and people with dementia. Except in situations where a person came into respite care with no warning (i.e. where a crisis precipitated entry to Oak Hall) the broad process of getting to know a person began even before s/he began to use the service, through obtaining information from the person's carer or family:

"...we usually ask the family, we send out before the person's come into the centre, they have a form to fill out saying "This Is Me" and obviously it's got to be a close relative, and all their likes and dislikes, what they've done in their life and perhaps where they were born and about their family, siblings. And then if they're married, it's all that kind of thing." [...] "cos sometimes, depending how far advanced the dementia is, they can't always tell you. Usually they can tell you from their childhood but they can't always tell you there and now or sometimes they just forget everything, do you know what I mean? So obviously you want to know this person, and you don't always get that person when they come in because... So you need to know a bit of the background about the family and like I say, their likes and dislikes."(Interview with care worker: August 2014)

In Galvin et al (2005:2-3) the experience of family carers of people with dementia was characterised as one of 'liminality': a term which, in Anthropology, pertains to "the figure and role of 'bridge-maker' between at least two domains of knowledge". Galvin and colleagues suggested that carers live in two worlds and have two ways of knowing: an experiential knowing derived from the private

world, and "a taken for granted knowing of the structured professional world". Carers and family members provided experiential knowledge of the person they were caring for to the staff at Oak Hall, often in the form of brief comments relayed when dropping a person off for respite or day-care. However, it was not a certainty that the "This is Me" paperwork would have been completed or available at the point which the individual with dementia first started using the day-care or respite service at Oak Hall and, moreover, the information provided could not cover every eventuality of useful knowledge about the person for their time at Oak Hall. Fragments of knowledge that carers provided about individuals had to be built on and expanded upon by staff through proactively getting to know a person. Moving towards knowing a person happened through different types of care interactions between staff and individuals with dementia. One example of interactions were those in which care was focused on the body, such as bathing, assisting someone in the toilet, or other activities such as using a hoist to transfer an individual, or getting the person up and dressed. These interactions involved a level of intimacy and relating to the person in an embodied way. During such enactments of care there was a need for staff efforts to harmonise with co-operation and willingness from the person (e.g. a person being hoisted) and, if the person was uncooperative, the onus was on the staff member to try to work out the root cause of the non-cooperation. Trying to understand the reasons for particular behaviours or responses was described by Sarah, a member of the care staff, as "very Sherlock Holmes". A way to conceptualise this is as missing or hidden knowledge in a given moment in time, which disrupts the care activity in some way and may prevent it from being completed. In some cases knowledge may be hidden simply because the person with dementia is unable to articulate it verbally. An instance of hidden knowledge was given by Sarah during an interview:

"There was a lady that used to refuse to get dressed, flatly refuse [...] so we went into her wardrobe and, 'Come on Gladys, up you get now, come on, let's get dressed. Let's put this nice skirt on.' 'No, no, I'm not getting dressed. Oh no, I'm not getting dressed,' and we ended up, you know how a teenager would go through the wardrobe and heap clothes on the bed. Like that one, don't like that one.

'What about that one?'

'Oh no! Not the black one!'

'What about the pink one then?'

'Oh no, not the pink one.'

'Alright then, what about this one?'

'Oh yes ...'

She chose the skirt with it and through we went, with the t-shirt, jumper, beads to go with it, she chose her clothes, she let us wash her, she didn't protest or anything but let us just wash her, change her, dress her, happy as Larry. All that was the problem, and we couldn't figure, it took us about a few days to figure out that the problem with this was the clothing. She saw that skirt on the wardrobe and thought, 'Not going out in that!' So rather than, because she didn't have a lot of speech, she couldn't say, 'I don't like that skirt, don't like that one it's too tight' or it's not right, she just flatly refused to get out of bed. So she'd just say, 'No!' And once we figured out why, you can assist her, and keep her calm. We can assist her to be happy and content in what she's wearing, because to some people it is the end of the world if the top doesn't match their skirt, and we have to respect that." (Interview with care worker 15/11/14)

Through a process of trial and error (the clothes sorting) the missing pieces of knowledge or understanding of the person had been surfaced, and the staff member was able to complete the care task. Furthermore, once the staff member had acted on this new knowledge the lady concerned then got her needs met, defusing her frustration and enabling her to become calm.

There were other instances where hidden knowledge - which would have made a difference to how care was enacted - only came to light later on after the event. A case in point that I observed involved Stuart, on a day that his parents and sister came to visit him at Oak Hall. Stuart was in the lounge, his parents and sister sitting next to him and chatting with him, and myself sitting next to his sister:

"Leanne [member of staff] comes over to Stuart to hoist him up to take him to the toilet. Stuart's sister is sitting next to him - and as the harness for the hoist is put behind Stuart he goes rigid and starts to shake/tremble. In doing so he slides right down the chair. Everyone rallies round and the hoist is

brought over. Stuart is on the floor by now and seems upset by what is happening. Another member of staff presses the emergency button and several more staff arrive. Stuart eventually is safely hoisted. Stuart's sister says to me that if he feels he is being forced he will resist."

[15 minutes later]

"Leanne returns and asks Stuart's family if they would like to go to his bedroom. Leanne smiles and asks Stuart's dad if he would like to take her arm [maybe she knows that he had a recent fall]". (Fieldnote: 16/10/14)

Because Stuart now had very limited mobility and generally used a wheelchair moving or transferring him safely was achievable only by hoisting him. Staff followed the policies and procedures for hoisting, including the summoning of extra staff when Stuart ended up on the floor. Stuart's sister's comment - 'if he feels he is being forced he will resist' signified intimate knowledge, knowledge that was relational in character. She had grown up with her brother and knew him. This knowledge of Stuart was conveyed to me, not staff, and retrospectively of the event, when it was useful only in explaining but not in informing. Had the hoisting of Stuart progressed without incident his sister would have had no need to make the comment at all, so the comment was perhaps contingent on this instance of hoisting, a sensemaking comment, maybe.

This seems to bring another issue into the foreground: that of 'timing' or knowing in time - as a temporal dimension of knowing. The timing of knowing in care provision is meaningful when thinking about the passing on of 'critical' knowledge about an individual. Both acquiring knowledge and conveying of knowledge in a timely manner (for example: knowing about allergies or intolerance to certain foods *before* there is any possibility that an individual may imbibe particular foods) is important in order to avoid unintended consequences. What mattered in Stuart's situation was knowing him, because knowing him meant it was possible to anticipate how he would react to a particular approach and thus the approach could be moderated and adapted to him. Stuart expressed bodily what he was unable to articulate verbally - he tried to resist, and went rigid when staff were attempting to hoist him. As I have drawn attention to in chapter 2, knowledge of a person is regarded as fundamentally different to *knowing* the person, and

knowing the person gives regard to human agency. (Liaschenko, 1997:27)

Stuart's sister's comment was also an acknowledgement of his individual agency being a fundamental strand of who he was, irrespective of his learning disability and regardless of him having a diagnosis of dementia. This also represented a bringing of knowing of Stuart (by his sister) from the past, when Stuart was known as a person without dementia, into the present.

The fact of Stuart's parents being, up until his entry into Oak Hall, his primary carers prompts a comment about intersectionality. Although Mrs Harris appeared to be an active woman and in good health both she and her husband were in their late 80s and Mr Harris looked quite frail and had recently fallen at home. One of the consequences of ageing for people with Down Syndrome (a specific learning disability) is that as they move into their 50s and 60s their chances of developing dementia increase. Estimates are that among people with Down Syndrome 1 in 3 people aged 50+ and 2 in 3 people aged 60+ will develop dementia. The "interlocking oppressions" (Hulko, 2009) between disabilities and ageing of carer and the person with dementia become highlighted in the situation of Stuart and his parents.

Timing, and time running out, for Oak Hall's service for people with dementia

Alongside business as usual at Oak Hall and the everyday lived experience of dementia of individuals with dementia and carers, there was a parallel story about the threat of non-continuation of two council-run respite and day-care facilities, Oak Hall and Long Edge. The experience of implicit time in lived experience of dementia was being touched by an explicit temporality that threatened to disrupt and change the experiences of people with dementia and carers.

The Minton Suite at Oak Hall was itself the product of the closure of Minton Lodge - a former centre of excellence for dementia care located in a village two miles from Northweston, funded and run by the local council. Closing Minton Lodge was expected to result in significant savings and, despite the protestations from carers and supporters achieving a delay in the final decision being made, Minton Lodge did eventually close. By 2012 the entire day and respite services, as well as staff, transferred from Minton Lodge to the newly-built wing at Oak Hall. It was

rather ironic then that within a month of commencing fieldwork, during my second progress meeting with the then manager Cath, I found out that the local council - Polshire - was threatening to close the day and the respite service for people with dementia at Oak Hall. The news was widely reported in the local press in July and August 2014 with quotes from several local councillors about outsourcing respite care to the private sector, and responses to those comments from dismayed carers whose loved ones used the respite and day-care services. There had been no warning of this news and the coverage in the local newspapers was the first that the manager, care staff, clients, and carers knew about the possible closure. In one of the newspaper reports the course of events leading to the story breaking were described. At the Polshire cabinet meeting in August 2014 members had decided to initiate a review of services at Oak Hall and its sister organisation Long Edge (located eight miles away in Crouston) as part of a new dementia commissioning plan being developed. The point of discussion that was likely to have particular impact on people with dementia and their carers was the proposal to block purchase beds for respite care in the independent sector. By implication this would render it unnecessary to have a respite service at Oak Hall and Long Edge respectively. The newspaper reported that carers who had attended this meeting alleged that their concerns about the review of services had not been listened to, and that this was then both reframed and denied by the chairperson for the committee scrutinising the cabinet decision, who was quoted as saying that the meeting:

"was not a forum for discussion of the future of the council's individual care facilities" [...] and "any future changes arising from the implementation of the dementia care plan will be subject to full consultation and robust scrutiny by members of this committee". (Newspaper One: 13/8/14)

Whilst no decision was to be made about closing the service until the autumn, the possibility of closure had been 'outed' and, critically, was now firmly in the public domain. Within the sphere of Oak Hall nobody was immune from the potential 'fall-out' from this news. For clients and carers it represented both the uncertainty of future care arrangements as well as a disruption to continuity of care, which itself was multi-faceted, comprised of continuity and ongoing familiarity of staff,

place, care practices and routines. For staff too there was concern - mainly about job security, but also concern about the impact closure would have on clients and what services they would end up with. Although I was not personally involved, a closing of the service during my fieldwork would have meant the loss of one of my field sites and I would need to consider other options: either identifying another social care site, or looking at the feasibility of 'following' individuals through their use of different respite services in the independent sector. For me, as for clients, carers and staff, closure would mean discontinuity and disruption in some form. One early reaction to the potential service closure was a Union meeting for staff one afternoon in late July in the main day-care lounge. This meant that day-care after lunch resumed in one of the much smaller lounges, with all clients being asked to move from their usual room and squash into the other lounge; not ideal:

"Quite a different environment, and less scope for doing activities in this room".(Fieldnote: 29/7/14)

During my visits to Oak Hall I heard virtually nothing more about its future fate until early September when I asked Cath about the details for the public consultation on the council's proposal. There were to be four consultation sessions available at Oak Hall during which 30 minute slots were to be provided for individual customers (clients) and carers. Thinking that it would be really useful to observe aspects of the process of the consultation I made contact by email with the lead person for this, and subsequently followed this up with a (what turned out to be fruitless) phone-call. I gleaned a little more insight into developments in mid-September when I visited the home of William, a man with dementia who I had recruited to my research study, and his wife Cherry. Cherry was opposed to the closure of the respite service at Oak Hall. She had given a response to the council's consultation document, and she subsequently emailed me a copy of the council's full consultation information pack. Around this time - mid September 2014 - also marked the moment when Cath, the manager of Oak Hall who had been in post only from around the time I began my fieldwork, left. No-one offered any explanation for this, but I did imagine that managing a service which had its future in doubt, and having to potentially wind things down, make

staff redundant, deal with the distress of carers, and so on - this was an unattractive proposition.

To councillors the proposals for change were framed and presented by Polshire as "moving towards local personalised carer respite", and the concept of "local" was particularly pushed as a key selling point to members and carers at the two subsequent meetings where decisions were made about the future of respite care services. In the consultation pack for carers and people with dementia the rationale for change was presented as:

"...the commissioning review has identified that more ways other than residential care should be developed to provide respite care to give carers a break so that people have increased choice and their preferences can be met."

Interestingly no absolute commitment was given by the council about respite provision. Rather, the consultation pack stated (my emphasis in italics): "we will *look at* developing more types of support that *may* include for example:

- "Care provided in the person's own home through home care services.
- Shared Lives service. Shared Lives is a service, where a carer approved by the Council, provides support to an individual within a family setting. This could be in the home of the approved carer, or in the home of the customer needing care.
- Receiving a Direct Payment – an amount of money which can be used by a customer to buy services/support from the independent sector or employ a Personal Assistant to meet their needs. A Personal Assistant is a care worker who is directly employed by the service user or their nominated representative. "

I heard more about client and carer experiences of the consultation in October 2014 during a visit to Oak Hall, when Paul told me that his wife Rose had already written to her local MP expressing her disquiet at the proposal to close the respite service at Oak Hall, and they had both now given their views as part of the consultation:

"Paul and his wife had asked to have separate appointments and be allocated 30 minutes each. As they had arrived ten minutes early, and Paul's wife Rose had the first slot, Paul had laughingly speculated that she might get 40 minutes (it turned out that she did)."

"Rose had forewarned the council staff consulting that whilst Paul came across as relatively unimpaired 'he does have dementia' and please to be mindful of this."

"During the consultation Paul asked what the basis was for the proposed new model of provision: had this approach already been tried and, if so, what were the findings? He had pointed out that on Trip Advisor and Amazon, for example, people leave reviews about their experiences, and similar information should be made available relating to the evidence and feedback about the model being proposed. Otherwise, Paul had said "You are going in blind". The reply to this was that those consulting '*thought*' that something similar had been done in two other large towns in the north west of England. I commented to Paul that they seemed to be proposing a mixed model of care. Paul said that what was mentioned was staff coming into people's homes to provide a service and give carers a break; but also staff also opening their own homes up to offer day-care and/or respite. I mentioned to Paul the issue of inspection and accessibility of these sorts of arrangements. Would that not 'up' the cost, and the complexity? Paul's view was that a whole *team* of people would be required per person." (Extracts from fieldnotes: 9/10/14)

Both the consultation pack and the conversation with Paul suggested that even if the evidence base for the proposed model of care had been considered it was neither central to, nor driving, the decision-making of Polshire council.

Paul had a view that there was some political manoeuvring going on involving the conservative leadership at Polshire. My view was that for all parties, whatever decisions were ultimately made about Oak Hall and Long Edge would represent winning or losing of political points. Even though the labour councillors strenuously opposed the proposal to close the respite service, undoubtedly there was a political dimension to this.

There was no evidence that certain outstanding practicalities involved in developing new respite provision had been addressed at the stage that stakeholders were being consulted. At Oak Hall there were twelve respite beds, yet under the new proposals Polshire council was undertaking to block purchase just *three* respite beds in local nursing homes. Paul had made the comment that from the perspective of nursing homes there was "shock" at how many bed days even three respite beds would equate to. The proposed three beds would need to be used solely for respite equalling supply of 1,000 actual bed days per year. However, this would represent a reduction in current capacity (i.e. Oak Hall's twelve beds) of seventy-five percent (75%). The capacity of twelve beds at Oak Hall facilitated not only pre-booked respite stays but also fulfilled an important role of admitting people when there was a crisis of some sort (e.g. a breakdown in care arrangements, or behaviour that became difficult to manage at home), or in instances where a person needed to have specialist assessment. How such scenarios could be managed with only three respite beds was unclear, and it remained to be seen whether carers would be convinced that the changes proposed to provision would provide a robust, good quality and safe service. In early November 2014 I took the opportunity to attend an overview and scrutiny committee meeting for Polshire council with the hope of hearing some of the discussion and narrative in relation to the proposed changes to local respite care services. There is always a slot provided at the start of these meetings for interested members of the public to speak, and two ladies spoke about their knowledge and first-hand experience of the respite care provision at Long Edge. One was a member of a local older people's forum, and she highlighted the value of the service provided at Long Edge: its accessibility to local people, the excellence of the care provided, that people are treated as individuals, and that their social, medical, and care needs are all addressed. The other speaker was a carer to her 92-year old father who had Alzheimer's disease, as well as a former carer to her husband with Alzheimer's disease (now deceased). She spoke about the alternatives for respite care provision should Long Edge be closed down:

"Of the three local care homes offering respite care one has three enforcements from the Care Quality Commission (CQC), another has one enforcement, and one failed its CQC inspection. Costs (for carers) are

'prohibitive'. Carers have asked 'countless times' where will respite care be provided."(Fieldnote: 6/11/14)

The significance of this comment was that it highlighted the view that the local alternative provision to Long Edge could not be relied on either in respect to quality or to continuation, yet there was a real possibility that respite in provision such as this would become part of the new landscape of respite care. The stated purposes of CQC enforcements underlines the risks that people may be exposed to in care homes that are subject to CQC enforcements. The definitions of purpose of CQC enforcements are: "To protect people who use regulated services from harm and the risk of harm, and to ensure they receive health and social care services of an appropriate standard", and "To hold providers and individuals to account for failures in how the service is provided." (Care Quality Commission, 2015). The alternative provision available to carers did not compare favourably with Long Edge which had been inspected by the CQC in March 2014 and was assessed as having met all of the required standards.

The expectation from carers and staff was that the consultation report would be discussed at the Polshire cabinet meeting in mid-November 2014, but it was not an agenda item. The day after the meeting at Oak Hall I heard about a letter published in one of the local newspapers written by the son of a lady who regularly used the day-care and respite at Oak Hall. The lady's daughter was dropping her off at day-care when the letter was mentioned. Several people had seen and read the letter, including Paul who thanked the daughter. Kate had a copy of the newspaper with her, and showed me. The letter's narrative highlighted flaws in the rationale that the council was applying in its proposals to close the respite and day-care services at Oak Hall. The council, the author wrote, was following a national trend of councils that were discharging to the private sector their legal responsibility to provide respite care. Unlike in other council areas, however, the proposed closure was not to save money but was about preparing for an alleged "onslaught of dementia sufferers, and offering greater choices". The author reframed this suggesting that the growth rate of people being diagnosed with dementia would amount to no more than a gradual increase over the next fifteen years. Choice would not increase but would diminish if

affordable respite care (Oak Hall) was removed because the cost of the remaining private provision would require carers or relatives to pay a top-up fee, the implication being that people unable to pay would have no choice. In the wake of the closure of a local, highly thought of respite and day-care service there would be an unknown and untested system for respite care in which people with dementia would be "shipped off to a different, remote care home for each period of respite". The letter ended with -

..."risks of poor care, uncertainty, long journeys, transport costs and top-up fees all serve to deter caregivers from seeking respite care. Caregivers foregoing respite care could increase the risk of themselves falling ill. This could remove the choice of dementia sufferers being able to live with or near their caregivers and increasing the likelihood of their requiring permanent care". (Newspaper One: 12/11/14)

The letter, and the fact that it was printed in its entirety, seemed to acquire an advocacy-like symbolism. The *giving voice to* (carers) was set out in a popular local newspaper and represented an action outside of the constraints of the official consultation process. The voice and opinions of the letter could not be reined in, reduced or made less controversial by people with political interests: the letter was out there for anyone to read. Implicit in the narrative of self-advocacy by a carer was a voice advocating for protection of the interests of people with dementia. The letter narrative also expressed the temporal dimensions of the unfolding situation: there was a looking back to the former service, Minton Lodge, considered to be a centre of excellence and the continuation of excellence through its reprovision at Oak Hall. The articulation of praise for the existing service was overshadowed by the council's proposals which promised an uncertain and unwished for future.

Decision-making about Oak Hall: December 2014

The discussion of the consultation, and the proposals it was linked to, did not take place until the meeting in mid-December 2014 of Polshire cabinet. This was not a meeting that I attended, but I watched the webcast subsequently. The meeting room was full, and a large contingent of carers were in attendance, several of

whom spoke. One of these was a man who was carer to his wife and daughter who spoke for six or seven minutes. He read from a script a beautifully crafted and considered piece describing what it felt like to be faced with the possibility that a service that he relied on may be withdrawn. He started by talking about his experiences of the consultation:

"I was offered a derisory 30 minutes in which to discuss this matter with representatives, three of them, from Polshire council. They couldn't answer my questions and 30 minutes is quite honestly not enough to get to know people, much less answer all the matters which arose in the consultation document. It really was an insult."

It was inevitable that naming a process as a 'consultation' would contribute to expectations of carers and service users about being heard, having their questions addressed, and confidence that due process had been followed by the council in the consultation. As the meeting unfolded there was a sense on one hand of strong carer opinions being voiced and, on the other, conservative members of the council attempting to conduct 'damage limitation' through managing (or trying to manage) carer expectations about the proposals on closure of the two services. This was a meeting in the public domain, broadcast live as well as being minuted, and the broadcast was accessible from the council's website for several months after. Politically speaking, the council was no doubt thinking about the forthcoming general election in May 2015 and may have wished to avoid a decision that would be viewed as unpalatable by the public in the two constituency areas (Northweston and Crouston) where the services were located. Both constituency areas were held by conservative Members of Parliament and it was possible that an unpopular decision by the council may have had a knock-on effect for the current political status quo.

As the gentleman carer continued to speak he started to deconstruct the lines of argument that the council had put forward to advocate for the changes:

"I'd like now to deal with the three points which were used to argue against my article in [newspaper one]. First of all the Care Act is a red herring. There is nothing in the Care Act - and I've been through it with a fine toothcomb - that says you are required to do what you're doing with Oak Hall and with

the situation in Crouston - nothing whatsoever. You can interpret it any way you like, of course, and you can make it sound like that's what being said, but it isn't. The second this is - choice. Quite candidly, when I was an infant I was taught basic arithmetic and that basic arithmetic is very, very simple and straightforward. If you've got two of something and you take one away you're reducing the options. How on earth anybody with any reasoning in their mind can say that it's increasing choices is beyond me!"

The carer moved on to speaking about the issue of affordability of paying for a respite break at one of the local alternative care homes, a topic which had been raised in relation to Long Edge by the two ladies who spoke at the start of the council's overview and scrutiny meeting a month previously. Cost factors, the carer continued, ranked alongside availability of respite beds at any moment in time that a respite place was required: under the proposed new system it could not be guaranteed that the time the respite was required would match with availability:

"...if my wife needs respite while I'm trying to entertain people at the Raven Arms or wherever I might be, my wife has got to go from where we live to maybe Hapleton or somewhere like that! You don't know - it's no good shaking your head - you don't know, you don't know, you can't know, you can't possibly decide when beds are going to be available. Anyway, in my opinion, it's impossible for anybody who's running a council, to dictate the terms to people who've got private businesses. The council appoints directors ...the only people who carry real weight are proprietors."

The matter of demand and supply regarding local respite services for people with dementia had a temporal dimension which was very clearly elucidated by this carer. The council run respite service was at that time able to respond directly to demand through providing beds at its own service. Demand for a bed 'in time' to meet an urgent need (e.g. a breakdown in carer ability to continue to care at home) could be met promptly through the council respite service at Oak Hall, and in cases of non-urgent, planned respite this was linked into assessments of need for respite care which were undertaken by statutory social care staff (council

employees). So time in, and time for, respite was negotiated and directly provided by the council in the current service arrangements. However, if the council run respite service was to close and beds be purchased from the independent sector on behalf of people with dementia this represented a relinquishing of direct control of supply towards marginal involvement via block-purchase, and so the responsibility of matching up demand for time (for respite) *in* time (e.g. in cases of urgent need) would also be surrendered by the council.

The carer's final point was:

"Finally, I've got to say that I utterly endorse everything that's been said by the previous speakers. How on earth can you shut these beds? How on earth can you do it? Did someone suddenly get a flash on the road to Damascus ...oh yeah 'let's close Long Edge, let's close Oak Hall!' I don't know what other explanation there can be".

The carer's narrative received a lengthy response from the leader of the council:

"Let me make it very clear to you, that this paper, which I support, is trying to offer people respite locally and y'know, you say that we don't know, - we're going to actually book beds locally to give people that choice. So we will make sure that they get beds in Langlet, in Wartle Bridge, in Plimley. But I want to make it very clear to you all - you seem to think that this road to Damascus thing...let me make it very clear to you that my father died of dementia two weeks ago. My mother is dying right now of dementia, this very minute. This cabinet knows how strong I feel on dementia. We're very clear about what we're doing on this - trying to make a win for everybody. We take seriously the comments you're making. But do not think for one minute that this is an easy discussion. We are genuinely trying, not to play politics, but trying to get it right for the many people. Not just today but also tomorrow. Now what I feel is important to look at is this is not us taking a decision on the road to Damascus - this is a well thought out process. We have to go forward - not just in terms with what we do with Oak Hall or Long Edge, but actually how we get early diagnosis of dementia which, if we had in my parents' area (which is not Polshire) they would be alive today. And

that's an important point to understand. [.....] So what I'm saying is that we are listening, we do listen."

This response illustrated an interesting juxtaposition between two sets of strands: of lived experience and implicit temporality with explicit temporality. The council leader spoke of having a parent living with dementia and recently being bereaved through the loss of his other parent from dementia. This, in a sense, placed him in the same camp as the carers at that meeting as having lived experience. Fuchs has suggested that the distinction between 'implicit' versus 'explicit' temporality is near to the distinction in phenomenology between the 'lived body' and the 'corporeal body' (Fuchs, 2006:196). The council leader seemed to privilege explicit time - "tomorrow" over the now moment ("today"), presenting an argument that suggested that the provision of respite care could not stay as it was in the now, but that plans needed to be made for tomorrow and further on into the future (explicit time).

His comments were followed by a response from a female councillor, KD, whose emphasis was on trying to pre-empt and allay any fears carers might have about ongoing respite provision:

"We would never expect you to move out of Northweton for your respite care, and the whole point of this paper today is to allow us, to give us permission as a cabinet to go forward and make sure that before we close anything we have services provision in place that actually provides the domiciliary care, the respite care, that people need. We would not expect you to go to the other end of the borough for respite - that actually is counter to everything this paper is saying. The one thing that we got out of the consultation and even the petitions (although they were limited) were three things: you want local care; you want good quality care; and you want it when you need it. That may be that you want to book a holiday, or you want regular respite every Saturday, or that in periods of acute need and crisis you can get the care that your loved one needs while you sort that particular situation out. So that is what this [the consultation] is geared up for, whilst at the same time having to make sure that we have enough respite care in place over the next two, ten, fifteen years. And from the questions that have been

raised here there is some confusion about the way that beds are paid for, the cost if you went out as an individual to the market you would have to pay - I'm not arguing with the figures you have given us, but that is not the fiscal relationship that a local authority has with its private providers. Because if it did, private providers wouldn't come here. They wouldn't set up their businesses here. They rely on our provision and our guiding of residents to them."

Similarly to the leader of the council this councillor expressed a prioritising and favouring of *explicit* temporalities of care over implicit, lived time, underlining the importance of focusing on: care when it is needed; care that can be planned in time; and the provision of care into the future. Neither the leader of the council or the female councillor directly raised the issue of continuity of care in terms of the impact on people with dementia of removing a service and its staff, nor how the effect of this at a personal level might be addressed. However, as the councillor moved on to speaking about choice, there was an obvious continuity of care narrative concealed beneath the account of choice. So, a narrative of privileging of choice of *type* of service over choice of *provider* of service in effect removed the question of continuity of care by taking choice of provider out of the equation:

"Are we talking about a choice of provider....in which case I would agree with you. If we close these two down we are reducing the choice of provider."

<interruption from carer who spoke previously> "Or are we talking about a lack of choice - in terms of choice of service then we are not reducing choice - we are actually increasing it. As we are required to do - we have to provide residential respite because people have told us they want it. You're quite right. We have to provide community-based respite, because people have said they want it."

Here KD gave an impression that the council and carers were seeking the same thing - choice - and made out that the definition of choice in the consultation had been specifically related to choice of type of service. This was followed by further attempts to pacify carers' concerns about the equation around the number of beds that would replace the existing provision:

"I would admit, it seems perverse, to close 50 beds....and you're right, we're not going to do that. Not until we know that we have sufficient capacity in the system to take over. And I think what people don't necessarily realise, and that we have done an awful lot of homework on, and that we actually have the experience of in relation to Crouston, is that when we look at respite - proper respite for carers - actually that didn't result in very many beds in the independent sector. We've actually been able to commission more beds in the private sector than were being used at Long Edge, which was a 34-bedded unit. Now that is mathematics, and we can give you that evidence, in fact I think that the councillor who asked for that information has already received that information from us. So we wouldn't do anything until we were sure that we had robust figures, quality of service, and range of choice available. And that is why we are looking to keep these two provisions open until such time as we are confident that that is the case. And we would bring that back to cabinet for your verification."

What seemed to happen at this point in the meeting was a calculated act by the leader of the council to diffuse a situation of irate and discontented carers. The leader of the council called for a suspension of the meeting and a fifteen-minute adjournment during which time he and two other councillors, plus some of the officers, would discuss the closure proposals in light of concerns raised by carers during the meeting. After twenty minutes the meeting resumed and an announcement was made confirming firstly that the social care budget would be raised by £1million for the next financial year which would provide the required expenditure to fund the services at Oak Hall and Long Edge for a further year; secondly, that although the consultation report would be endorsed overall, some of the original recommendations would be amended; and thirdly and most significantly Oak Hall and Long Edge would be given a reprieve for a 12 month period:

"This is about doing things the right way. Although many of you have consulted, many of you have come here to tell us what you think, we should listen. We should listen to the silent majority as well. To have had many of the comments put forward, and perhaps we have heard them louder than

you realise" [...] "There'll be no views put forward from cabinet. We've heard from the people today - that's more than sufficient for me. So Oak Hall and Long Edge remain open. Ok, they remain open" <applause begins>

In temporal terms this might be described as an intervention that brought about a stopping or pausing of the clock (explicit time) in conjunction with "promised time" by legitimators, the members of the council (Glaser and Strauss, 1971:37). There was a sense of at least a minor victory being achieved by carers and people with dementia who would be affected by any proposals to close the service, and the feeling of victory was reflected in headlines in local newspapers in the days following the meeting. Newspaper 1 had as its headline "SAVED! Delight as respite centre reprieved for year after users' pleas." In Newspaper 2 the header for the same story was "Council U-turn on respite care plan".

The implications of the pausing of time for carers and for people with dementia were that the pause provided some temporary relief from concerns that the service at Oak Hall might soon end, and assured them of at least a temporary continuity of the service and all that this represented in terms of maintaining familiarity of environment, staff, other clients, and care approaches. However, just six months later - one month after the general election in which the conservatives held their seats in Northweton and Crouston - the closure proposals were brought back to a cabinet meeting. In the weeks leading up to the meeting there was a feeling amongst carers, people with dementia, and staff at Oak Hall that the council would this time recommend closure of the two services. I planned to go to the meeting and had requested a slot to speak during the allocated public speaking time at the start of the meeting. This choice to speak meant that I would be, in a sense, adding to my role as researcher and entering the periphery of terrain of data sourcing: i.e. the sense that the interaction between me and the meeting was about the producing of new data in my own research project.

Decision-making about Oak Hall and Long Edge: out of time

At the end of June 2015 a meeting of Polshire Council Cabinet took place. There were a large number of carers and other representatives present and the meeting

room was full to the point where all the seats were taken so that new people coming in had to stand. The proposals for closing the respite and day service for people with dementia at Oak Hall and Long Edge were towards the bottom of the agenda at item 11, and the first words from the leader of the council were proposing to move agenda item 11 forward to be considered at the start of meeting. There were seven speakers (identified here as Speakers 1, 2, and so on) of which I was Speaker 6.

Speaker 1 expressed concerns about the alternative provision of care: would private sector homes pay minimum living wage to staff? Can Oak Hall and Long Edge be kept open by running them more efficiently? Will the quality of care be as good in the private sector as it is in local authority run care? How will quality of care be measured? Can we have a guarantee that no member of staff or council member would make a profit if you decide to close these care homes? Can there be a discussion about raising council tax in order to pay for care for the old and vulnerable - you need to look at these people as having worked and looked after you all their working lives and now it's your turn to do the same for them.

A female councillor, KD, responded, emphasising the point that working with the Care Quality Commission (CQC) Polshire was -

"...delivering better care than almost anywhere else in the north west and we will continue to do so, and that is why we can say that the independent sector is an excellent way to go forward."

This seemed to fail to recognise something of a disparity in CQC findings between care facilities in Northweton and those in Crouston, which had been raised at an earlier meeting by two carers who had spoken about the poor CQC ratings given to care provision that was proposed as an alternative to Long Edge. Clearly there were inconsistencies in quality across independent sector dementia care provision about which there was significant concern amongst carers.

Speaker 3, even before she had started to speak, was pressed by the leader of the council who told her she had less than a minute and a half to make her point.

"I've taken some time out of some severe family problems to be here today. As you are aware I have already made arrangements to present a petition on behalf of 4028 people, to the full council meeting in July, but because of this

discussion at the moment I felt I was obliged to come and speak here"
[...]"The document presented by your head of adult services states lots of
fluffy hope and cheer with little or no substance. It makes the obvious point
that the services at Long Edge and Oak Hall are both very much valued. So it
is shutting down? Why? Extreme old age and disability is growing greater as
we speak [...]"

(At this point the council leader interrupted saying "you have had your time" and
then instructed the man who was passing round the microphone around to take
the microphone from Speaker 3, which he attempted to do. The leader of the
council then said - "you're not going to be rude in my meeting". Against this
backdrop other people in the room said "let her speak", and she continued)

"I wish to point out one last thing in respect of the Carers' Strategy - which is
being proposed here. That is in respect of your Carers Together part of the
Carers Strategy, which was before the governing body of Polshire Clinical
Commissioning Group on the 29th April where what they said was - the
governing body agreed it could not explicitly support the strategy without
clearer evidence of the benefits to carers and without clearer governance
arrangements of how those benefits will be delivered. This is what I came
here to tell you today, that this is acting against Caring Together, thank you
very much." (this was followed by a round of applause from people in the
room).

At this point the leader of the council deflected attention away from the content of
Speaker 3's words announcing that because she had taken two and a half minutes
of time that reduced time for other speakers. Speaker 2 interjected saying that
"you should not stop people from speaking at a cabinet meeting where you are
discussing something that is really, really important." This was followed by
another round of applause from those in the meeting. The council leader
continued with tactics that seemed to be designed to discredit Speaker 3, but this
was met by yet another round of applause for the speaker.

Speaker 4, a man, spoke about carers' needs, pointing out that carer health and
wellbeing was of prime importance because if a carer became ill this created a
problem of who would look after the person with dementia. The leader of the

council responded, indicating that the solution being proposed would give carers "more time" in terms of the amount of respite that they would get, and that care would be local so that carers would have to travel less.

Speaker 5 was a man who introduced himself as speaking for the Long Edge campaign, from Crouston. He wanted to question the Chair and the council officer about how many beds have replaced the thirty that were axed. This drew a response from the leader of the council - "One thousand". Speaker 5 repeated his question, emphasising the word "beds", and the same response was repeated by the council leader.

Speaker 5 continued:

"That's bed nights. With due respect you're talking about bed nights. How many beds? Thirty beds were at Long Edge - how many are still there? And where are they?"

Speaker 5 continued to press the council leader for an answer to his question, and then asserted that the council wanted to cut costs, but that these costs will transfer to carers and clients. A round of applause followed this speaker, and then the council leader responded not by answering the question but by describing how Long Edge and Oak Hall have slipped over into the provision of "permanent care", evidenced by instances where people have been there for more than six months. This was a problem because the standard stay was set at no more than 29 days, and the council was not licensed to provide permanent care. This issue came up several times more, the next when I spoke (Speaker 6). I read a short, scripted piece about types of value that can't be quantified and may be hardly noticed until a service that encapsulates the value is removed. The closure of Oak Hall as I saw it would represent a loss of the value hidden in the knowledge, skills and experience of staff, and this value was irreplaceable. About two thirds of the way through reading I was cut short by the leader of the council, who then questioned me about how many people I had come across at Oak Hall who had been there for more than 29 days, people he described as "overstayers". Without waiting for my answer he proceeded to say that those long stays were not the job of the council to support. There had been, throughout the meeting, comments from carers, other members of the public, and even opposition councillors, about

the attitude of the council leader towards them and how the meeting was being run. This became very noisy soon after I had spoken and the leader of the council then said to those in attendance that if they would like to leave they could; if they didn't like what they were hearing. This also marked a point where the leader of the council began to talk about the basis for closure of the services at Oak Hall and Long Edge being in order to address the longer than 29 days 'rule'.

Speaker 7, a lady, provided an account of the independent sector in Crouston, characterised by a lack of beds, 'rules' about a minimum stay of two weeks for respite, and top-up costs. One home didn't accept social services funded stays, and none of the homes had respite care facilities. In fact, some didn't even have full-time care places available at all. There was more applause for the speaker. The picture that Speaker 7 painted seemed to catch the leader of the council unawares as he provided a blustering response that there would be a need to pre-book beds, and that the council would be ensuring the availability of beds.

The allocation of time for the public to speak ended, and the debate was then opened up to other councillors. EH, a labour councillor was the first to speak. I knew EH from previous employment with the local branch of the Alzheimer's Society where she had been the chair for a time. In relation to Oak Hall she had started an online petition through the network '38 Degrees'. Her first question was about how much the council had paid (2014/15) to the private sector in cases where residents could not pay for their care costs. This information had not been possible to find, and she asked for a written response.

The next speaker was a young male labour councillor, LR, who put it to the leader of the council that he was "obsessed" with listening to the public prior to getting elected, but what of this now? LR said he would pay homage to Oak Hall for providing the bridge for his granddad who used the service and then went into long-term permanent care, describing those who worked at Oak Hall as "fantastic, fantastic staff". There was another round of applause, followed by further comments from the council leader about how badly labour councils in other areas have handled scenarios involving transferring of services from the council to the independent sector, and that Polshire council has had to make tough decisions in tough times. LR tried to continue speaking but was cut off by the council leader with the words - "this is my meeting". This generated further angry comments

from people in the room, including shouts from some people. A conservative councillor from Crouston then spoke, saying that "the older generation doesn't understand the difference between respite, intermediate and long-term care". She requested that if Long Edge is closed could information be sent out to reassure people that the care they will receive in the independent sector will be as good as the care they receive at Long Edge. This prompted another off-the-cuff response from the council leader assuring her that the care would be as good.

It was at this point that item 11 (regarding future provision to replace Oak Hall and Long Edge) was introduced by KD. This was the paper that was brought to the December meeting in a different format. KD described how the council had started to implement the Care Act, and that it was incumbent on the council to provide not just one form of respite care for residents, but multiple forms. Other forms of respite care had started to be implemented, such as "at home respite". At home respite was clearly not viewed by carers as appropriate for the needs of the people who used respite at Oak Hall and Long Edge, and the noise level in the meeting increased again. KD expressed the view that providing care from Oak Hall and Long Edge was very expensive, and followed this by saying that the numbers of people with dementia using Oak Hall and Long Edge were actually "very few". Again, this was followed by more rumblings from members of the public present. KD made her recommendation to cease carer respite at Oak Hall and Long Edge as from December 31st 2015. This timeframe would allow enough time for the council to ensure that what was put in place would meet people's needs, finishing her line of argument with - "I will guarantee that it [replacement respite services] will be of a similar quality".

Councillor N was asked to propose the motion, and he addressed the carers and other members of the public present by saying: "It's up to you to monitor where we go with this and to monitor the outcomes from it."

A labour councillor SB then spoke against the proposed closure:

"The cabinet changed their minds about the closure of both establishments and agreed to a reprieve for a year. Many people admired that decision for the stance they took, believing that you cared about what would happen to them and those they cared for. Today, on behalf of those same people, I would ask you all to reconsider the plans to close Long Edge and reduce the

service at Oak Hall. Nothing has changed since December 2014. Indeed, we know that month by month more people are taking on a caring role, saving local authorities millions of pounds a year. Carers have not been properly consulted in the time between December and the present, there are fewer places in the private sector than this time last year, the independent sector are clear that they cannot provide respite care for what local authorities are prepared to pay, and may say that they can only provide respite in the short term because somebody has left or died."

He highlighted that, for some people, models of respite where the service was provided in the person's own home were not desirable because too many arrangements had to be made, and in any case it can't be assumed that a carer would want to leave their home, or change their own sleeping arrangements to accommodate the person coming in to care. Whilst it had been said that the closure of Top View (a respite service for older people) was without negative consequence this did not seem to have been borne out in practice, with anecdotal evidence that some carers were left unsupported.

SB asked councillors to think about local people and their needs: "after all, they're not asking for much". He pointed out that the issue of "overstayers" begged the questions - why hasn't anything been done about this before; and why not fix the problems rather than close the facility? This councillor's last comment drew murmurs and nods of agreement from people in the room, and then a big round of applause.

It seemed to me that if the decision about keeping Oak Hall and Long Edge open had rested either on arguments about quality, or arguments about carers' lived experience, the evidence provided via the consultation and at the meeting itself would have been more than sufficient to prevent the closure. Clearly this was not what the decision rested on, and the leader of the council then confirmed this, saying that respite needed to be increased for thousands of people and that closing the two services would make savings that would then be ploughed back into providing respite; and that evidence would be provided to support this view. The savings argument was then picked up by the labour councillor, EH, who outlined what she called 'facts': there have been some notable failings in decisions

made about spending in the council and some of these have cost a lot of money. The £1million needed to fund Oak Hall and Long Edge was the cost of one of these failings. This comment was immediately refuted by the council leader, amidst growing signs of dismay in the room: shouting and questions, and a mini slanging match then ensued, with one woman describing the behaviour of the council leader as "awful", "nasty" "arrogant". Her comments were applauded, but the leader of the council then declared that if the woman did not stop talking he would stop the meeting and clear the audience. This outburst contained, EH continued. She had tallied up the various pots of money in the general reserves and earmarked reserves. Even after schools costs were deducted from the council tax income there would still be about £700 million remaining for the current year. Whilst it was not disputed that there needed to be savings made the savings outlined for reinvestment from the potential service closures were £1.3 million, which she considered fairly modest in the light of the council's total reserves. The respite service the council provided prior to Oak Hall (Minton Lodge) closed and the savings made were then reinvested in Oak Hall. The portfolio holder at the time had given assurances to carers that they would always have Oak Hall. EH's comments were met with another round of applause.

The distances carers had to currently travel to take their loved one to a respite facility was raised by the leader of the council, and then by another conservative councillor who stated that her constituents were having to travel a minimum of eighteen miles to get respite. Another councillor's view was that he didn't want his residents travelling anywhere if at all possible, but wanted local care homes for them or for them to have respite in their own home.

Here KD provided a summing up about resources in the form of sixteen new senior social workers, and the current social care budget from which greater efficiencies would have to be made over the following twelve months. In what seemed to be a political manoeuvre she then said:

"...but I hear what the PhD student says, because she's absolutely right - it's about more than money - it is about the quality of care, it is about the nature of the relationships that are built between those that are cared for, their carers and the staff who they trust to look after their loved ones, and it is about place and time and appropriateness."

I was struck by the way that KD had taken my narrative and recast it using the expression "place and time". It seemed to me that this was a rather odd situation where my narrative was being used to justify (or at least to support) a decision that involved completely changing the "place" (of service provision), and imposing a different temporality ("time") on carers and people with dementia than the one which already worked for them.

After KD's summing up there were more murmurings and questions from members of the public. Then, seemingly in a final act of reputational damage limitation, the leader of the council reiterated that he had lost two parents to dementia and that he understood the heartache. At this point he had to virtually shout to make himself heard, as he proceeded to call for a vote on the proposals to close the services at Oak Hall and Long Edge. The voting itself was very brief, and the council leader stating that the call to close the services was carried unanimously.

A five-minute recess was announced to allow time for anybody who wished to leave at this point. Apart from a handful of people who remained to hear the debate on other items on the agenda all carers, other members of the public (including myself) left at this point. A carer whose husband was a participant in my PhD study was there and looked very upset. I had a brief conversation with her outside, and then with two town councillors and with Speaker 3.

Whatever the fall-out from the meeting and the decision that was made, it did not result either in any back-tracking on closing the service at Oak Hall, or resignations from the council. The story was reported on in Newspaper 1 with the header: "Respite care reprieve at site to be short-lived". This provided an interesting, if unintended, reference to the temporal dimension of the service provision. One vote at one moment in time and the service quite suddenly did not have a future.

Chapter 6: Discussion

Introduction to this chapter

The two previous chapters (four and five) are ethnographic case studies in which the accounts of my data and findings are set out.

In chapter six my aims are: to try to distil the points that I surfaced in my case accounts about the specifics of 'knowledge', 'time' and 'practice'; to set out my perspective on the interplays and interrelatedness between knowledge, time and practice in the two service settings; and then to illustrate using examples from fieldwork how I have envisioned knowledge, time and practice as converging. This chapter is set out in several sections. Initially, I discuss my approach to making sense of the data in the context of my interactions with the field settings. I then restate the core elements of knowledge, time and practice, from a perspective shaped by understandings that have 'grown' through the journey of doing a PhD.

Based on examples taken from the two case study accounts I present a set of notional convergences that I have envisaged between knowledge, time and practice in each of my service settings. I then suggest an overarching convergence of knowledge, time and practice that helps in making sense of the two case studies – how they differ and yet how they also display these common abstract properties.

I close chapter six with some reflexive thoughts about knowledge in each of the service settings, conscious that the account of it I have produced is essentially *my* account.

I reflect on what has been surfaced about each fieldwork context in terms of the differing knowledge regimes and currencies; and I consider questions regarding what do I now know (that I did not know when I began my PhD), and can I surface what I now know?

It is important to revisit, briefly, the characterisations of tacit knowledge that I found helpful in my reading of theoretical and empirical bodies of literature. Fundamental to the building of my argument here is that our understanding of the nature and the practical worth of tacit knowledge might be extended by giving attention to the specifics of knowledge, time and practice.

The accounts in chapters four and five helped to reveal and clarify the nature of knowledge, time and practice interrelatedness, which are the subject of work in the theory of practice (e.g. Liaschenko in Thorne and Hayes, 1997; Reckwitz, 2002; Hopwood in McLean et al, 2014; Hopwood, 2014; Falk et al, 2017).

Characterisations of tacit knowledge that were helpful in terms of their relevance to the two service settings were Gabbay and Le May's (2011) "inexpressible knowledge" (aspects of practice knowledge that cannot be linguistically articulated); Eraut's (2002) "intervisibility of practice" where practice might be conceived as oscillating between being visible and invisible - an idea that prompts thoughts about the knowledge embedded in practice (Polanyi, 1961); human bodily sensorial faculties (sight, smell, touch) through which the external world is perceived and by which a practitioner can come to know about/know their patient or service user (Goodwin in Buscher et al, 2009; Polanyi, 1961); and practice experience as one means for knowledge acquisition and accumulation by practitioners (Benner, 1980, 1982; and Dreyfus and Dreyfus, 1980).

Making sense: data and interactions in the field

The data I have presented in chapters four and five signal theoretical pathways for analysis and understanding. Notwithstanding this assertion, an indispensable ally in my sensemaking has been my own imagination. During the fieldwork stage and in the periods when I was making sense of my data, imagination is what enabled me to simply wonder about the experiences and concerns of my research participants, to sit with my data and let thoughts and possible meanings arise, and to envision the possible connections between ideas.

Georg Philipp Friedrich Freiherr von Hardenberg (known by his pen name, Novalis), a German poet, author, mystic and philosopher of early German Romanticism, was writing during the late eighteenth century. In an unpublished fragment he wrote:

"To romanticize the world is to make us aware of the magic, mystery and wonder of the world; it is to educate the senses to see the ordinary as extraordinary, the familiar as strange, the mundane as sacred, the finite as infinite." (Novalis, cited by Beiser, 2006:101)

If making sense of the world is an imaginative endeavour then imagination should not be dismissed from the researcher's repertoire of resources for sensemaking during the various stages of a research project. Additionally, Novalis' call to see the "ordinary as extraordinary" and "the familiar as strange" are ways of seeing which are fundamental to the ethnographic tradition.

In Weick's (2006) work there are also allusions to imagination's involvement in sensemaking. Weick endorses the idea that it is a feature of everyday life that people "believe ahead of the evidence" (Weick, 2006: 1725), illustrating this with an example from pre-1950s (clinical) practice: paediatricians believed that brittle bones was the explanation for injuries in children because they would not believe that the injuries may have been inflicted deliberately by parents. In explaining this Weick suggests that events happen and then we make sense of these sometime afterwards: "[t]he after-the-fact, ex post, life-trailing nature of consciousness - occurrence first, formulation later on" (Geertz, 1995:19, cited by Weick, 2006:1725). Sensemaking involves people noticing, then extracting cues, and then embellishing what they extract (Weick, 1995:49). Citing Charles Peirce's approach known as "abduction" (Weick, 2006:1731), Weick elaborates further on this process:

"[W]hen people imagine reality, they start with some tangible clue and then discover or invent a world in which that clue is meaningful." (Weick, 2006:1731)

'Clues may be "obscure" or "remote" (Harrowitz, 1988:184, cited by Weick, 2006:1731) and the taking of a tangible clue, seeing it as a "meaningful symptom", and then wholeheartedly following it results in the enactment of a complex reality not directly observable. (Weick, 2006:1731). Embellishment, imagination, and invention are all terms Weick uses for expounding his ideas about sensemaking.

The respective ideas from Novalis that an imaginative sensibility is one orientation to the world that we can adopt to make sense of it, and the guiding theoretical underpinnings of sensemaking from Weick, are now followed with some brief points about my own sensemaking and how *I* practiced imagination during and after leaving the field.

In an early, though undated, field-note made at Oak Hall I wrote:

"Karl Weick (1995) uses the word "sensemaking" and this is interesting because this is what we all seem to be trying to do. Staff, clients, the researcher, visitors who come in, are all trying to make sense."

This was a reflexive point based on my own noticing, and my interpretations, themselves filtered through my past experiences of working in care homes, NHS and social services day centres, my knowledge about dementia, my values and beliefs about the world, and my personal orientation to knowledge and towards resolving what I had constructed as problematic about knowledge.

Imagination involves a creative act of conceiving mental images or visualisations that are not accessed as material or tangible. Imagination allowed me creative licence to wonder about individuals, based on encounters with them. My reflections were oriented towards aspects that engaged my attention such as: what a person had said or their demeanour and emotional expression. Whether or not a person with dementia can linguistically articulate aspects of their current experience does not matter. What matters is that the person is continuously having experiences. Thomas Fuchs - writing both as psychiatrist and philosopher - suggests that being in a state of memory impairment does not diminish or change this certainty that a person had experiences previously and continues to have them. (Fuchs, 2016: 7-9). My imaginings about an individual were how I tried to connect the pasts, presents and possible futures of that individual. Stuart, for example, I had already encountered fifteen or so years earlier and I could remember my interactions with him before he developed dementia. Even though Stuart was not physically present at his parents' home during my visit, he seemed held there in his parents' remembrances of him - their anecdotes about him and photographs of him in the home that he had shared with them until recently. I wondered about the experience for his mum and dad in relinquishing caring for Stuart, and I thought about what Stuart might have felt at being separated from his parents and familiar surrounds of home. He was now unable to articulate linguistically his wishes for the future, which caused me to wonder whether he would have wanted his end of life care to be somewhere other than his family home. Another scenario - that of Ms Evans who was seen by Laura at home -

prompted reflections about how she experienced living alone: how did she fill the long stretches of time when there was no-one present?

My imaginings became written into my narratives about individuals. One instance of attempting to extend an individual story was based around my observation of Mr Burton's appointment with Laura in clinic. Mr Burton was aware of his forgetfulness: forgetting people's names, and forgetting to lock the door of his house during the day. He did not state that leaving the door unlocked was a problem, but I speculated on the scenarios that might result, such as the house being burgled. I took this idea - that forgetfulness might become a problem in certain situations - and elaborated it further to open up insights about associations between forgetting and exposure to risks.

I stated in an earlier paragraph in this chapter that data presented in chapters four and five signalled theoretical pathways for sensemaking. Weick offers the perspective that in building theory researchers use imagination (Weick, 1989; 1995):

"[T]heorizing consists of disciplined imagination that unfolds in a manner analogous to artificial selection." (Weick, 1989:516).

The analogy of "artificial selection" conveys the idea that the imagination is used for envisaging or speculating about how (for example) a set of ideas, or the complex arrangement of narratives within a story, or items on a list of variables, may be interrelated or linked. In Weick's example of the theorising process oriented to organisational problems he writes:

"Organizations are complex, dynamic, and difficult to observe, which means that whenever we think about them, the thinking will be guided by indirect evidence and visualizations of what they may be like, often captured in metaphors." (Weick, 1989:529)

I can relate my own attempts to provide a theoretically oriented account of tacit knowledge in the two services to this quotation from Weick. Without empirical means to differentiate between tacit knowledge and explicit knowledge – that is,

being able to definitively state in a given instance that only tacit knowledge or only explicit knowledge is involved – it becomes helpful to use imagination for visualising connections that cannot be substantiated empirically.

The way that I found helpful for envisioning tacit knowledge was through seeing tacit knowledge in relationship to practice and time.

Knowledge: articulation

For this PhD I set out with the intention that I would investigate tacit knowledge in two dementia service settings. Initially my interest was in the tacit knowledge of practitioners in their day-to-day interactions with people with dementia.

However, once in the field, the conversations and interactions I had with people with dementia sparked my interest in the tacit knowledge of people with dementia and carers.

Before I turn to developing my argument about the convergences between knowledge, time and practice, I give some consideration to types or aspects of knowledge in the two services that it is possible to articulate linguistically.

Beginning with knowledge at the NHS memory service, I list instances of knowledge that can or could be articulated in written or verbal form:

- Guidelines for assessment and treatment that assist in determining memory status and/or mental and physical health status.
- Scan and test results.
- Knowledge of dementia drugs: what drug to prescribe for specific symptoms and for the type/stage of dementia, and contraindications and possible side effects.
- Knowledge of symptoms and their manifestations.
- Knowledge of difficulties that people diagnosed with dementia face, and their families and carers.
- Knowledge of the support the team offers, and what support and help is available outside of the team.
- Knowledge about what people can do to improve their own health and wellbeing.
- Knowledge of a range of interventions for people diagnosed with dementia.

Although not included here, the knowledge that is behind the conception of material objects - on which clinical practice is reliant - might be added to this list. By this I mean aspects such as: the knowledge represented in pharmaceutical drugs prescribed to persons with dementia; the knowledge represented in the actual material onto which an image is taken of a person's brain; or the knowledge signified in a piece of equipment such as the sphygmomanometer.

At the local authority service knowledge that is articulable linguistically is:

- Knowledge of individual clients: individuals' key relationships (e.g. with family, friends pets), their likes and dislikes, their needs.
- Technical knowledge such as for operating a hoist, or transferring people from wheelchair to chair, or bed.
- Knowledge of how to organise, design or support activities appropriate for people with dementia.
- Procedural knowledge - such as administering medication or following safeguarding procedures.
- Knowledge of good practice in dementia care such as how to respond to people behaving in particular ways.

Just as knowledge in the NHS service could be further added to by thinking of knowledge in material objects, so too the local authority service list. Additions might be the knowledge represented or embedded in specialist equipment such as hoists, beds and mattresses.

In giving attention to knowledge at the two settings one important question that surfaces concerns how knowledge and practice are related: whether, in an instance of practice, it is possible to differentiate between the practice part and the knowledge part. For example: when a clinician is making their assessment and deciding on appropriate treatment is it possible to articulate precisely the 'what' and the 'how' of the combination of practice and knowledge? We can say that codified knowledge is available to the clinician in the form of the assessment and treatment guidelines for determining memory status; and that the clinician acts purposefully in orienting tacit and explicit knowledge in the practices required to assess the individual. We might describe practice as being powered by knowledge in the sense that Corradi and colleagues (2010:267) have alluded to: that

"practical and 'hidden' knowledge" is what supports practice. Whilst not resolving the questions raised about whether and how knowledge and practice might be disentangled, the idea that knowledge and some form of action (e.g. doing, speaking) *together* are required for practice might be one strand of conceptualising how knowledge and practice are related. This idea adds to the already stated problematisation of tacit knowledge in chapter two: if knowledge and practice overlap and intertwine in a given instance of practice (e.g. assessing a person's memory status) then within an account of practice will always be contained (though not necessarily articulable) referents to knowledge.

I now turn briefly to consider from the service settings the knowledge repertoires of people with dementia and their carers, and the positioning of these in relation to the idea of a knowledge-practice dyad which has become highlighted through thinking about knowledge at each service.

Becoming a clinician or care practitioner to work with people with dementia is a matter of choice. It involves training in order to acquire the requisite knowledge so that one is equipped for practice. We may assume that becoming a person with dementia and having first-hand experience of dementia is not consciously chosen or sought out. Nor would it be supposed that - when physical changes to the brain start to occur - an individual has any inkling about what is happening. By the time that memory becomes affected by cognitive decline an unstoppable process is already in motion. Dementia is experienced first-hand only by a person with dementia. Regardless of whether the person can convey to others what it feels like to have dementia, the person *knows* experientially what it feels like. Likewise, a carer knows experientially what it feels like to be a carer, and knows (sometimes in an intimate way, depending on the nature of the relationship) the person, which is a knowing of how the person was and how they seem different now.

Articulating the knowledge of people with dementia and carers as experiential is about as much as can be stated, in that we cannot know the nature of the actual experience. We can only linguistically refer to the experience of dementia from an outsider perspective, as those who lack the direct experience. What we *can* state is:

- People with dementia have lived experience and lived knowledge of their dementia.
- Carers have experiential knowledge of caring for someone with dementia.
- Both carers and people with dementia may know about aspects of the specific type of dementia they have been diagnosed with.
- People with dementia have knowledge of and experience of using particular services (e.g. Oak Hall).
- Carers have knowledge of local services specific to people with dementia, and have knowledge of risks that might arise at home and how to reduce risk.

In encounters between carers and practitioners, carers' knowledge is both historical (a carer has known and knows the person) and practical: the carer knows the tasks of care, how to ensure the person's safety, and how to support adherence to treatment.

Individuals with dementia themselves are positioned as recipients of practitioners' knowledge. Yet, it is also the case that a person's own "lived knowledge" (Nygard and Johansson, 2001:89) - exclusive to the person and experiential - is useful to the practitioner in constructing a picture of the current situation (so long as the individual is able to give an account of some of this). For example, in chapter four I described Mr Seward's appointment with Dr Ozha, where Mr Seward described his hallucinations. He 'saw' - as though they were material - snakes, people in the house, people down the toilet, cameras outside, a man with a moustache, and furry creatures. The vividness of Mr Seward's account of what he had seen would have been significant to Dr Ozha in a clinical knowledge sense. It confirmed to Dr Ozha that these were hallucinations. Dr Ozha could not himself know what Mr Seward's experience felt like, but Mr Seward's articulation of what he 'saw' was sufficient to provide Dr Ozha with enough clues on which to base the diagnosis and subsequent specifying of appropriate treatment.

What might be reasonably concluded from this practice example is that at least some parts of experiential knowledge can be surfaced (thus are articulable) when individuals speak about their experiences. Since the account provided by Mr Seward was helpful to Dr Ozha, it might also be suggested that thinking in terms of

interdependencies between the knowledge of practitioner, person with dementia and carer is a useful characterisation of knowledge in practice.

In the context of the social care setting the interdependencies between different individuals' knowledge can be illustrated when thinking about the brief conversations that take place between a carer and a member of care staff when the carer brings the individual with dementia into day-care. Through even such brief exchanges the member of staff might gain new knowledge about the person with dementia - e.g. about the person's particular interest or skill, or that s/he has recently been on holiday, or that the person is not sleeping well. This knowledge might be incorporated into practice through, for example, directing a conversation or an activity towards the interests of the individual.

This discussion about the articulation of knowledge, and how this might be relevant when applied to practice, opens up some ideas about the relationship between knowledge and practice. It does not, however, resolve the problems concerning tacit knowledge specifically. That is, if the dimension of comprehensive knowledge that is tacit cannot (in any practical sense) be extracted from the 'whole' of comprehensive knowledge, even in aspects of practice that are observable or audible it is impossible to determine the part that tacit and/or explicit knowledge plays in shaping practice at any given moment. Acknowledging that the question of isolating the action or activity of tacit knowledge in practice remains unresolved, it has been highlighted in this discussion that experiential knowledge of people with dementia and carers' knowing of the individual with dementia, respectively, has worth to practice. In the memory service the worth of this knowledge might be in how it helps in informing diagnosis or specifying treatment. In the social care setting its worth might be in influencing how the practitioner interacts with the person, or in the selecting of social care activities by the practitioner.

Knowledge, practice and time

Having established that conceiving tacit knowledge in terms of its relatedness to practice is helpful for surfacing ideas about the knowledge of practitioner, person with dementia and carer, I now move attention to the day-to-day practice in the

two services. I introduce the idea that the knowledge-practice relationship is occurring in and through 'time'. Temporality in relation to practice is a recurring theme in Nick Hopwood's work. One way that Hopwood (2014:140) has conceptualised the relatedness between practice and time is as "bodies" being required for practice, and bodies coordinated "in space and time in order to perform practices [...]."

The way that I started to think about a relationship between tacit knowledge, practice and time was by identifying interactions between practitioners and individuals with dementia that seemed typical. I then elaborated through speculating on how time might be implicated. For example:

- An individual or a carer can articulate to a clinician the 'when' of memory becoming problematic. This knowledge is not insignificant in that it contributes to the picture of what stage the memory problems are now (e.g. mild, moderate), a picture that is added to through means such as memory test, and physical/mental health history.
- In the social care setting good 'timing' – in the sense of practitioners knowing when to intervene (e.g. timing of intervention in an emergency situation is different to timing when a person needs assistance to mobilise from a wheelchair to a chair) – may be directed or informed by the practitioner's knowledge or knowing of the individual.

There are a number of time conceptions that are helpful for orienting time to the two services in terms of their everyday activity and practice, and the people with dementia and carers who use the services.

Barbara Adam's Timescapes (2008) perspective of irreducible elements for understanding time is helpful for thinking about the two services in terms of how the practices of each were differently organised in relation to time, and how time was differently emphasised. 'Arriving and departing', highlighted in chapter 5, marked the beginning and the end of a day in day-care, or the start and finish of a respite stay. The bounding of time in this manner Adam (2008:7) conceptualises as a "time frame". The memory appointments in the NHS setting may be similarly characterised as bounded time frames although, unlike the day-care service, these are fixed and if a person missed their appointment a new time frame has to be

scheduled. "Sequence" (Adam, 2008:8) refers to ordering, and this offers a way of thinking about the typical entry-and-moving-through pattern and structuring of NHS memory appointments: referral in, initial assessment appointment, referral for scans and tests, and then the appointment at which a diagnosis is given. The terms of the sequence are prescribed by the memory service, and individuals are slotted into it through allocation of appointments in the sequence. Glaser and Strauss (1971:36) write about the overseeing of sequencing, timings and stages of passages by "legitimators".

This is a useful strand to pull in because it serves to highlight an emergent point about the structuring and imposing of sequences according to service-driven objective frames of calendar/clock time *onto* an experience of dementia that is being individually lived. This is perhaps an unavoidable tension between service timeframe agendas and those of individual realities which, as Adam points out, are "personal frames of life time and family time, and/or times of illness and stress", which are "relative and mobile". (Adam, 2008:8). "Timing" in terms of synchronisation, co-ordination, the right/wrong time (Adam, 2008:8) is another way of thinking about time, which may be applied to my two service settings. For example, decisions made by the council about when to close Oak Hall profoundly impacted on people with dementia using the Oak Hall service, their carers, and staff working at Oak Hall. Even if timing was 'right' because it fitted the council's political or financial agenda, timing did not, and probably never would feel 'right' for recipients of the service. "Timing" has its roots in 'Kairos', a concept that has been largely lost to the English language, but which is an essential expression of 'a time to': "the right or opportune time to do something often referred to as 'right timing'." (Smith, 1986:4). Kairos-relevant questions are "When?" and "At what time?" The conception of time that seems to directly contrast with Kairos is time "as measure, the quantity of duration, the length of periodicity, the age of an object or artefact, and the rate of acceleration of bodies [.]" (Smith, 1986:4). This is the Greek conception of 'Chronos', the root of the word 'chronological'. "How fast?", "How frequent?", "How old?" are all questions to Chronos. (Smith, 1986:4). Thinking about time conceptions that are useful in relation to the individual histories of people with dementia, Abbott (2001) offers two ways of seeing types of historical process such as a life course. One way of seeing focuses on finding

causes of (or for) something that happened, and the other focuses on narratives, with the aim of finding typical patterns. Applied to a life course of a person with dementia, Abbott's latter conception is one of seeing the life course as a logical narrative with an inherent purpose or end point. (Abbott, 2001:161-165). To think narratively, Abbott (2001:164) suggests, is to think "along cases rather than across them", indicating a focus on following the individual. During a life course the person concerned participates in "events" in the social world (Abbott, 2001), and according to a narrativist perspective an "event" is defined as "a combination of particular values of many variables". (Abbott, 2001:166). Abbott draws particular attention to the inherent complexity of events and individual subjects that participate in them. Thinking specifically in terms of the life course of a person who later in life is diagnosed with dementia: a way of appreciating complexity might be through highlighting that the multiple variables (and their combinations) operating at the many different stages of a person's life, create such complexity that ascertaining 'how' dementia arose out of these combinations of variables seems impossible. One of the helpful insights that Abbott's (2001) 'thinking narratively' surfaces is that one particular value of a variable may become significant. Abbott writes that a value becomes significant either:

..."because it is the first reversal of a long, steady fall or because it initiates a long steady state. In either case, it is the general temporal context, not the immediate change that matters". (Abbott, 2001:172).

Thinking in terms of life courses of individuals who develop dementia, Abbott's quote offers a helpful focus for thinking about temporal contexts, including how the temporal context may vary in accordance with the type of dementia. In chapter five I highlighted Paul's situation of living with Pick's disease. The particular temporal context of Pick's disease might be described as 'a given' in terms of an individual's life expectancy in years from onset and/or diagnosis. Although, in Paul's case, some time after diagnosis it came to light that his symptomatology was atypical for Pick's disease. This unexpected reality was potentially very impactful for Paul, who joked that he might now outlive his wife.

One further conception of time from Abbott which I would like to draw attention to as relevant in thinking about dementia is "trajectories" (Abbott, 2001:248). Abbott (2001:249) suggests that trajectories may be referred to as "master narratives" in the sense of being comparable to "master statuses":

"Just as a master status like race overrides subordinate statuses like occupation, eradicating them in a simple comparison, so a master narrative is an overarching social process that has the character of coercing processes within it, and indeed of preventing those processes from creating combinations that disrupt it. It is this coercive characteristic that makes trajectories master narratives."

The idea I considered in chapter two, of non-reversible passages (Glaser and Strauss, 1971) being a possible way of conceptualising dementia, seems to resonate with Abbott's idea of trajectories. Qualities that are conjured up by Abbott's idea of trajectories are their pervasive and all-consuming nature: the sense that they are unstoppable like courses set that are unalterable.

One other conception of time I think is illuminating for my work is from Bluedorn (2002). He writes about the way that people connect with the future, either through activity whereby people connect by creating in front of themselves, or through expectation: we see the future advancing towards us, and we wait for what we expect to become present. (Bluedorn, 2002:237). One illustration from the NHS memory service is of Merfyn Jenkins who was being supported by Keith (a CPN) through regular home visits. An important aspect of Keith's visits which Merfyn looked forward to and expected would happen, was a game of snooker played with Keith. The idea of the future advancing towards people might be illustrated in instances where individuals seemingly reject or try to push further away into the future the prospect of living with dementia. 'Resistance' in the face of a diagnosis being given was articulated by Dr Ozha's patient, Ms Baker: "That's not very nice, telling me that! Won't it go worse?" In contrast, Mr Wooler - reviewed in clinic by Laura - seemed upbeat about the future, describing keeping going on his project of building a dolls' house.

Most of the people with dementia I met at Oak Hall had been living with dementia for years rather than months and most were noticeably less independent than

people I encountered through the NHS memory service. However, people at Oak Hall did engage with time, albeit in a different way to people I came into contact with through the memory service. One illustration of this was when I noticed that individuals in singing sessions demonstrated that they knew the words of a song and its melody, which I viewed as an indication that they anticipated what was coming next in a song. This might be conceptualised as people connecting with the very near future. Similarly, the occasions I was present at when individuals verbalised that they were looking for a person or a personal item that appeared 'lost' - the very fact that they were looking indicated that they were orientated to finding what was lost, hence describable as a 'future' (time) concern.

Having introduced some ideas about how I am orienting knowledge, practice and time (respectively) for making sense of my two case studies, I now set out how I have approached the challenge of representing how I see the interconnectedness between knowledge, time and practice.

An essential consideration for representing relations between a set of essentially abstract and non-spatial concepts is that the descriptor selected should not be suggestive of spatial dimensions. Metaphorical terms such as 'interlaced' or 'interwoven' suggest spatial properties, and even the seemingly abstract term 'connectedness' still implies spatiality. The term 'configuration' seemed initially promising to describe notional interrelatedness, but 'configuration' implies spatial properties, and lacks a sense of dynamic qualities. In the absence of a perfect descriptor I have used the word 'convergence' (in its noun form) which seems to capture a state or quality of things meeting, and also has a dynamic, active sense.

My aim has been to assemble two sets of convergences for the respective case study sites, to try to illustrate a way of making sense of events or happenings I considered to be significant (e.g. the diagnosis at the NHS service; 'knowing' the person at the social care service). For the NHS service the convergences I have selected reflect aspects of how the service responds to or is mapped around individuals with memory problems in terms of both the appointment chronology and the complexities involved in working with people with dementia. For the social care service the convergences reflect crucial elements of the service's

orientation to people with dementia such as 'knowing' the person, and events that derail or interrupt continuity of knowledgeable care.

Using these convergences my intention is to try to illustrate how knowledge, time and practice feature in health and care services to people with dementia. The proposition that follows each convergence is where I try to glean what is surfaced about tacit knowledge through the envisaging of its interconnectedness with practice and time.

NHS case study: convergences of 'knowledge-time-practice' and associated proposition statements

Convergence 1: the first appointment following referral of the person to the memory service

The structure for clinicians to see patients is through a prescheduled appointment at which the patient and the clinician meet, often with a carer also attending. The job of the clinician at this early encounter is "to sort out mild memory problems from more severe ones", a description given by Laura. The chief means for discriminating between dementia and any other types of problems with memory (e.g. mild cognitive impairment/MCI) is the mini mental state examination (MMSE) devised by Folstein et al (1975). The single cut-off for abnormal memory function is a score of less than 24 out of 30 when tested using the MMSE, and scores are further graded in ranges of "mild" (20-25); "moderate" (10-20); and "severe" (0-10). Other factors that might be involved in memory impairment, and therefore need to be considered alongside the MMSE result, include the person's physical and mental health history, symptoms, and the results from other tests (which may not be available at this initial appointment) such as brain scans. Thinking in terms of what is actually observable and/or linguistically articulated in an appointment, and what is hidden and/or silent, examples may be given of both. Some parts of the administering of the MMSE are observable and audible, such as the paper folding exercise where the clinician hands the piece of paper to the individual and instructs her/him to fold it and drop it on the floor. What is hidden and silent are the thought processes and perceptions of the clinician as she watches the individual, and the thought processes and perceptions of the individual performing the task.

The process of human perceiving is itself innately complex, involving human sensorial faculties: "actions and stimuli" that are interior to the body (Polanyi,1961:461) are in some way assimilated to form perception which ultimately leads to knowing.

Laura in interview talked about prescribing of medication (knowledge that is codified) whilst intimating that she did not entirely rely on this formulaic knowledge for making decisions:

"I probably use the dementia medicine more than most other people do, so people come to me and say, 'What do you think about that, what do you think about that for this patient?' And some of the drugs, particularly things like Memantine are reasonably new in clinical practice and using them with different kinds of patients and does it have a benefit for aggression, *does it have a benefit... what are the drawbacks to it, are the things that are not always evident from clinical research, and perhaps it is about shared experiences and using it in practice.*" [Emphasis added].

Laura also referred to assessment and diagnosis as impressionistic, and oriented towards getting to the core of what was happening with the person. This is reminiscent of Polanyi's words:

"Clinical practitioners call the peculiar indescribable appearance of a pathological condition its *facies*" (Polanyi, 1961:458)

Reaching the level of expertise that enables a clinician to diagnose a complex condition such as dementia seems to involve a knowledge-practice mix. In her early training as an Advanced Practitioner Laura spent time with consultant psychiatrists while they practiced, observing and listening as they assessed patients with dementia. This was the basis for her to build her own way of assessing people:

..."so that at the end of an hour's assessment I could come up with some kind of impression and know whether I was going to refer for tests or a review or discharge or whatever. And I started looking at how I could write down what they were saying, how I could capture what the essence of what all these different consultants were doing and what was important."

The stacking up of the various sorts of 'evidence' that enable the clinician to come to an understanding of the individual's memory status, and to reach conclusions about that status is not an instantaneous process. Time is implicated, and a way of thinking about time that might be helpful here is Abbott's (2001) "events". Thus, one way a value may become significant is in initiating "a long steady state" in which the general temporal context becomes important, not the immediate change that has occurred. (Abbott, 2001:172). The general temporal context might be viewed as time that is of indefinite duration, in the sense that neither the clinician (nor probably the individual) know when memory problems first started to develop, and nor is it known how much future time will elapse before the person's life ends. Ramakers et al's (2007) conclusions that changes in the brain begin as many as ten years before the signs of cognitive decline become apparent point rather poignantly to a decade of living with a pre-stage of dementia before diagnosis.

Even though it would be unusual for a formal diagnosis to be given at an initial appointment with the memory service because evidence from brain scans is not usually available at this point, the initial appointment does set the stage for whatever conclusions will be ultimately reached. A scan can reveal whether there is general age-related brain shrinkage or specific dementia symptomatology, the former which may be an indication that the person has mild cognitive impairment (MCI) rather than dementia. For example, one of Laura's patients - Mrs Bourne - underwent a CAT scan and an ECG following the initial referral appointment. When Laura reviewed the scan results during a follow-up appointment she concluded that at that time there were insufficient grounds for a diagnosis of dementia.

As a referral appointment is the first encounter the clinician has with the person and their memory problems, the clinician's knowledge might be described as partial: she knows *about* the person from notes and correspondence provided by other agencies involved (there is usually a GP letter) but she doesn't *know* the person. However, the clinician does have her own repertoire of knowledge accumulated from past practice which includes the conversations and encounters

she has had with people with dementia, and the accounts those people have given about their experience of dementia. Past experience might provide insights for a present situation: e.g. clues about *where* the person *is* on a memory problem trajectory. Yet, interaction with the person and their carer is as important for honing the emerging picture of the particular memory difficulties of the individual. The clinician makes enquiry in the here and now by asking the person and their carer about the experiences they are having in relation to memory, asking first some questions about the recent past - what has the person noticed about their memory and what are their concerns, and what account is given by the person who knows them well. A person with memory problems may wish to play down or make light of the problem, perhaps for the reason of not being aware of the nature or extent of the problem. Accordingly, differences may exist between an individual's account and that of a carer. This was illustrated in the differing accounts of Mrs Ladley and her daughter in the first set of clinic appointments I observed, detailed in chapter four.

It may well be a carer rather than an individual with memory problems who provides an account about a particular moment at which an individual stopped being able to perform a particular activity or task. One way of getting at the knowing of an individual or carer about emerging memory problems is to ask 'what happened' to bring the memory problems into the person's awareness, and 'when' did it happen? The making sense by the clinician of what is happening in terms of the person's memory, I suggest, could be regarded as involving connecting with time and engaging different forms of knowledge. The following ideas help to illustrate how we might see time and knowledge being involved: the clinician connects with past practice experience in order to bring insights into the present situation; the clinician draws on her knowledge of symptomatology of dementia; the clinician picks out from the accounts of individual and carer *clues* about the impact of memory problems on both the individual and carer, and these become relevant for aspects such as gauging risks and predicting future support needs. A important aspect that potentially can be surfaced during the clinician's investigation of memory problems is where the person *is* on a trajectory of dementia. Having an informed idea of this can guide decisions about whether (or what) medication is likely to be effective for symptom management, and what

information is most likely to be useful to the individual and carer at the current stage.

Whilst understanding when memory began to become problematic for an individual and whether symptoms are worsening are the sorts of concerns a clinician may have about time, for an individual with dementia the concept of time might take on a very different complexion. For some individuals with dementia questions posed about the 'when' of memory problems emerging are difficult.

Whilst a person may easily recall memories from the more distant past s/he may struggle to sequence, or even to remember, recent events. It may seem as though the person has difficulty tracking or locating their experiences in calendar time, suggestive that event time may break down as a basis for ordering experience.

Nygaard and Johansson (2001:86) suggest that temporality is a "quality" individually lived rather than a quantity that can be measured. Their empirical study of the temporal experiences of five people with dementia highlighted experiences whereby everyday events like 'when to get up' were strongly influenced by "inner personal temporal rhythms". (Nygaard and Johansson, 2001:88). Outer, calendar time - in terms of remembering the past, gauging how long an activity would take, and expressing thoughts about the future - became a source of worry and confusion, and participants expressed "apprehension of time passing in everyday life". (Nygaard and Johansson, 2001:88).

Adam's (2008:8) ideas about "personal frames of [...] time" are helpful as a way of attending to different standpoints on time which are highlighted in encounters between the clinician, person with memory problems and carer. Adam (2008) differentiates between situating research subjects in objective timeframes of calendars and clock time which are stable and fixed (Adam, 2008:8) and placing research subjects:

"in their personal frames of life time and family time, and/or times of illness and stress [...]. These latter frames are relative and mobile. They move with every new moment, situation and context. Their implied past and future expands and contracts as people move along their life course." (Adam, 2008:8)

Another dimension involved in the clinician's enquiry is the corporal. The questions the clinician asks are deeply encoded in physical expressions of the body. Bodily gesture and gaze are employed in a manner that is congruent with the words voiced. In Laura's practice, ways she expressed empathy included selectively disclosing information about herself. For example, with Mr Powell who Laura thought was drinking heavily she told him that she herself needed to lose weight - intimating that she empathised with his fallibilities in relation to alcohol. Even though the smell of alcohol was apparent of anyone near to Mr Powell, Laura neither commented on this nor did she position herself to sit at a distance from him. The assessment of memory through the memory test is a process which is 'exposing': it is seemingly impossible to feign a normal-functioning memory when that is not the case. I imagined that undergoing the test may cause the person to feel vulnerable, anger, or perhaps be in denial about memory problems. Laura's approach was pragmatic (the test needed to be completed) but empathic also in that she allowed individuals time and did not rush them. As a person looking in I did not observe any 'joins' or 'seams' between what I heard Laura say and what I saw her 'do' (i.e. doing in terms of actions involved in practices, and bodily gestures such as eye contact). At one level this might be interpreted as congruence between saying and doing, and at another level it might point to the impossibility of separating out the practitioner's knowledge and know-how from practices themselves.

The physical examination is a diagnostic tool, yet it also has a corporal dimension. The examination involves standard procedures of checking blood pressure and taking the pulse. Taking the pulse involves direct physical contact between the clinician and the individual: the clinician positions her hand on the person's wrist and this action enables detection of signals from the body through *feeling* the pulse beating. A watch is used by the clinician as a measuring device for determining the number of pulsations per minute, and from this it can be ascertained whether the pulse is slow, normal or fast. The pulse rate is a significant factor in terms of future prescribing of medication, should it be that the person is ultimately diagnosed with dementia. For example, prescribing Donepezil if the pulse rate is <60 is not advised, because this medication can cause slowing of the pulse.

There are typically two possible outcomes from the referral appointment. The first (and most favourable to the person) is where the individual's memory problems are deemed relatively mild and are categorised as mild cognitive impairment. The clinician explains that memory will be kept an eye on, and that if further concerns about memory arise the individual should contact the team. The second possibility is that the clinician suspects dementia and refers the person for tests or a scan, and then for a follow-up appointment to discuss the results. This process sequence was the one followed by practitioners in the memory team, and it was aligned with the local dementia pathway. NICE (National Institute for Health and Care Excellence) in association with SCIE (Social Care Institute for Excellence) provides comprehensive guidelines concerning "identification, treatment and care of people with dementia and the support of carers" ([nice.org.uk/guidance/cg42](https://www.nice.org.uk/guidance/cg42)), which I discussed in chapter 2. NICE guidelines are specific about the use of structural imaging in the assessment of people with suspected dementia. The preferred practice modality to help clinicians in reaching an early diagnosis is magnetic resonance imaging (MRI), although CT (computed tomography) scanning is suggested as an appropriate alternative. (NICE guidance CG42: 1.4.3.2).

Proposition 1:

The initial memory appointment is defined as being the first encounter between the memory service clinician, individual and carer. The clinician has read the referral letter and any relevant case notes available, but it is the face-to-face contact that represents the start point for the person and their individual memory difficulties becoming known by the clinician. This appointment is not a 'stand-alone' event, but is linked to a previous event where memory problems were suspected (typically a previous appointment with the GP).

One way of expressing the initial appointment is as knowledge repertoires converging. Essential to the building of an accurate picture of the person - their past, their health and memory status, needs, living situation, and any risks involved - is the cooperative engagement between the knowledge repertoires of the individual, carer, and clinician.

Even though giving of a diagnosis at a first appointment is rare, the initial appointment does 'set the stage' for this future likelihood. The score from the memory test, the individual's and carer's responses to the clinician's questioning, the individual's medical history, provide evidence about memory status. A carefully worded phrase used by Laura to one of her patients at first appointment: "I do think that your short-term memory isn't so good" brims with consequences. It represents a tacit acknowledgement that memory difficulties have slipped beyond a 'normal' range of age-related forgetfulness into a state that is more troubling.

The initial appointment is the basis for defining and initiating sequences of future events, such as referring the person for a scan. In these terms it can be said that knowledge, invoked and engaged, commands time. It also orders the past as sense is made of previous events that may, until now, have been seen as random unrelated events but now appear as a pattern.

Convergence 2: the appointment at which a diagnosis is given

After the initial appointment, and before calling the individual in to discuss conclusions about their memory status and offering a diagnosis, it is usual to conduct brain imaging - a brain scan which the individual undergoes in a hospital outpatients department.

Even though individual and carer know that there is *some* sort of persistent problem this has not yet been named. Nonetheless, the contact with the memory service signifies the strong possibility that if a diagnosis is given it will probably be dementia - a non-reversible condition. This possibility must surely engender some sense of trepidation in the individual and their caregiver.

Dhedhi et al (2014) suggest that from the perspective of health professionals, diagnosing dementia is a process which may be described as - "the slow unfolding of *becoming* a person with dementia" (Dhedhi et al, 2014:3). The sense of process is signalled by the word becoming, and becoming is itself an ever-present phenomena, as Smith (1986:8) highlights:

"Process, the ubiquity of becoming, stretches over the entire physical and organic world. We are by now well aware that nothing happens in an

instant". [...] "The serial order of before and after constitutes the continuity of becoming which in turn leads to a definitive outcome."

Another set of ideas that provide a lens on becoming a person with dementia are from Glaser and Strauss' (1971) status passage. The term "transitional status" (Glaser and Strauss, 1971:47-52) might be a way to conceptualise the course of dementia over time, starting with having a normally functioning memory, then starting with indistinct problems of forgetfulness. Transitional status may go on for a long time (Glaser and Strauss, 1971:48). Early changes in the brain that ultimately result in realised cognitive decline, Ramakers et al (2007) suggested, may begin as many as ten years before dementia becomes perceptible. The transitional status frame of reference positions people with as yet undiagnosed memory problems spending, literally, years in transitional status.

Becoming *a person with dementia* has a start point that is probably impossible to determine with accuracy because the moment at which changes to the brain reach a critical point is unobservable. Somewhere on each individual trajectory there is a worsening of memory that likely signifies some sort of deterioration but which might not mean dementia, yet (as with Mrs Bourne to whom Laura said that 'Alzheimer's Disease could not be ruled out entirely'). The point at which 'becoming' a person with dementia arrives at 'being' could be viewed in various ways: for the individual and their loved ones it might be at the point when they accept the dementia diagnosis as the giving of a name for real and severe memory problems; whereas for the clinician it might be when she sees irrefutable evidence of damage and change in results from a brain imaging scan.

'Being' and 'continuing to be' a person with dementia might be viewed using the time conception "trajectories" (Abbott, 2001:248-249) which offers the quality of "inertia" whereby large amounts of minor variation can be borne "without any appreciable change in overall direction or regime". Trajectories, as Abbott goes on to suggest, might be called "master narratives" equivalent to "master statuses", which are characterised by coercive processes within them. The sense of the course being set without possibility to alter it, and the coercive, entrapping quality brings to mind the occasion when Laura saw Mrs Maddox in clinic. In Mrs

Maddox's words is the sense of comprehending a pathway that she does not want to get onto, leading to a state she does not wish to experience:

"I've seen people a lot worse. I never want to go like that."

Master statuses, as Abbott (2001:249) suggests are all consuming in terms of identity: a master status such as race prevails over "subordinate statuses like occupation", essentially making these subordinate statuses seem not to exist. Whether clinicians actually name 'dementia' as the diagnosis is probably variable. Laura - in the appointments I observed - did not use the word in front of individuals and their carers, and this was probably for good reasons relating to the stigma and identity issues that may accompany a diagnosis of dementia. Thinking about the meaning of a diagnosis for the person's spouse or close family members - whether this impacts on *their* identity(ies) - is an important question. A spouse, partner or family member may have been 'supporting' (minimally or comprehensively) the person over a period of time prior to diagnosis. The fact of a partner or family member being present at a memory appointment almost certainly indicated a relationship involving 'caring' about the person. Yet, going from 'caring' (which might be one amongst many facets of a relationship between two people) to being the 'carer' suggests a subtle shift towards greater dependency of the cared-for person, and implies a singular role which has the dominant character of 'care'. Moving into being a carer for someone with dementia indicates that the person is not fully capable of looking after him/herself - that capability has been 'lost'. So, loss might not only be experienced by the individual with memory problems, but might also be part of the carer's experience: loss (or erosion) linked to how the two people relate to each other, a fundamental change in the nature of the relationship which the 'now' carer has with their mum, dad, partner, wife.

During my observations of the seminar for carers at the CSD Centre comments from carers about the changes they witnessed in their loved one such as "loss of interest", "passivity", "loss of independence" were suggestive of quite fundamental changes in the person being cared for which it may be assumed would have some effect on the dynamic in the relationship. The metaphor of a

'line' was used by the partner of someone with dementia to convey the idea of a theoretical line being the divide between being simply 'you' and being 'a carer':

"There's no 'line': today you're you, and tomorrow you're a carer..."

The mental image invoked is one of a shadowy landscape where, perhaps, familiar and long-held roles of being a husband or wife to someone are now blurred (or perhaps temporarily disappear) as the relationship shifts, gradually accommodating changes in the person with dementia.

Unlike receiving a diagnosis of a condition which is treatable and has a good prognosis, a diagnosis of dementia - essentially a non-reversible condition - is unlikely to bring about a sense of relief for the individual and carer concerned. It is likely that there is a period of time required for coming to terms with a diagnosis, but in the immediate aftermath it is clear that elements of the person's and their partner's life have been rearranged in some fundamental and irrevocable sense by this news.

Thinking about how a person with dementia may be affected gradually over time, this would suggest that carers themselves steadily adapt to caring in a way that corresponds to their loved one. For example, in the Wellbeing College session I observed carers talking about the need to make ordinary activities easier for the individual with dementia. One strategy was described as:

"It's reducing choices, isn't it. I ask my wife to put her 'black shoes on'".

There was obviously a time when this man's wife had been perfectly able to independently choose what shoes she would wear. By the same token, at a time in the future it would be probable that her ability to follow such an instruction from her husband would be diminished, or disappear entirely. Yet, even though carers witness sudden or subtle changes, continuing to care requires that they accommodate change and adapt. For example, Mr Maddox - whose wife was seen by Laura in clinic - reflected on the fact that he was intervening with greater frequency to assist his wife in activities of daily living.

A diagnosis, regardless of whether the word 'dementia' is expressly used, is directed to the individual. Yet, the individual continuing to manage in their current living situation is likely to be contingent to some degree on a family carer. Inherent here is a tension between the clinician's primary duty of care to the

person with memory problems, and consideration towards a carer. Laura referred to this in interview:

"...a patient that I saw in clinic today attended with her husband but was very clear that she wanted to be seen alone. And so I saw her alone and said goodbye to her and then the husband was saying, 'But don't I have any time with you?' And unfortunately no they don't, but I think sometimes there is a tension between carers wanting to have time to express their concerns about people, and from my point of view it's always best if they can do that and I'm always very, very happy to help them in clinic but if the patient really doesn't want to, then that can sometimes cause some tension." (Laura, interview)

This instance highlights the personal agency of individuals with memory problems, and the question of how this should be balanced in relation to the needs or wishes of carers.

The articulating of a diagnosis through the naming of the type of dementia I observed in two of Dr Ozha's clinic appointments with Ms Baker and Mr Seward respectively. To Ms Baker the diagnosis was articulated unambiguously:

"Clinically, I would say you have a mild form of dementia".

In Mr Seward's case Dr Ozha's delivery of the diagnosis of 'Lewy Bodies dementia' provided confirmation to Mr Seward's daughter of the diagnosis she was expecting. Important to note is that Mr Seward's response to the diagnosis was rather nonplussed, yet this was fully explainable by giving attention to the context: diagnosis explained the frightening hallucinations Mr Seward experienced, and diagnosis prompted Dr Ozha to review and alter the medication which should reduce the hallucinatory symptoms and ultimately provide relief to Mr Seward as well as reassuring his daughter and wife.

In both instances described the naming of 'dementia' elicited words about the future from either the person diagnosed or their carer. Ms Baker expressed shock, and a reference to the future - "Won't it go worse?" Her partner Damien seemed unsurprised at the diagnosis, as he had noticed over the past months that during conversation she would forget straight away what had just been said.

Mr Seward's daughter expressed what seemed to be relief at Dr Ozha's proposal to change the medication her father was taking as a way to stop the hallucinations, and that a plan was in place.

Selecting to name 'dementia' at diagnosis (as opposed to a less clear articulation such as 'memory problems') is decided by the clinician, and probably involves taking into account different variables about the individual, their situation, and how well the clinician knows them at the point of the judgement about their memory status.

Ms Evans, a lady seen by Laura and the occupational therapist during a home visit, lived alone and without a family carer involved. Laura voiced to Ms Evans her presumption that she was "very committed to staying here, in the home you know and love?" This presumption was indirectly (at least) confirmed by Ms Evans. Laura's words and the implied acquiescence by Ms Evans seemed to link the past, present and future together. Ms Evans knew her home because she had lived there for a long period of time. Laura had concerns about Ms Evans at home alone *now*, and the risks of this current arrangement. Of the two possible futures - remaining in the familiar, known environment of home, or entering into an unfamiliar and not desired situation of permanent care - Laura understood that Ms Evans' wished-for future was to stay at home. Personal agency is brought to the fore in Ms Evans' case. For some people remaining at home might be the factor that makes life seem worth living: retaining independence, choice and control may take precedence over the risks that have to be accepted in doing so. Accumulated life experience - the repeated activities of daily life, and the general managing of oneself over time - is what humans fall back on in order to get through duress. This is personal and tacit knowledge. In Ms Evans' case her own personal resources to continue to manage at home were unknowable, and neither Laura nor Ms Evans could predict how she would fare over time if she continued to stay in her own home.

Proposition Statement 2:

The diagnosing of dementia is, at one level, a distinguishing of significant memory impairment from 'normal' forgetfulness. Taking this perspective diagnosing

involves the clinician 'pulling into the present' (or into the immediate, the particular) a combination of various forms of knowledge, both codified and tacit. A diagnosis provides an explanation for memory problems that the person has been exhibiting over a period of time.

Actually communicating a diagnosis to the individual and the person who is with them requires a nuanced approach, with the need for a clinician to take account of the life-changing nature of a diagnosis of dementia for those involved. For the individual and their carer, in one instant of receiving a diagnosis there may be both a sudden making of sense (i.e. of gradual alterations in the person's abilities that have been noticed - a sense of things being 'not quite right'), while simultaneously the future may suddenly appear uncertain and undesired. From the individual's and carer's perspective the rapidity of deterioration, how long the person will be able to continue to live at home, and will we 'cope' may be questions and thoughts that arise.

Convergence 3: working with complexity

A way of thinking about Dementia is in terms of the peculiar combinations of complexity it seems to represent. There is inner complexity involving changes to the brain and how these may impact on the mental wellbeing and abilities of an individual, and outer complexity such as that of being catapulted into a difficult to navigate service system, or facing situations of everyday life that used to pose no likelihood of harm but become risky and difficult to negotiate. The proclamation in the title of a report by the All Party Parliamentary Group on Dementia (2016) is: 'Dementia rarely travels alone'; a statement which draws attention to the reality that people live not just with dementia but also other mental and physical health problems.

For memory services to be equipped to help people with dementia, clinicians need to be well versed with working with situations that are innately complex, and to which there may be no obvious resolutions.

Laura said that referrals she dealt with were "reasonably straightforward, not too complex", yet risks, and the sometimes precarious nature of health or of a living situation (for example, care arrangements could suddenly break down, or health could deteriorate rapidly) did indicate complexity. Mr Powell's drinking Laura

thought might be affecting his driving, yet she had no way of knowing for sure. His behaviours in this respect seemed unregulated: his ability to self-regulate diminished by dementia, and his family seemingly unfazed by this risky combination. With Ms Evans, her symptomatology of dementia, unsteadiness, seizures, headaches and behaviour change, were related to Meningioma, and she was living alone which carried obvious risks that if she fell there was no ready or reliable help available.

How is time implicated in this complexity? I read a comment from Mr Powell's son as being rather telling: "my dad has his moments but nine times out of ten everything seems to be ok". It reveals a relaxed attitude to how things are now and - because as *yet* nothing untoward has happened - there is no sense of urgency to put in place particular provision or safeguards. Laura seemed unconvinced that the family had followed the legal requirement of informing the DVLA about Mr Powell's diagnosis of dementia.

The cases of Mr Powell and Ms Evans highlight the combination of personal agency with risks, and how these weigh against each other. Time is implicated in the sense of how long a situation continues until either the risks to the individual become so significant that incisive action must be taken, or there is a crisis or incident that forces something to change.

In the face of situational complexities, and the reality of the infrequency and short duration of face-to-face contact between individuals and clinicians, the 'timeliness' of knowledge surfaces as an important concern. What timeliness of knowledge might mean given that appointments are, by definition, events *fixed* in time, is an interesting point. From individuals' and carers' perspectives timing of an appointment might feel out of kilter with particular problems or concerns arising that may need addressing straight away. One way to talk about 'timely knowledge' is that it is about *dealing with priorities*. For example - highlighting precarious situations and associated risks, offering options for managing risks, and having a sense of how to 'pitch' these sorts of conversations with the particular person with dementia and carer(s) present.

Another frame for approaching timeliness of knowledge might be through an appreciation that the manner in which life is to continue for the person (and maybe carers) is of great consequence for that individual. So, timely knowledge

might mean giving thought to the general 'shape' of the individual's life and situation currently: the person's general health, what the person actually wants, and how they (and possibly carers) are/have been managing generally. So, in practice this was characterised by often very informal 'settlements' between clinician, individual and carer about the way of proceeding. For example, one of Laura's patients, Mr Wooler, had lost the argument with the DVLA over whether he could continue to drive but he accepted this. His memory problems were well managed with Donepezil. Problems he had with his legs could not be dealt with surgically but were not so severe as to be unmanageable. His mood remained positive and upbeat. So, although there were some rough edges to life that could not be entirely smoothed away, things seemed settled and the 'plan' from Mr Wooler's perspective was "I'll just keep doing what you say and I can't go wrong then."

Proposition Statement 3:

Knowledge, time and practice converge in individual situations of complexity. The timing of an appointment in which the clinician's knowledge is brought to bear may not match the when that risks become highlighted, or may be mismatched with the when of individual's concerns or needs arising. From a clinician's perspective the time frames for addressing the complexities involved in individual's situations of living with dementia are the appointments themselves. The clinician therefore must optimise the help she can provide to the individual within the time frame of the appointment. This involves thinking around what is happening *now* for the person (concerns, difficulties and risks), and what would help - e.g. - referral to the occupational therapist. It also involves the clinician trying to pre-empt possible catastrophes linked to high risk situations. The clinician's foresight may be translated into, or activated as giving advice to the individual and their caregiver about practical adjustments for staying safe in the home, or making provisions for the future such as updating their Will.

Social Care case study: convergences of 'knowledge-time-practice' and associated proposition statements

Here I move the discussion of ideas about convergences between knowledge, time and practice to the social care setting. The day-care and respite service provided at Oak Hall are for people who have already been diagnosed with dementia. As such these services represent support for individuals and their carers negotiating what it is to 'live with dementia'; their reality that began before a formal diagnosis, and is ongoing. Here I consider different sorts of knowledge and practice in terms of their usefulness, and how they are framed by, or frame, time.

Convergence 1: Time matters for getting to 'know' a person

In a day-care service setting 'knowing the person' may be realised through time spent together. The frequency and regularity of individuals attending day-care, alongside the duration of time spent on a respite care stay, is the basis for spending time together and the establishing of relationships. In some cases individuals come to Oak Hall because care arrangements at home are no longer viable, perhaps because the individual's needs have changed and the carer is no longer able to cope, or maybe the individual lives alone with domiciliary care support and this is no longer sufficient so an assessment of care needs is required. Such situations necessarily involve an extended stay at Oak Hall, and may ultimately result in the individual entering permanent care.

There is an important distinction between empathy and rapport with an individual (which I saw being skilfully established in memory clinic appointments), and 'knowing' an individual. At Oak Hall 'knowing' the person is core to providing care, and knowing unfolds through time spent together. Everyday care practices such as assisting a person with bathing, or dressing, are vehicles for getting to know a person with dementia because during such practices aspects of the person's self may be revealed. These routines of care have a dimension that is intimate and occur in private spaces such as bedrooms and bathrooms. I had deliberately chosen to limit my observations to communal spaces (e.g. lounges) and therefore the only data that surfaced about personal care activities was that which came up in interviews conducted with care staff. Sarah, a member of care staff, provided several examples during interview, one which is

discussed in the Oak Hall case study section on how staff got to know clients. A different example from Sarah highlighted how staff undertook personal care from a perspective of intentionally recognising personal agency:

"looking at the person and saying now what would you like, how would you like it, when would you like it, down to the last little thing. For example I can't bear socks with holes in – how would I know that of somebody with dementia?"

Here, Sarah's words highlight the attention to detail required for gleaning the wishes and preferences of people who may not be able to express their views in ways that others can make sense of. Once a member of staff has made sense of an individual's particular preferences in the context of care this 'knowing' can be relayed to other members of staff who, knowing this about the person, can incorporate it into care practice with the individual.

It seemed, from Sarah's accounts, that staff took their cues from the individual client in terms of the 'pacing' of care. Time, it appears, may have different dimensions of worth: staff allowing enough time (duration) for one-to-one care activities; staff making optimum use of time for getting to know individuals; and staff allowing individuals to direct the 'pacing' of the care activity. Stuart ending up on the floor whilst staff were trying to hoist him might be an illustration of a process taking over and the individual having no control over the pace, which his sister's words seemed to confirm: "if he feels he is being forced he will resist."

Another temporal aspect of care might be described as 'anticipatory': the idea that instances arise where staff get an impression that an individual is *about to* become distressed, angry, or move into some other emotional state. An instance described in the section on the lived experiences of people with dementia, chapter five, illustrated that when Andrew declined Jan's offer of drink and biscuits, Jan picked up on this being an indication of Andrew's restlessness (she mentioned it to Kate), and within moments Andrew had removed the blanket from his lap in an action to get up. The worth of being able to anticipate what will happen next is that the member of staff is prepared for what is about to happen, and can decide whether a particular intervention is necessary (or not) and, crucially, when to intervene. Intervening from the position of having this sort of foresight may be helpful in terms of preventing further escalation of situations.

More generally, any interaction between staff and individuals with dementia provides an opportunity to get to know the person. The frequency of occurrence of certain scenarios, such as Michael misappropriating the cutlery spoon, perhaps make these instances less noticed by staff. However, such scenarios offer clues as to the individual's world, the person's 'take' on the world at that moment. If noticed, clues may nudge staff into attempting to understand and make sense of how the person is reacting or behaving.

Historical information about a person such as their profession, interests, or where they grew up might be helpful for revealing a sense of who the person is. Staff at Oak Hall would draw on what they knew about the lives of individuals as a way of engaging with people, even in instances where it was no longer possible for the person to verbally respond.

Reminiscing was one of the ways used by care staff to encourage clients to talk about their past. In one activity involving passing around items from the past (e.g. an old penny; carbolic soap; a ration book) the objects were themselves 'cues' to opening up memories about which an individual would talk. These sorts of narratives staff could use as the basis for extending the discussion further and encouraging clients to elaborate on their experiences of the past. The articulations of individual clients about aspects of their life when they were younger were often retold by staff in the group setting (something which I observed). This signalled that things that were particular to a person such as a hobby a person had enjoyed or a job, were known about by particular members of staff. This validating of features of an individual's earlier life might be interpreted as affirming an individual's identity in the presence of the person and other clients and staff who are present. Affirmation of identity is encapsulated in Fuchs' idea of continuity of self (as subject) carried in the 'remembering' body:

"...the lived body also manifests a specific form of memory whose continuity comprises not only explicit memory, but all the habits, capacities and skills which a person has acquired". (Fuchs 2016: 7)

This perspective seems to open up possibilities for positively framing identity in respect of people who have been diagnosed with dementia. One conclusion that

might be drawn from the reality that staff talked about and highlighted the past experiences and achievements of people with dementia, is that the totality of an individual's experiences is the material to look to in order to know the person.

At Oak Hall a notable feature was that so many of the staff had worked in the service in its previous incarnation at Minton Lodge. Most staff had been at Oak Hall for at least five years, and the combination of a low staff turnover combined with long service may justify describing staff as a 'constant'. This seemed important in a service where the day-care and respite service were used by individuals with dementia over time, and in a planned, prescheduled manner. Whatever the permutation of service use by an individual the same staff were doing the caring: they were staff who knew, or were getting to know, individuals using the service. The knowledge and knowing of individuals by staff augured well in cases where individuals entered permanent care. Knowledge about individual preferences and 'what works' with the person could be passed onto the care provider.

Proposition Statement 1:

Aspects of the worth of care practice are revealed through convergences of knowledge and time. During time spent together aspects of the person's self are revealed which are the grounds for a member of care staff to get to know the person with dementia. A care practice such as helping someone to dress can, if the staff member is attuned and attentive, reveal knowledge about how an individual prefers to be assisted, which can be shared more widely with colleagues for integration into future practice.

A staff member taking cues from the individual in terms of the 'pacing' of care entails attentiveness to the individual and the noticing and following of clues. Personal, tacit knowledge is implied here.

In care settings the art of 'anticipating' (through making sense of clues) is valuable: it allows a member of staff to be prepared to intervene to change the course of an event that it is anticipated will occur.

Continuity over time of a style or particular philosophy of care may be carried through the knowledge of long-serving staff in terms of: their witnessing of the

service evolving over time, their experience of working with people with dementia, and their knowledge of theories about dementia. Because carers and family members see the same staff over time this fosters the building of relational trust and trust in the care institution.

Convergence 2: responding to a crisis in a practice setting requires good timing and knowing what to do

At Oak Hall two situations that I came to know of during the period when I was doing fieldwork required urgent responses. One of these I witnessed - the incident where Stuart was being hoisted - and the other, in which Michael suddenly became very unwell and stopped breathing, was recounted to me by one of the Seniors who was present during the incident. In both incidents the wellbeing of the person with dementia was jeopardised in some way. In both cases there were visual and audible 'clues' that signalled to staff that the individual was in distress, and that urgent intervention was needed. In the incident involving Stuart being hoisted he became rigid and started to tremble precipitating his sliding down off the chair and onto the floor. Staff acted by pressing the emergency button immediately summoning additional staff, and Stuart was then hoisted from his then supine position on the floor. Stuart's parents and his sister were present and witnessed this unfold. Although they did not appear unduly alarmed, it was likely that staff would have wanted to demonstrate their competence by bringing the incident to a swift conclusion and with no detrimental effect. Staff recognised that this was an emergency and followed the procedure to resolve it.

In the situation of Michael becoming unwell and not breathing, a particular set of events preceded the incident. Michael had undergone hospital treatment for a blocked vein behind his eye, which was initially unsuccessful and had to be repeated. Additional complications of a build-up of pressure in the eye were causing Michael to have headaches.

It was only realised that there was something seriously wrong with Michael when a noise from where he was sitting alerted Kate to look round and then see that Michael was shaking and his skin was white. Kate's understanding of what these physical signs meant prompted her immediate call for an ambulance. Kate's

knowledge about the events that had occurred in the weeks prior to this incident helped her make sense of Michael's rapid deterioration.

Proposition Statement 2:

In care settings situations can suddenly or rapidly arise which are unpredicted and have not been, or cannot be, anticipated by staff. Some of these events take a course that is potentially harmful or detrimental to an individual.

An event that is unanticipated is one in which foresight is not available. The event is already in progress so a response is required to halt or change the course of the event in order to stop or limit harm to a person. The essential characteristics of the response are: rapid appraisal (knowledge of the situation and events that may have preceded it); knowing what to do (which may well be a mix of knowing the procedures alongside experiential tacit knowledge); and swift action.

It is the speed of knowledge-infused action which counts in these types of events, so switching rapidly between various modes of knowledge performances is a way of expressing how knowledge converges with time.

Convergence 3: a threat to close a service may prompt people to try to get more time by delaying the action, or trying to prevent it happening

When Polshire council mooted the possibility of the day-care and respite service at Oak Hall closing it should be remembered that something very similar had happened in 2012 when the council decided to close the Minton Lodge facility and reinvest the service at Oak Hall. The sense of 'déjà vu' surrounding the news of possible closure might not have been a cause for concern to users of the service and their families had the proposal been to simply relocate the service elsewhere. However, unlike the closure of Minton Lodge the proposed plan did not involve continuation of the service and its philosophy of care. Rather, the idea was that the council would cease providing respite and day-care at Oak Hall and would purchase respite care beds across a number of nursing homes which would be available for use by individuals. Alongside this there would be the development of other forms of local respite care to include arrangements whereby a carer approved by the Council would provide "support to an individual within a family setting", and Direct Payments where the individual would receive a payment with

which to buy in their own care and support, usually by employing a personal assistant. (Consultation Information Pack, 2014).

Carers, people with dementia, Oak Hall staff, and the public first found out about the council's intentions through the publication of the proposals in the local newspaper. Following their publication the proposals were swiftly rebuffed in written responses (also published), alongside which were published views of several councillors who were defending the proposed scheme. With news about the proposals now 'outed' it became clear that consultation with users of the service and carers had not taken place nor was there any evidence to suggest that consultation had even been considered.

Autumn 2014 was mooted as the likely time for councillors to make their decisions, and consultation activities (ostensibly hastily planned and assembled) were now mapped around the autumn date and formally announced. There was also a political backdrop to the council's proposals: a general election was expected to take place in May 2015, and shrinking financial settlements to local authorities were continuing to be a pressure point for council spending on public social care services.

It is highly probably that 'timing' for making what would be unpopular decisions was all important. The scrutiny committee and cabinet meetings that took place in the autumn of 2014 came and went without news of what would happen to the service at Oak Hall. There were definite rumbles of discontent and disquiet amongst carers, service users and staff. A question mark hung over the survival of the service at Oak Hall, and neither service users, carers or staff really knew how they would be affected if the service was closed. Some ideas about alternative provision had been put forward for consultation, but these 'possibilities' failed to allay the fears of carers and service users. Some carers lobbied their local Member of Parliament, and there was a letter written by a family member of a client at Oak Hall published in full in one of the local newspapers. In the autumn of 2014 service users and carers were consulted on the proposals, but not staff. Continuity of care - as it was perceived by carers and clients - meant day-care and respite components would continue in the same or in an acceptably similar form. For current clients and carers who were benefiting from the service at Oak Hall

delays in the decision-making bought more time for lobbying and were to be welcomed.

There are echoes here of the notion of an encroaching reality that an individual wishes to push away into the future, an idea which surfaced in chapter 4 in the describing of responses by individuals to the clinician informing them that they had significant memory problems. In the case of being faced with the likely closure of the service at Oak Hall there was always the possibility that a critical factor would change - perhaps there would be a rethink, or maybe the leader of the council would be ousted - and the service would be saved.

In this situation we might view delay and timing as both being involved in how events unfolded. Delay was a source of hope for carers and clients as it kept the threat of closure at bay, pushing it away into the future so that it represented only a distant or weak threat. The timing for decision-making, however, was dictated by the council, and carers and clients were not party to the *when*.

The meeting in December 2014 where the proposals were discussed drew a strong lobby from carers and groups representing service users from Oak Hall and Long Edge. The outcome from the meeting was that Oak Hall and Long Edge would for the next twelve months remain open, representing, metaphorically, a temporary stopping or pausing of the clock. One way of seeing the interlude created is as "promised time" (Glaser and Strauss, 1971:37) which enabled care continuation as normal for as long as the promise held. Another way of thinking about this is in terms of a sequence of events in which 'closure' was shifted to a different position in the sequence: closure would still happen, but was not imminent.

The re-election of the Conservative party in Spring 2015 put the council back in a strong position. There was now no particular need to direct efforts towards attracting votes, and unpopular decisions that had been put on hold could now be reactivated. Continuation of the Conservative led council was the circumstance in which a meeting of the cabinet took place in June 2015. Here - in spite of the protestations of carers, town councillors, Labour councillors and members of the public - councillors voted to close the services at Oak Hall and at Long Edge, setting the date of closure for January 2016.

Proposition Statement 3:

For people to accept changes in services such as service closure, legitimisation in the form of a sound rationale needs to be provided in advance of consultation and decision-making. Both the sequence and sequencing of steps (Chronos) that lead to final actions, and timing (Kairos) are significant factors for seeking consensus and agreement for change. The threat to continuity of care that is implicit in service closure is highly significant for service users and their carers and families. For staff, the implications relate to uncertainty about continuation of employment. In conditions where services are not threatened with closure, time ticks away in the background and is not viewed as consequential, except in an ordinary sense of time slipping away. However, in times when undesired change looms time acquires a particular significance related to the proposed changes. Responses from people most affected may include delaying tactics, or interventions to try to stop change. These sorts of responses signify that people are engaging with time and its meaning to them in a given situation. "Promised time" bestowed by those making decisions about service closure on recipients of care may feel like a reprieve, or at least a delay to closure. As the duration of "promised time" in this context is clearly defined, so the inevitability of change is not removed altogether but is pushed away further into the future.

Convergence of 'knowledge-time-practice' across the two case studies

Taking stock

An individual's forgetfulness starts to become noticeable and problematic, yet memory problems themselves do not arise in an instant. In the background of a person's life memory problems have been gradually edging to the surface and taking form, a process that may take years. When the 'problem' becomes noticeable it might initially be defined by the individual - and those who know the person - as a problem of forgetting, but the nature of the problem is as yet unknown.

Another idea about how time meets forgetfulness is to think of time as experienced by an individual. This is time conceptualised as "lived time" - an "implicit mode of temporality" (Fuchs, 2006:195). Outer time *is* passing, and marks the progression of memory problems, but for the individual, absorption in

personal lived time feels most meaningful and eclipses any sense of the ticking of clock time. This is not to say that the individual with memory problems lacks awareness that something is not quite right, but the person may not fully recognise the impact memory problems are having on her everyday life. To lead into the account of the unification of the two case studies I present a gathering together of insights that are distinctive to one or other case study.

Insights from the NHS case study

There are several different modes of emphasis that may be useful for comprehending knowledge in the NHS service:

- Knowledge can be viewed as ordered and configured through practice, an illustration of which is the accumulation of evidence about memory status through practices of the memory test, the physical health examination, and brain scanning.
- Whilst it may be claimed that knowledge is involved in healthcare practice there are no means to 'prove' this by isolating knowledge from practice. And, in instances of practice, attempts to differentiate between personal tacit knowledge and explicit knowledge are similarly fruitless as there are no methods to achieve this.
- Characterising knowledge as enmeshed in practice expresses the quality of indivisibility. Thinking of observations of memory appointments this idea has some traction: in an appointment some parts of practice are observable, such as the clinician holding the person's wrist as part of checking the pulse rate. And knowledge is involved - what is normal or abnormal for pulse rate, coupled with perceptual knowing - e.g. the condition of the skin (cold/hot clammy / blotched / pale/trembling), and from this the judgements and impressions formed by the clinician.
- In the encounters between healthcare practitioners, individuals with dementia and their carers it becomes apparent that there are multiple perspectives on knowledge of dementia. Knowledge repertoires of clinician, individual and carer differ, and are grown and formed through experiences unique to each person. Laura, for example, spoke of when she was first training as an Advanced Practitioner and was learning from Consultants

through observing how they assessed patients with dementia, and from this she was building her own ways of practicing. In contrast, an individual with dementia experiences first-hand what it feels like to live day-to-day with dementia. The knowledge of the carer is knowing the person before and now, and knowing what is changed.

It is the process of diagnosis through the memory service that engenders 'becoming' a person with dementia. Becoming is ubiquitous in the fundamental sense that everything in the world is subject to change and flux from one state to another. In "becoming" a person with dementia time is implicated: the discussion in an initial memory appointment involves asking questions about the past - 'when' and 'for how long'. The memory test ascertains the status of a person's memory now, and if this indicates there is a problem then the next steps are set out - usually a referral for a scan. "Transitional status" (Glaser and Strauss, 1971) captures the idea that there is a non-delineated period of time during which brain changes occur but there are no obvious or debilitating problems with memory. Abbott's (2001) time conceptualisation of "trajectories" expresses the sense of being carried along on an inescapable course: changes to the brain that may ultimately manifest as dementia have been set in motion and cannot be undone. Trajectories have a quality "of enduring large amounts of minor variation without any appreciable change in overall direction or regime". (Abbott, 2001:248). Mrs Maddox's words to Laura "I never want to go like that" (Fieldnote 24/6/14) are wistful, yet also seem futile in the face of the direction of a dementia trajectory. "Becoming" is a way, also, to conceptualise how a person closely involved with an individual with memory problems may silently step over a line into being a carer.

The memory service sees people whose situations are complex, and in some cases the type of risks involved indicate the precariousness of a situation: for example, the unknown quantity of Mr Powell's drink/drive combination. The prescheduled appointments and time frames that are fundamental to how the memory service operates may limit whether a pressing need or risky situation can be responded to promptly. However, what may be possible is for a clinician to anticipate or in some way pre-empt a growing risk or problem. In Mr Powell's case Laura did

what she could by pressing on the family the fact that there was a legal responsibility to contact the DVLA regarding the dementia diagnosis. Knowledge of a current situation might also be helpful in predicting *when* something will need to happen. By way of illustration, establishing a Lasting Power of Attorney (LPOA) is a future-proofing measure which the clinician will generally advise as a sensible course of action. The clinician knows there is a timing aspect to this of gaining signed agreement from an individual whilst s/he still has capacity, and can advise the individual and carer accordingly.

Insights from the Social Care case study

Different from the orientation of the memory service where there is a very clearly bounded time sense of time, is the open ended feel of time at Oak Hall.

Nonetheless, there are some certainties: the fixed shift work pattern of staff, some elements of pre-scheduling such as booking people in for a respite stay, the set time set for lunch, and times for administering of medication are all indicative of working in time frames. However, beyond this relatively small set of examples time overall has a rather relaxed feel. Notably, it was common for clients staying in respite to appear for breakfast mid-morning, having only just got up; or a staff member leaving a person to sleep in because they had had a bad night. One insight regarding flexibility that allowed individuals (in these instances) to sleep in is that it suggests a respect towards "personal frames" of time (Adam, 2008:8); and the allowing and supporting of individuals to continue in their own natural rhythms of time. This flexibility also supports continuity of a person's routines and preferences across home and care setting. Another insight is time oriented to the person's own sense of time - "implicit time" (Fuchs, 2006). This can be further elaborated on by thinking of the inner temporal rhythms of an individual that alert a person that it is time to get up (discussed in Nygard and Johansson, 2001:89).

From a pragmatic perspective an insight about conditions that make the service's relaxed approach to time possible is generous staffing levels: getting up later presents no particular problem in terms of any knock-on effect like causing other things to be delayed, because there is a member of staff available to assist the

individual with dressing and getting breakfast. Generous staffing is a condition that supports time spent together during which staff get to know individuals and relationships are established.

Through practice - in its typical scenarios of group activities (quizzes, games, crafts, reminiscence, singing along to music, entertainment that is brought in), or one-to-one interactions with individuals (such as personal care, giving medication, and assisting with mobility/movement around the environment) - different sorts of knowing a person are opened up. For example, personal care opens up knowing the person at a most personal, embodied level; administering of medication may provide insights about how an individual feels about taking medication, or whether the person understands why a particular medication has been prescribed.

Activities where remembering, recall, or knowing how to do something are involved open up a different sort of knowing: of experiences people had in the past; of individual skills and talents that an activity reconnects a person with. Remembrance itself opens up possibilities for a person to re-experience a feature of how they were in the past (e.g. remembering times at school). The reminiscing may be seen as representing an idea that past and present are (and continue to be) aspects of this person's self. So, whether or not it can be declared that a person remembers the past, the person *has* a past, made up of a flow of experiences which the person continues to have. Fuchs' (2006) notion of "subjective self" represents a way of expressing this complex idea of how self-identity is constituted through the totality of life experiences, each experience unfolding into the next, and each having a placement in time that connects it to the time placement of another experience.

These points about ways in which practice might be viewed as opening up knowledge and knowing about people with dementia, and about how dementia may affect people, start to form a notional argument about a convergence of practice, knowledge and time.

Personal knowing, of one's own experiences - regardless of whether these are or can be declared - is one of the ways that knowledge carries time.

The past experiences of individuals with dementia come to the surface in situations of practice through activities involved in care: this is a way that knowledge carries time.

Another temporal dimension of care knowledge is being able to 'anticipate' a next event, through interpreting of what is perceived visually or audibly - picking up on the signs that something is about to change. In care work this is a valuable attribute that enables a state of preparedness to be assumed, and mental garnering of ideas about what to do (including not doing anything) and when. However, also important in this is the requisite authority to act or intervene; the question of whether intervention is in one's own sphere of influence.

Thinking of contexts other than care practice, what would anticipatory knowledge have meant regarding the threat of closure of the day-care and respite service at Oak Hall? An important defining characteristic of this scenario is that it bore such similarity to the previous situation of the threatened (and then realised) closure of the service at Minton Lodge. The sense of familiarity induced in a current situation because of its similarity to a previous one is nicely captured in the term *déjà vécu* which refers to the (subjective) feeling of having already experienced or lived through something. Yet, in this instance two situations that appeared similar took different trajectories.

The letter, written by a family member of a person using the Oak Hall service, anticipated the closure at the stage it was being threatened. So too, the representations that carers and representatives of people with dementia made at council meetings were premised on anticipating the closure that was at that stage a possibility. The council seemed unprepared in the sense of not having anticipated the strength of the anger and desire for the service to remain open expressed by carers. There were complexities to the evolving situation which included financial factors and a forthcoming election.

Although the question of *what* provision would replace the current service was pressing, the time question of *when* was the immediate concern, and the different

engagement with 'when' is the insight that is gained from these points about service closure. The priority of the council was *how soon* could the service be closed - a matter that was contingent on demonstration that consultation with stakeholders had been conducted; based on results from the consultation both sides entering into some form of negotiation and compromise; and a final decision being reached.

How carers and representatives of people with dementia engaged with time might be summed up as a wish to delay an event in time, even if there was also a realisation that closure was probably inevitable eventually. Carers' anticipation of closure was valuable, probably, only in two senses: that an aspect of carers preparing for the finality of closure was that they interrogated the council about plans for continuity of respite care services; and that it was the case that some carers did explore other possibilities for respite for the person they cared for.

The 'reprieve' to closure that was initially given provides an insight about a further orientation of time. A representation of reprieve is as the delaying of an event, and this might be viewed as aligning with Glaser and Strauss' (1971) concept of "promised time". The council essentially deferred what it wanted (and intended) to do which was to close the service, and the effect of this was continuation, temporarily, of the service. Although this delaying of a decision about closure placed the council in a favourable light, and might have appeared benevolent, from a position of hindsight the view expressed by Labour councillors and some carers was that the Conservative-led council was simply delaying the decision until it had been re-elected the following Summer: a strategy for maintaining the support of the electorate.

Unifying aspects across the two case studies

In dementia services terms there is an ordering of knowledge processes starting with identifying the nature of the problem through memory assessment, followed by diagnosis and any treatment. Beyond this are the various services and facilities that might be available for the longer-term care and support of individuals with dementia.

Thinking about what contingencies might be highlighted between the memory services and Oak Hall, a dementia diagnosis confirmed through a clinician (usually at the memory service) is essential criteria for then accessing services at Oak Hall. So, whilst the memory service and Oak Hall service are distinct and separate from each other, they are also linked through the ordering of 'memory assessment-diagnosis-treatment,' and subsequent 'assessment of care-needs and care provision'.

Three concepts that are used to characterise dementia in the case studies are "becoming a person with dementia", "status passage" and "trajectories".

'Becoming' - the idea of changing 'from' - 'to' is one way to represent aspects of the individual's contact with the memory service: knowledge is brought to bear during the clinical encounter where dementia is revealed, validated and made sense of through assessment, diagnosis and prognosis. 'Becoming' from the service focus of recognising and acknowledging the nature of the problem is primarily a concern of healthcare professionals rather than social care professionals.

From the individual's perspective "becoming" a person with dementia might be regarded as lived experience of forgetfulness, a knowing that something has changed and that things are not as they were.

The disease-of-the-brain "formulation" of dementia, referred to by Cheston and Bender (1999) and described in chapter two, refers to physical changes in the brain that indicate cognitive change. The effects of dementia can actually be seen in a brain scan. Brain changes represent another dimension of the idea of "becoming". Importantly, the result from a brain scan is not a definitive indicator of a person becoming a person with dementia. The Nun Study (Snowdon, 2003) which I referred to in my introduction reported exceptions where post mortems on physical brains showed advanced stages of dementia but right up until the person died cognitive test results showed no indications of mental deterioration. By contrast, in the social care setting the notion of "becoming a person with dementia" might be a peripheral concern to the priorities of knowing and getting a sense of who the person is, facilitated through 'time together'. Whilst it is an unalterable reality that the person has a diagnosis of dementia, the focus in the

social care setting is 'knowing' the person, and seeing *the person* rather than sets of symptoms (e.g. behaviours exhibited) associated with dementia.

The concepts of "status passage" and the related concept of "transitional status" (Glaser and Strauss, 1971); and the concept of "trajectories" (Abbott, 2001) are each helpful for characterising temporal aspects of the whole journey of dementia in terms of moving through different stages and various types of contact with services that a person may have.

Transitional status provides a way for considering and conceptualising states that might seem to have an 'in-between' or 'not yet' quality such as the period between memory problems starting to impinge on daily life, and the diagnosing of those problems as dementia; or the transitioning from living at home and accessing a day-care service to moving into permanent care. So, for the two services I suggest that transitional status is useful for conceptualising and highlighting these various transitions.

I have considered the idea of dementia as a whole status passage that is non-reversible (Glaser and Strauss, 1971:14-32). "Trajectories" (Abbott, 2001) similarly, are characterised by a sense of a direction being set - the idea of a singular course even though large amounts of minor variation may exist. The priorities at the NHS memory service are identifying people who have dementia and symptom management in people who are diagnosed. This singularity of focus on dementia as the main concern lends itself to Abbott's idea of trajectories as overarching processes to which other statuses are subordinated. We can say that dementia as a 'condition' is the determining factor for a person to be seen by the memory service.

In the social care setting attention is given to the individual's wider statuses. Present statuses - such as grandparent, pet owner, husband - along with past statuses that might relate to former job roles, talents, and interests, are considered relevant and important. Features of a person's life currently, or from the past, can be explored through conversations and activities and can be helpful as a basis for getting to know the individual.

The complexity associated with individuals' situations is clearly seen in the memory service, where Laura and other clinicians try to steer through or look for

resolutions to risks and precarious living situations, and emergent problems. In the early stages of memory problems when individuals are able to articulate how memory problems are affecting them the individual's knowledge can be harnessed alongside the knowledge repertoires of carer and clinician.

In the social care service, arguably, it is the set of unknowns that are presented (aspects of individual history and past experiences, reasons for behaviours, and feelings, any of which the person may now be unable to articulate) which requires complex detective work of noticing and following clues, and trying to make sense of these.

Knowledge in the memory service is ordered and configured through practice primarily, in conditions of time frames: appointments of short duration, focused around assessment, diagnosis, treatment and review. Yet, the complexity of individual circumstances and life situations outside of appointment times requires the anticipating of risks, of how a situation may become unsustainable or unsafe, and advising individuals and their families about these potential problems.

Anticipatory knowledge in the social care setting involves noticing visually or audibly signs or clues that something is about to change, and this enables a state of preparedness to be assumed. Knowledge is also oriented to making sense of behaviours - particularly important in the social care setting where individuals may not be able to articulate why it is that they are unhappy, uncomfortable or distressed. For example, a person may be seen to be searching for their spouse. The individual has clearly forgotten that their loved one dropped them off in the morning and will be returning 'later' to take them home; or a person may repeatedly ask members of staff 'when' will they be going back home. Seeing these cameos (as another member of staff, a carer, or a researcher) may bring to the surface certain emotions: sadness or anger that the person seems unable to manage. However, a way of making meaning of such scenarios is by viewing them as examples of how that individual is experiencing time: possibly s/he is disoriented in time, or is unable to reconcile his or her personal sense of time with clock time.

Unifying proposition across the two case studies

Dementia services are sites of knowledge where the knowledge of health and care practitioners, which is interwoven with practice (van Manen, 1995:11), meets the knowledge repertoires of individuals with memory problems and carers, which are enmeshed in experience. All knowledge can be considered as a mix of tacit and explicit, the tacit dimension being inarticulable. This 'inarticulable' quality renders it impossible to give an account of tacit knowledge. If, in health and care settings, there is a requirement to explain or justify a practice, only a partial account is possible.

Knowledge and practice expertise of clinicians and care staff in the respective services is both oriented to and characterised in the work of practice, which itself is directed towards people with dementia. Today's knowledge and practice is an accumulation of a practitioner's knowledge and practice performances in the past. A claim to 'know' dementia in the experiential sense of knowledge is, by definition, a claim that only a person who is on a trajectory of dementia can make. Carers' knowledge is characterised by knowing the person, often in intimate, personal ways. The relationship of a carer to an individual with dementia has a past times dimension characterised by continuity of knowing: both before memory problems began to develop, and into the present.

In the two service settings the quality of tacit knowledge as being 'inarticulable' is revealed and becomes distinctive not *only* through instances where there is a requirement to justify a practice, but also in instances when practitioners are trying to make sense of the lived experience of an individual with dementia: how the person's everyday life is being affected by dementia. At the stages of referral to the memory service and being diagnosed, although the individual's memory is impaired, she or he is usually able to verbally articulate some aspects of difficulties experienced. Yet, at another, later encounter between the clinician and the individual (perhaps at a home visit), or when a person's needs have changed and she or he is regularly accessing day-care at Oak Hall, dementia may now impinge on a person's ability to articulate difficulties or wishes. What can compound the problem of articulation further is loss of insight that memory *is* a problem.

In the social care site this problem of addressing the needs of individuals whose abilities to verbally articulate are diminished might be viewed as partly resolved through 'knowing' the person, which is made possible through time spent together. Getting to know the person involves a practitioner's tacit knowledge in the noticing of clues through visual and auditory perceiving and sensemaking. Time is implicated in the two service settings, and a way this might be expressed is as various convergences between time and the different knowledge repertoires of practitioners (performed in/through practice), individuals with dementia, and carers.

In this chapter I have discussed a perspective that orientates tacit knowledge to practice and time. Through this I have started to assemble a set of ideas and materials about knowledge, time and practice converging. I end this chapter by putting forward a set of possible categories that distil these knowledge-time-practice ideas. These are:

- Personal knowing of one's own experiences - regardless of whether this is or can be declared - is one of the ways that knowledge carries time.
- Knowledge of a person's past and present, and how that person's future may be, is one of the ways that knowledge may carry time.
- In practice settings during various activities that are part of care, the past experiences of individuals with dementia become known about by care practitioners. This is a way that knowledge carries time.
- The initial memory appointment is the basis for defining and initiating sequences of future events, such as referring the person for a scan. In these terms it can be said that knowledge, invoked and engaged, commands time.
- In an initial memory appointment knowledge orders the past as sense is made of previous events that may, until now, have been seen as random unrelated events but now appear as a pattern.
- Practices of the memory test, physical health examination and brain imaging accumulate evidence about memory status. Knowledge is ordered and configured through practice.
- Knowledge - in the anticipation of an event or sequence of events - predicts and shapes time.

Concluding reflections

I end this chapter with some reflections about knowledge, starting with differences that have been surfaced between the knowledge regimes and currencies at the respective services; and then giving some consideration to the equally important question of - have I done justice to what *I now* know? The strands of this question are what do I now know at the end of my PhD, and can I surface and articulate what I now know?

A way of characterising the NHS memory service is as a cycle of dynamic activity and processes directed towards the sole purpose of investigating memory problems through the lens of clinical knowledge. During a cycle there are points at which conclusions are reached, such as the point at which a clinician sees and makes sense of a scan result, or reaches a decision about the probable diagnosis. Knowledge is inherently involved and engaged in the activities and processes that this cycle represents, and may also be viewed as authoritative in the sense that knowledge indicates or provides the grounds for particular conclusions, and is enmeshed in such conclusions.

From the first interaction between the practitioner and the person with memory problems there is a clear intent (on the part of the clinician) to find out the nature of the memory problems. There is a whole diverse gamut of processes mobilised for this investigation, all of which intrinsically involve knowledge. Knowledge is embedded in assessment of memory and health status; scans and tests (conducted in other specialist NHS settings); interpreting scan/test results; diagnosis; prescribing of medication and other treatments; making sense of an individual's current situation (e.g. care arrangements, risks); and referring and signposting to other support. Even though a specific process might appear to signal either explicit or tacit knowledge coming to the fore, or being expressly involved, adopting such a view requires making assumptions about the relations between tacit and explicit knowledge.

For example, in terms of the knowledge involved in prescribing Donepezil to a person with Alzheimer's disease it might be presumed that prescribing involves and is oriented to explicit knowledge. This assumption seems to hold up initially if we think about Donepezil in its material form - as a tablet - representing

codified knowledge. Prescribing, in the sense of the practice, involves the clinician and the individual to whom the medication is prescribed. Available to the clinician is information about who the drug is suitable for (NICE) and drug dosage, side effects, monitoring requirements, directions for administration, patient and carer advice (BNF). Guidance and information in a protocolled format may give the impression that prescribing is dependent on following a protocol, with no particular involvement of the clinician's personal knowledge. However, not only is it impossible to say categorically that clinicians follow such protocols without deviation, it is also impossible to disregard individual knowledge and experience having a part in this. By this I mean aspects such as: a clinician's experience of prescribing this particular medication, the norms and accepted prescribing practices in a given memory service, and the clinician's knowledge of the individual with dementia - including whether the clinician believes the person will be compliant in taking the medication.

Thinking of the investigatory process and its cycle, once diagnosis is made and - if appropriate - medication is started and dosage reviewed, the individual is discharged back into primary care with provisos that s/he can contact the memory service if problems arise. The total face-to-face contact time between a memory service practitioner and an individual with memory problems during this investigatory process in most cases is actually very brief: typically running over three appointments. Based on such brevity of contact it would be imagined that the knowledge surfaced is of a clinical nature concerning the disease process, and thus represents only a thin 'slice' of knowing the person: knowledge of the person's memory problems viewed through a clinical lens. Given the substantial catchment area from which individuals may be referred to the memory service, we can say that this rather narrow knowledge is of many individuals - a whole population of people with memory problems.

In practice, knowledge in the NHS memory service is valuable in identifying the nature of a memory problem - distinguishing dementia from other factors that might be affecting memory (e.g. brain tumour or delirium). Confirmation of dementia through diagnosis enables the person to access relevant treatments such as medication, and also practical support in the form of local respite and day services. For families a diagnosis can prompt planning and preparation activities

such as establishing Lasting Power of Attorney, reducing risks in the home, or updating a Will.

A key characteristic of the social care service setting which differentiates it from the NHS memory service is the duration of time practitioners and people with dementia spend in face to face interaction. Unlike the NHS memory service - where the purpose of investigating memory problems can be conducted over, typically, three appointments - the social care service setting offers regular support over time to individuals living with dementia. The social care service is purposed around providing day-care and respite care to individuals living with dementia, and closely allied to this is that during the times when an individual is at Oak Hall their spouse, partner or other family member is not directly caring, and so effectively has a break from caring. At Oak Hall 'care' - in the broad holistic sense - might be viewed as the primary activity. 'Caring' ranges from responding to physical needs and preferences (e.g. food, drink, warmth, mobility, toilet assistance) through to health needs (such as administering medication), and to social needs and preferences - such as engaging the person in activities and conversation, and recognising and supporting the person's sense of self. The provision of a clean, comfortable, attractive and safe environment is also a part of caring: a setting that is specifically designed with the needs of people with dementia in mind. The garden at Oak Hall is particularly well designed - being fully accessible for people to walk in alone (should they wish), linking two areas of the building, which enables walking a whole circuit without encountering any barriers to access (e.g. locked doors).

Knowledge is inherently involved in all aspects of care. Knowledge of the particular concerns and 'problems' associated with dementia is imbued in the material environment (e.g. bedroom mirrors that can be covered). In the administration of medication knowledge (codified) is in the material liquids and tablets that are the medications, and in the policies, procedures, and practices involved in the administration and safe storage of medication.

In the social care service the knowledge emphasis is on the person as a whole, rather than just one aspect. Activities and practices which are essential to care (e.g. hoisting, giving medication, personal care such as bathing) become tailored

and specified to individuals on the basis of *knowing the person*. Knowledge, in this sense of knowing the person and what matters to the person, might be best described as experiential knowledge. When particular conditions arise 'knowing the person' might become a critical facet of care. An example is if an individual suddenly becomes unwell, yet is unable to articulate verbally this experience and thus does not alert others. Subtle indications that something is not right with the individual are most likely to be noticed by a practitioner who knows the person. This knowing can be what activates a timely response.

I now turn to the question of have I done justice to what *I now* know, and what can I articulate of what I now know? The account I have given is about tacit knowledge in two dementia services, and how understandings of tacit knowledge might be aided through the envisioning of knowledge in relation to practice and time. This is essentially *my* account, which represents one version of what I know. What I now know is that if we approach tacit knowledge with the orientation that it is separate, or could be separated out from explicit knowledge, we introduce limits (or even shut down other possibilities) to ways that tacit knowledge might be comprehended. Related to this is my sense that, in practice settings, tacit knowledge is deeply involved in practice. Even in the NHS setting where forms of codified knowledge are fundamental to the assessment and diagnosing of dementia (e.g. the memory test; brain scan imaging) tacit knowledge is involved in the doing of practice and in the interpreting of results and subsequently considering what this means for a specific individual. In the social care setting, tacit knowledge is involved in the knowing a person – a complex process involving getting to know the subtle clues that can be used to make sense of a person's behaviour, and what the person may be trying to express. However, a little more surprising in the social care setting is that adherence to rules and procedures can sometimes become immediately important, and override or 'trump' tacit knowledge: for example, following emergency procedures in a case where a person becomes ill and requires urgent treatment.

I recognise that my account of tacit knowledge is partial, in that I have given my account of it which is one version of my own sensemaking. I have, for example,

upheld a stance that it is valid and useful to consider tacit knowledge in its own right, even though I have concluded that it is not possible to differentiate between instances of using tacit knowledge and those of using explicit knowledge. For another researcher investigating tacit knowledge in dementia services, different conclusions might have been reached about what tacit knowledge means for practice, individuals with dementia, carers, and knowledge.

Chapter 7: Conclusions

Introduction

There are some challenges involved in concluding this thesis. My aim in this PhD was to open up and explore some ideas about tacit knowledge in dementia services, but as I have progressed through the PhD there has been a burgeoning of thoughts and ideas about the concepts of practice and time. These concepts became important to me for opening up insights about tacit knowledge, and I feel that my consideration of them has enriched this thesis. However, grasping and assimilating these concepts and drawing them into my work has felt like a considerable undertaking. A thesis has to be brought to an end regardless of whether the author feels that it is 'finished', yet trying to craft an ending that fits this thesis given the scope of what has been opened up, is no small undertaking.

In this chapter I bring the focus back to tacit knowledge. I start by looking back to the conceiving of my research project, briefly recapitulating my original intentions and reflecting on the limitations of this research. My second and more critical aim is consolidation: to express where I have got to in terms of enquiry into tacit knowledge. The third aim is to set out the implications of this thesis: what it means for people with dementia, practitioners and carers; what it means for knowledge; and what it means for social science and myself as a social sciences researcher.

Recapitulation and review

In the introduction to this thesis (chapter one) I described my vision to 'trace' in two service settings expressions of tacit knowledge. My primary motivation I expressed as 'giving voice' to tacit dimensions of knowledge. I also drew attention to the main challenge I expected to contend with: that of marrying practice perspectives with theoretical perspectives on tacit knowledge within the scope of an empirical study.

With the hindsight that comes from being in the field, I now view my intention to 'trace' tacit knowledge as representative of an over simplification of the concept of tacit knowledge, underpinned by a certain naivety about what was entailed in the handling of quite difficult concepts.

Whilst my two fieldwork settings provided enviable scope for ethnographic work, actually getting to the point of starting fieldwork involved compromises, particularly in the way my work needed to be presented in order for me to obtain NHS and social care ethics and governance approvals. My encounters with the research approvals system left me with a sense of a non-messy world in which concepts, ethical issues, research methods, organisational settings, and data collection have the *appearance* of being unproblematic, reducible to simple notions. This was typified in a question from a member of the NHS Research Ethics Committee during the meeting at which my application was reviewed. I was asked:

..."how tacit knowledge could be transferred, if useful, to others?"

The moving away from the clearly delineated and tidy processes of NHS research approvals, and into fieldwork, felt like a defining transition: a certain security induced by the predictability of the approvals process was replaced by a feeling of looking out at an amorphous mass of concepts and ideas. For me, this transition was certainly characterised by feelings of doubt in my own abilities to create a credible research project. To move past these doubts I found that I needed to relinquish the idea that it was possible to isolate or pinpoint tacit knowledge, and start to see everything in my fieldwork activities as being potentially relevant. This way of looking I attribute to starting to think in terms of interconnections and inseparability as a possible frame for understanding.

Over time, my focus on tacit knowledge spawned other ideas and concepts: continuation of self, identity, personal agency, and 'becoming'; status passage and trajectories; memory; practice; and different conceptions of time. My interest in seeing interconnections between tacit knowledge and these other ideas propelled my thesis in a direction that I had not anticipated at the point I started my fieldwork.

Limitations

I consider first the limitations of this research concerning practical matters related to the fieldwork, and then limitations regarding methodological and conceptual matters.

There were various factors relating to the system of scheduling of memory appointments which made it unachievable for me to attend and observe individuals' appointments more than once. The gaps between an individual's appointments were such that even if I saw a person at their initial referral appointment I had no idea whether or when a second appointment would be scheduled. Having a day job necessitated juggling my fieldwork around work hours, and work reduced my flexibility for being available to observe particular appointments. Appointments were scheduled in advance and I was limited to doing fieldwork on one day or two half-days per week. It was only in one instance that two home visits to the same person were scheduled less than three weeks apart, providing me with the opportunity to attend both.

Seeing each person only once made it difficult to gain anything more than a fleeting sense of each individual. I had no opportunity to see how individuals were over time. The impact of this was that the narratives I constructed around individuals were almost exclusively based on data collected during any given memory appointment. Very rarely was it possible to extend an individual's narrative beyond these confines.

As a researcher, having 'face-to-face time' to establish rapport with participants – which I have thought about as being instrumental for care practitioners to get to know individuals with dementia – was curtailed in the memory service setting. This limited any claim I could make about establishing rapport with appointment attendees. In the clinic appointment setting - even if it had been feasible to see the same individuals in clinic several times (i.e. by 'following' people through their journey of contact with the memory service) - the characteristics of the purpose of a clinic appointment including its focus on assessing memory status and physical health examination excluded the possibility of me spending time with participants. In contrast, the sense I had of being able to establish rapport with Merfyn Jenkins – a man who I twice visited at home with a clinician – has provided me with an important learning point regarding the design of my research project. In hindsight, the study design might have been improved had I built in the option of visiting the individuals I encountered in clinic at home, or elsewhere in the community.

A further limitation was that the perspective of a consultant psychiatrist is not reflected in the data, as I was unable to secure an interview with the psychiatrist whose appointments I had observed. The psychiatrist's explanation of practice and knowledge would have provided further insight alongside my observational data from his clinics.

Regarding the social care service the limitations related to recruitment of participants with dementia, and to what I would call certain 'boundaries of propriety' concerning being a researcher in a setting which has temporarily become a person's home.

Of the potential research participants with dementia there were about four people who I would have liked to recruit into the study - but who I felt were not able to give informed consent to participate - and my attempts to obtain consent via the nominated consultee route were variously thwarted. Either my fieldwork visits never coincided with the presence of a relevant relative who I could have approached, or I was unable to obtain an address and so could not write to the relative. Even my attempts to gain retrospective consent from relatives to use selected fieldnotes made at the time their loved one attended Oak Hall failed: individual's files (containing relatives' contact details) were closed and moved elsewhere as the service began to wind down prior to its closure. In the cases of only two individuals unable to consent was I able to obtain nominated Consultee consent. The words and expressions of people who might perhaps be considered to be furthest along a trajectory of living with dementia are less well represented than those of people who were able to consent for themselves.

There are no accounts from direct observations in the respite care part of the building: essentially the corridor and bedrooms, sluices and a second lounge. Any insights about the respite service I have included in this thesis are based on interview data: what staff talked about in terms of personal care; and insights from conversations I had with people with dementia in day-care who spoke of their experiences of staying in respite care. Even though I had approvals to conduct observations in the respite service, once in the field I came to the view that this would be intrusive.

I consider that the main conceptual limitation is one associated with difficulties in identifying a descriptor sufficient to represent relations between abstract and non-spatial concepts (knowledge, time, practice). For example, I tried but then rejected the term 'configuration' because it implied spatial properties. My eventual choice of 'convergence' I considered to be adequate although imperfect. This limitation signifies a problem of greater proportions which is to do with the limitations of language to adequately convey particular ideas.

My own capabilities sometimes felt like a limitation. An example of this was my moments of reflection during writing my thesis when an unformed idea or insight would arise. I would try to grasp the insight but, frequently, the sense of its meaning would evade me, as an impression that floats (frustratingly) at the periphery of one's awareness yet is resistant to articulation.

In terms of how I have structured this thesis, and whether this particular structure diminishes the impact of the ethnography, is a point to consider. In the lead up to starting to write my first draft I discussed in some detail with my supervisors the shape and structure of the thesis. For me the considerations were that: it felt risky to try to pull off a thesis of a very free format without previous experience of writing a piece of this size; having a framework of chapters with specific content I felt would provide a focus that would help me in writing the thesis; and I anticipated that the chapters would 'naturally' provide the source of material for future publications.

Where I have got to in my enquiry into tacit knowledge

The tacit dimension of knowledge is unproblematic unless or until someone wants either to define it, explain how it relates to explicit knowledge, or assess its function or value. Collins succinctly captures this idea of letting something *be* without interrogation:

"...nearly the entire history of the universe, and that includes the parts played by animals and the first humans, consists of things going along quite nicely without anyone *telling* anything to anything or anyone. There is, then, nothing strange about things being done but not being told - it is normal life." (Collins, 2013:7).

But, in health and care practice telling of practice might well be required. For services, learning both from situations that end badly and those that end well is important. Yet, a complete account of practice - i.e. one that includes the tacit dimension of knowledge in practice - cannot be given if we concur with Polanyi's view that the tacit dimension is 'inarticulable'.

In introducing where I have got to in my understanding of tacit knowledge, I have found that a helpful way of considering tacit knowledge is that there are *ways*, rather than *a way*, to envisage it.

In the memory service I viewed one pointer to tacit knowledge being the impressionistic aspect involved in the assessment and diagnosing of memory problems: the manner in which impressions arise and are perceived by the clinician. In this, it is the clinician's personal (and therefore individual) sensorial faculties of touch, sight, hearing and smell that are involved. For example, when a clinician is sitting in close proximity to the individual it might be the case that the clinician smells alcohol emitting from the person. In the context of assessment, knowing that a person is drinking may well represent information that is valuable for the clinician in considering risks. Similarly, when a person is giving an account of their own recent memory problems, the clinician's faculties of hearing are engaged in the act of listening. Hearing - in terms of what and how the clinician hears - is individual and personal, as is the impression that the clinician arrives at about the individual and their memory problems. Investigations into the individual's memory problems may involve looking at symptoms, physical health presentation, care arrangements and the carer's account. The meanings of the 'results' from investigations are not only mediated and made sense of through the clinician's prior experience and knowledge, but are also filtered through the sensorial faculties of the individual clinician.

Another way that I have envisaged tacit knowledge is as an individual know-how that individuals acquire and retain. In terms of health and care practice I view individual know-how as arising in such instances as clinicians knowing how to craft a question to an individual about their memory problems; or care workers knowing how to diffuse an incident where an individual is becoming agitated.

In relation to individuals who are becoming cognitively impaired by dementia, the idea that know-how may be retained was a possibility that I felt was worthy of proper consideration. The know-how that Merfyn Jenkins demonstrated in snooker whereby he played competently, even skilfully, and won, is a particular example. Individuals at Oak Hall - many of whom seemed severely impaired and many whose verbalisations were infrequent and limited to a small repertoire of words - showed flashes of knowing how. This know-how, as I viewed it, was demonstrated in singing the words to a song, dancing a waltz, or producing as if from nowhere a correct answer to a crossword clue or quiz question. These sorts of instances struck me as surprising, given people's impairment.

From observing and listening to people with dementia I thought about whether the actual 'living' of an experience of dementia might be viewed in terms of experiential knowledge. I also thought it was a possibility that people might retain the know-how required for adapting to instances where they view themselves, or are viewed by others, as forgetful. In clinic appointments, where assessment and diagnosis exposes the presence of a significant memory problem, it is conceivable that know-how (i.e. of norms for responding to bad news) is demonstrated in an individual distancing her/himself from, or 'talking down' problems with memory.

I also considered the tacit dimension of knowledge in terms of its relation to the explicit dimension. The two interrelated questions that came to be important were - how might the relationship between tacit and explicit be comprehended, and what would be the implications of it being possible (even if not currently) to differentiate instances of using explicit knowledge from instances of tacit knowledge. In practice settings the way that I found helpful for framing these questions was in terms of individual repertoires of knowledge which I conceive of as representing the full scope of an individual's knowledgeability across tacit and explicit dimensions. In practice terms, the knowledge repertoire idea is helpful for envisaging the *entirety* and variety of a practitioner's knowledge, and for thinking about how knowledge is brought to bear in helpful ways to individuals with dementia and carers.

Differentiating between instances of explicit and tacit knowledge used in practice might become a relevant exercise if the goal was to understand (a) what the tacit dimension added to practice, or (b) what practice might look like without tacit knowledge if there was only explicit knowledge. Accounts of practice might be a useful means through which to consider this. Sarah, a care worker at Oak Hall, gave an account of a care practice involving helping a lady to dress who initially refuses, but then through Sarah's imaginative approach ultimately concedes to getting dressed. What comes to attention is that the dressing 'goal' is set in a situation with features that are unique to it, such as the ways of communicating the individual with dementia uses and the clues that the care worker picks up on. Sarah's adaptation of her practice around the individual is what seems to achieve the desired result. Yet, if Sarah was required to give an account of *how* her practice accomplished the outcome of the lady being dressed, this would seem unattainable. It would require Sarah to break down the whole process into mechanistic steps, and to provide a complete commentary which detailed aspects such as the basis on which she picked out particular clues from the lady's behaviour; the words she had used; the manner in which she had spoken (the volume and tone of voice); her gestures; her facial expressions; and so on. The dissection of a care practice - even if it were possible - would at most only result in a sequence of steps, and would fail to capture the subtleties and complex contingencies involved.

My experiences in the two service settings, and connecting experience with theoretical and empirically-based perspectives have opened up to me some very absorbing ways of thinking about tacit knowledge. Where I have got to as a result of my enquiry is summarised thus. I began this PhD with an interest in the value or worth of tacit knowledge within health and care services for people with dementia, and a curiosity about why tacit knowledge seems to be given little attention relative to the attention given to explicit knowledge. What has become apparent to me is that, on the one hand, thinking about tacit knowledge as a distinct dimension of knowledge within practice settings allows or even promotes consideration of the non-obvious or normally overlooked aspects of knowledge in practice. On the other hand, I suggest that this does not imply that tacit knowledge can be 'isolated' or seen in isolation from the explicit dimension of

knowledge. In a very pragmatic sense explicit and tacit knowledge can be viewed as working together mutually in whatever the intent (or perhaps 'direction') of a situation.

Implications of these conclusions about tacit knowledge

What this means for knowledge

I gave some thought in the previous section to ways that we might conceive of or think about tacit knowledge.

The most important implication for knowledge, as I see, is whether the questions of interest and debate about tacit knowledge that have been considered through and framed by a theoretical lens, now need to be made relevant and engaging to practice and practitioners. Scholars and researchers coming together with practitioners to discuss ideas about knowledge *per se* might provide starting points for defining questions about knowledge relevant to practice. For example: what ways of knowing are relevant or inherent to practice; what constitutes knowledge in practice; how do we see knowledge in relation to evidence?

A linked concern is whether more might be made of the 'knowing' the person aspect of knowledge. Aspects of health and care (e.g. assessment and diagnosis; providing personal care, or engaging a person in an activity) necessarily involve human interaction, during which the practitioner gains at least some knowledge of the person as an individual. The ability of individuals with dementia to articulate linguistically wishes or needs does become impaired over time so, arguably, 'knowing' the person and what matters to the person is helpful when considering care and treatment options over time. Some situations illustrate knowing of an individual with dementia by a group of practitioners (e.g. a respite care shift handover meeting). However, it would be interesting to explore ways that knowledge in the sense of 'knowing the person' could be passed on from existing care providers to new care providers in instances such as the transition from living at home into permanent residential care.

What this means for people with dementia, carers and practitioners

For people with dementia continuing to know how to do something and demonstrating this to others (e.g. Michael still knew how to call the numbers out

for bingo at Oak Hall) is significant. Exercising know-how is one way that individuals with dementia continue to engage and interact with the world. A carer or practitioner - seeing that a person with dementia knows how - might see this as an opportunity to encourage the person and try to cultivate and maintain the capabilities involved. Clearly, there are particular or exceptional circumstances where exercising know-how might expose the individual to risk. For example, a person with dementia who continues to exercise know-how in driving a car but fails to remember what a red traffic light signifies or which side of the road to drive on, will be considered at risk. But, the principle of nurturing and perhaps even actively stimulating people with dementia to carry on using their know-how, seems like a progressive tenet that would be worthwhile to embrace in care practice.

This line of thought opens another idea about tacit know-how in relation to people with dementia: that of adapting and improvising in a given circumstance or set of conditions. During Merfyn's snooker playing he changed from one cue to another in order to adapt to the positioning of the ball and the particular shot he thought would be needed to pot the ball. This suggests improvisation. A patient of Laura, Mr Wooler, was building a dolls' house - a non-formulaic endeavour involving imagination and creativity. And there was Paul at Oak Hall who continued to sketch pictures, even though his eyesight was deteriorating. In both fieldwork settings practitioners did notice and comment on individuals' know-how. One practical way to make the most of know-how might be to link individuals at the fairly early stages of dementia into hobby/interest groups that could support them in maintaining individual interests.

In care settings *time* seems significant. Establishing a relationship - and the trust and confidence that is involved in this - requires time. Time is an essential requirement for getting to know a person with dementia: time affords the learning to pick up on clues about possible needs or wishes that the person may be unable to verbally articulate, or to talk in such a way that grounds the person in the familiar such as talking about family or places that are familiar. Conversely, when there is not time to get to know a person, potential consequences include

the missing or overlooking of vital clues such as those which indicate that the person is becoming unwell, or that a behaviour is starting to escalate.

Practically speaking a shift towards placing value on time for getting to know individuals with dementia in residential or respite service settings would manifest as changes to work patterns, staffing ratios, and supporting appropriate staff development and training. Alongside this some form of evaluation or appraisal of the impacts of staff spending time getting to know people would be important. This might become part of the remit of formal inspection regimes such as Care Quality Commission inspections.

Findings from a recent NIHR-sponsored multi-site study about improving the care of people with dementia in hospitals (Godfrey et al, 2018) highlight both 'time' and 'knowing' for good practice in hospital care:

“ ‘Knowing the person with dementia’ posed challenges at several levels: in the time and skill required to communicate with the person, especially with loss of language, and in the nature and depth of knowledge required to understand the person ‘in their world’.”

“For staff with an understanding of dementia, ‘knowing the person’ involved more than biographical knowledge. It encompassed a deeper knowledge of the person, including what was personally meaningful to them and what evoked emotion (whether positive, such as joy, or negative, such as anger, irritation and distress). A prerequisite to acquiring such knowledge was an ‘imaginative connection with the person’, whether professionally or experientially derived.” (Godfrey et al, 2018:58-59)

What this means for social science and me as a social science researcher

The implications for social science and me as a social science researcher relate to (a) health and care services as fieldwork settings, and (b) the engagement of empirical research with theory.

The settings where health and care are provided are essentially non-public settings, where permissions and approvals have to be sought in order to conduct research involving people who use health or care services. Whilst these settings offer potential for obtaining very rich data, in order to gain access to the setting a social science researcher has to be prepared to go through a lengthy process of

having their proposal scrutinised by both an NHS research ethics committee and local NHS research and development staff, who may or may not be versed with the methodology and methods proposed. For the full-time PhD route, candidates might rule out doing fieldwork in an NHS setting because of the length of time it might take to obtain the necessary approvals. A further factor is how a social science researcher feels about what the process actually entails: subjecting their research project to scrutiny by NHS systems and processes that are paradigmatically different to those of the social sciences, during which a social sciences project may be queried or challenged on methodological or ethical grounds.

More optimistically, research conducted in such settings might be viewed as positive by those who manage or work in health or care settings, perhaps seeing that there could be gain for the service in having a researcher (an outsider-visitor) involved. The implications of social science research not being conducted in such settings is that valuable critique and enquiry concerning aspects of practice, service user and carer experiences, or organisational culture is not available to the social science research community.

For a PhD the choosing of a particular combination of topic, setting for enquiry, and method seems to symbolise a commitment, a sense of choosing something and sticking with it. My relatively smooth experience in the field with no insurmountable obstacles to collecting data, and the possibilities that seemed available to me in terms both of the method and how I might make sense of the data, indicated to me that ethnography had been well paired with topic and setting. What I had not envisaged was how my project, which I originally conceived of as grounded in and oriented to settings of practice, would require me to engage with theory at a level that felt like a stretch well beyond my capabilities. However, the moments of clarity where I could see how ideas and theories might fit together felt immensely rewarding at a personal and professional level. I do not know of work by other social science researchers which has considered tacit knowledge, time and practice together and in relation to dementia services. However, there are several PhD theses which overlap with my work in terms of method and population. These are: Dennis' (2016) ethnography of music in the

everyday lives of people with dementia; McColgan's (2001) ethnographic study of relationships of people with dementia; and a thesis by Börjesson (2014) whose ethnography concerned how, and what knowledge is expressed and made visible in everyday care practice with older people, including people with dementia.

The manner in which social scientists engage with people with dementia is an aspect that is highlighted through my work. How to 'be' in service settings; how to approach and initiate conversations with people with dementia; how to describe or explain one's role; how to manage seeing things that might cause distress in oneself; how to observe in ways that draw least attention, and knowing when to stop or pause observation or note-taking are all challenges that may well come up. My prior knowledge and experience of service settings for people with dementia meant that I was not perturbed about being in dementia service settings, and what I might see or hear. I also had a good understanding of what norms of behaviour might be expected from someone in a work or study capacity in that setting. One conclusion I have drawn is that exposure to service settings prior to entering the field can be helpful for sensitising researchers to those sorts of environments and the people in them.

Signals for future work

In this PhD some substantive questions have been opened up which signal future directions for strands of research - both empirical and conceptual.

A significant focus which is indicated is the development of ways for empirically investigating tacit knowledge, in terms of paradigmatic and theoretical frameworks, methods for data collection and modes of analysis. Development along such lines could make a contribution not only to how *tacit knowledge* is studied but also to the investigation of other intangible forms.

Several areas concerning dementia are also signalled for research. Making sense out of the experience of people with dementia was highlighted in the two case study chapters, and work in this area could include: the experience of people with young onset dementia; people's experiences and perceptions of time and space; and individuals' and carers' experiences of different types of transitions involved in living with dementia. A particular area of transition which has been highlighted

in the two case study chapters concerns the movements into and from 'precarity'. A potential implication of, for example, precarity of care arrangements is the changes in status that it might bring to the individual with dementia and related carers – such as hospital admission of the person with dementia or the carer. Also signalled for enquiry is *time* in health and care services. There is considerable scope to pursue conceptual and empirical work, but just two possible areas for enquiry are timings of care and interventions across different sorts of health and care settings; and different perspectives about time in service settings from managers, frontline staff, service users, and families. The availability of 'time' for people with dementia admitted into acute general hospitals is clearly a topical issue, as emphasised in Godfrey et al (2018) whose findings I have briefly described in the 'limitations' section of this chapter.

In terms of developing my own research, two areas of enquiry that I would like to explore further are, firstly, "status passage" (Glaser and Strauss', 1971) specifically in relation to dementia and the perspectives of the individuals and institutions involved. Secondly, I would like to explore further the idea of continuation or perpetuation of know-how of individuals in spite of real and ongoing dementia-type memory problems. I would see this as collaborative enquiry with others who have special interest in this topic, to explore the dimensions of know-how. Potentially, a grounded and multi-stranded description of know-how could emerge which could inform focused empirical work in this area.

Appendices

Appendix A: Participant information and consent materials

PhD Research Study - Information Sheet

Title of the research

An Ethnography of the tacit dimensions of knowledge in the management, organisation and delivery of services to people with dementia.

Researcher's name and place of study

Sue Molesworth, Keele University, North Staffordshire.

Your involvement

Before you decide whether you want to take part it is important that you understand why this research is being done, and what is involved. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you have further questions then please ask me.

Purpose of the research and where it will take place

This research is investigating how individual staff such as care workers, managers, nurses, doctors, and social workers, use their knowledge when they are providing and managing services for people with dementia.

We know that staff in health and social care organisations rely on and use different types of knowledge. For example:

- knowledge about dementia;
- Knowing an individual's preferences, dislikes, and wishes;
- knowledge about *what works* based on previous experience;
- Knowledge about medication.

All of us use many different sources of knowledge in everyday life, and most of this is easy to find: for example - in books, policies, and even recipes.

My research is interested in a particular type of knowledge in health and social care organisations, known as 'tacit' or 'personal' knowledge.

Tacit knowledge tends to be hidden and is often quite difficult for people to express or describe.

For example -

- *the ability to ride a bike*
- *the ability to recognise faces*

Research in this area suggests that health and social care practitioners are constantly drawing on personal, tacit knowledge as they provide care and support to service users and carers. In my research I will be trying to bring to the surface some of this hidden, tacit knowledge, and to investigate what its importance might be for providing and managing services to people with dementia.

I will be using an approach called 'Ethnography'. This will involve using two methods:

- Observing everyday activities in a particular organisation or setting;
And,
- asking people to talk about these everyday activities in an interview.

I will be observing and taking notes of everyday interactions between people with dementia, carers and staff at [REDACTED] I will also interview frontline staff and managers, and I will be observing organisational meetings such as reviews of care, and team meetings.

Why have I been invited to take part, and what will it involve?

You have been invited to participate because you are using the services at [REDACTED] or you are a carer of someone [REDACTED]

Participation in this study involves giving your consent for me to observe interactions between health and social care staff and you.

Taking part is voluntary, and you can stop participating at any time without giving a reason. Be assured that whether you choose to participate or not it will not affect your statutory rights nor the care or support you or your loved one receives.

What are the hoped-for benefits?

It is hoped that findings from this research will help social care and health organisations to be more aware of tacit knowledge and understand its potential value (e.g. to open up debate about how this type of knowledge could make a positive difference to services to people with dementia and their families).

What are the possible disadvantages or risks of taking part?

I do not know of any risks or disadvantages of taking part in this research.

Will my participation in this study be kept confidential?

All information collected during the course of the research will be kept strictly confidential to the researcher and her two research supervisors

- If you agree for the researcher to conduct observations when you are present the researcher will make field notes. These notes will be made anonymous so that there is no information that could identify you, or others, in these notes. Notes will be stored in a locked filing cabinet at the researcher's home.
- All reports and publications arising from the project will be made anonymous. No information will be included that would identify you as an individual. If any quotations from you are used, then your name will be removed.
- If during the course of the research you disclose to the researcher a previously unknown serious criminal offence (for example – involving serious harm), then she would be bound to discuss this with her supervisor to check whether it would be necessary to report this to the police in the public interest.

What will happen to the findings from the research?

The research will be written up for a PhD thesis. Findings may also be published in journals and be presented at conferences.

Who has reviewed this research study?

Keele University has peer-reviewed this research. It has been reviewed by an NHS Research Ethics Committee and has also been reviewed through [REDACTED] Research Governance Framework.

Thank you for your consideration to participate in this study.

If you agree to participate, a copy of this information sheet and a signed consent form will be given to you to keep.

If, during the study you wish to raise a concern or make a complaint about the conduct of the research please contact the researcher in the first instance:

Sue Molesworth

E-mail: s.molesworth@keele.ac.uk

Version2/170214: Health and Social Care staff: [REDACTED]

PhD Research Study - Information Sheet

Title of the research

An Ethnography of the tacit dimensions of knowledge in the management, organisation and delivery of services to people with dementia.

Researcher's name and place of study

Sue Molesworth, Keele University, North Staffordshire.

Why I am inviting you to be involved

This study is interested in the knowledge of health and social care staff (nurses, care workers, managers, doctors, social workers, therapists, receptionists), and how this knowledge is used when staff are providing and managing services for people with dementia.

I will be using observations and interviews to study a particular type of knowledge called "tacit" knowledge. I will be observing how health and social care staff interact with patients and service users and their carers.

Your participation in this study involves giving consent for me to observe conversations between you and people with dementia, and the interactions that take place. For example, observing when people are having their appointment at [REDACTED], and observations at the [REDACTED]

Taking part is entirely voluntary, and you can stop participating at any time without giving a reason. Whether you choose to participate or not, it will not affect your statutory rights.

Purpose of the research

Staff in health and social care organisations rely on and use different types of knowledge when they are providing care and support to people with dementia and their families. For example:

- knowledge about dementia;
- Knowing an individual's preferences, dislikes, and wishes;
- knowledge about *what works* based on previous experience;
- Knowledge about medication.

A lot of the knowledge we use is easy to find: for example - in books, policies, and even recipes.

However, there is a type of knowledge called 'tacit' or 'personal' knowledge which tends to be hidden and is often quite difficult for people to express or describe. For example -

- *the ability to ride a bike*
- *the ability to recognise faces*

In my research I will be trying to bring to the surface some of this hidden, 'tacit' knowledge, and to investigate whether 'tacit' knowledge is important for providing and managing services to people with dementia.

I will be using an approach called 'Ethnography'. This will involve going into services and observing how health and social care staff use their knowledge in practice, and then asking staff to talk about the different types of knowledge they draw on in their practice.

Study Setting and fieldwork sites

I have identified two points on the care pathway for people with dementia which are (1) - [REDACTED] and (2) [REDACTED] I will be doing the research fieldwork over a period of about 1 year.

How I will investigate 'tacit' knowledge

- I will conduct detailed observations in services of the interactions between people with dementia and health and social care practitioners;

- I will observe different types of management meetings (e.g. service management and care management);
- Using interviews, I will explore the views of health and social care practitioners and managers about how they use tacit knowledge in their work.

Benefits of taking part in the research

This research has potential to lead to a fuller and better understanding of tacit knowledge amongst staff in health and social care services. It is also hoped that people with dementia and their families will gain a better awareness of tacit knowledge and the part that it plays in making services more person-centred.

Risks of taking part in the research

There are no known risks of taking part in this research.

Obtaining consent for the research

I will be seeking consent from staff, people with dementia, and carers to allow me to conduct observations at [REDACTED]

In all cases I will seek written consent, but where this is not achievable (e.g. where people with dementia have difficulties reading and signing a form) I will seek verbal consent which I will record using a digital audio recorder.

Participant Information Sheet

I am carrying out a study to look at the knowledge of staff and how staff use their knowledge.

This study is looking at -

- What knowledge do staff have?
- How can they use their knowledge to directly help people with memory problems?
- How can this knowledge be used to improve care services for people with memory problems?

I would like you to help me.

I am asking you whether it is ok for me to spend time at [REDACTED] so that I can look at what happens here, and take notes of what I observe.

I will be visiting [REDACTED] about once a week for one year. I will write a report at the end of my study.

People who attend [REDACTED] and people who work here will be able to see the report.

My name is Sue. You can ask me any questions about the study. I will be happy to answer them.



PARTICIPANT CONSENT FORM: OBSERVATIONS

Title of Research Project:

An Ethnography of the tacit dimensions of knowledge in the management, organisation and delivery of services to people with dementia.

PLEASE NOTE: No observations will take place in the bedrooms of individuals, and no observations will take place of personal care nor in any areas where personal care is provided (e.g. bathrooms, toilets).

**Please
initial
box**

Prior to the observations:

I give my permission for the researcher to conduct observations in [redacted] when I am present. I understand these observations will take place in the respite and the day service.




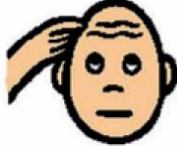

I give my permission for selected field notes from observations to be reproduced in the researcher's final PhD thesis and in any publications that result from this research study.

Your name: _____

Your signature: _____ **Date** _____

Researcher/name of person taking consent

Consent form

	Have you read the information sheet or had it explained to you?	YES NO
	Have you had time to ask questions and talk about the study?	YES NO
	Are you happy with the answers you have been given?	YES NO
	Do you understand that it is your choice to take part in the study?	YES NO
	Do you understand that you can <u>stop</u> taking part in the study at any time?	YES NO

Your name: _____

Your signature: _____ Date: _____



PARTICIPANT CONSENT FORM: INTERVIEWS

Title of Research Project:

An Ethnography of the tacit dimensions of knowledge in the management, organisation and delivery of services to people with dementia.

**Please
initial
box**

Prior to the interview:

I give my permission for this semi-structured interview to be audio recorded and for the recording to be transcribed into an electronic document that will be stored securely on a password protected computer.

After the interview:

I give my permission for selected anonymised quotations to be reproduced in the researcher's final PhD thesis and in subsequent publications resulting from this research study.

Your name: _____

Your signature: _____ **Date** _____

Researcher/name of person taking consent

Poster for displaying in [REDACTED]

Research Project [REDACTED]

This study is investigating 'knowledge' in health and social care organisations.

For organisations to provide care and support to people with memory problems and their carers they must use knowledge. For example:

- knowledge about memory problems;
- Knowing an individual's preferences, dislikes, and wishes;
- Knowledge about medication.

Knowledge in books, policies, and even recipes, is easy to find. However, there is another type of knowledge called 'tacit' or 'personal' knowledge which tends to be hidden and can be difficult for people to explain. For example -

- ***the ability to ride a bike.***
- ***the ability to recognise faces.***

I will be trying to bring to the surface some of this hidden, 'tacit' knowledge, and to investigate whether 'tacit' knowledge is important for providing and managing services to people with memory problems.

My name is Sue. I am doing this research for my PhD at Keele University. I will be doing observations in [REDACTED] and I will also do some interviews with staff.

I will be visiting about once a week for the next 12 months. Please do ask me any questions you have about the research. I look forward to meeting you!



My contact email: s.molesworth@keele.ac.uk

Participant Information Sheet

I am carrying out a study to look at the knowledge of staff and how staff use their knowledge.

This study is looking at -

- What knowledge do staff have?
- How can they use their knowledge to directly help people with memory problems?
- How can this knowledge be used to improve care services for people with memory problems?

I would like you to help me.

I am asking you whether it is ok for me to spend time at [REDACTED] [REDACTED] so that I can look at what happens here, and take notes of what I observe.

I will be visiting [REDACTED] about once a week for one year. I will write a report at the end of my study.

People who attend appointments and people who work here will be able to see the report.

My name is Sue. You can ask me any questions about the study. I will be happy to answer them.



PARTICIPANT CONSENT FORM: OBSERVATIONS

Title of Research Project:

An Ethnography of the tacit dimensions of knowledge in the management, organisation and delivery of services to people with dementia.

PLEASE NOTE: No observations will take place of personal care nor in any areas where personal care is provided (e.g. bathrooms, toilets).

**Please
initial
or tick
box**

Prior to the observations:

I give my permission for the researcher to do observations in [redacted] [redacted] I attend when I am present.

AND / OR

I give my permission for the researcher to sit in on and observe a home visit appointment

I give my permission for selected field notes from observations to be reproduced in the researcher's final PhD thesis and in any publications that result from this research study.

Your name: _____

Your signature: _____ **Date** _____

Researcher/name of person taking consent _____

PARTICIPANT CONSENT FORM: INTERVIEWS

Title of Research Project:

An Ethnography of the tacit dimensions of knowledge in the management, organisation and delivery of services to people with dementia.

**Please
initial
box**

Prior to the interview:

I give my permission for this semi-structured interview to be audio recorded and for the recording to be transcribed into an electronic document that will be stored securely on a password protected computer

After the interview:

I give my permission for selected anonymised quotations to be reproduced in the researcher's final PhD thesis and in subsequent publications resulting from this research study.

Your name: _____

Your signature: _____ **Date** _____

Researcher/name of person taking consent

Nominated Consultee Declaration

Title of the Research Project: An Ethnography of the tacit dimensions of knowledge in the management, organisation and delivery of services to people with dementia.

My relationship to the person I am nominated to give consent for:

Main carer Family member Friend Advocate Other _____

The person's name is _____

	Please initial to show you understand and confirm agreement
1. I confirm that I have read and understood the information sheet about this study.	
2. I confirm that I have had time and opportunity to ask questions about the study in my role as a Nominated Consultee.	
3. I understand the purpose of the project and what the participant's involvement would be. In my opinion he/she would not object to taking part in this study.	
4. I understand that taking part in the study is voluntary and that the participant will be withdrawn if at any point and for any reason they do not wish to continue taking part.	
5. I understand that if the participant is withdrawn from the project this will not affect in any way the care or treatment they receive, nor affect their legal rights.	

Name of Consultee	Date	Signature
Name of researcher who has discussed the study with me and given me information	Date	Signature

Appendix B: Semi-structured interview schedule

Semi-structured interview question schedule/Health & Social Care staff. Version 06.09.13

Semi Structured Interview Question Schedule: Health and Social Care Staff.

(Adapted from Habersam and Piber, 2003, with permission from Michael Habersam)

(To all staff)

1. What characterises a 'good' service to people with dementia?
2. Please describe your personal contribution to it.

(To Managers only)

3. At times when you have sufficient access to money, personnel, rooms/space and time, how do you continue to improve your service?
4. In the face of chronic shortages of money, personnel, rooms/space and time, how do you ensure that the service continues to be 'good'?
5. What are you doing in order to become an even better service in the future?

(To all staff)

6. How do **you** know/realise that you are doing a good job, day to day?
7. How do **others** know/realise that you are doing a good job, day to day?
8. What aspects/parts of your daily work could you explain and transfer to your colleagues? And how does that process work? **(prompt: ask for any examples)**
9. What aspects/parts of your daily work can be written down? **(prompt: ask for any examples)**
10. What aspects/parts of your daily work may be quantified? **(prompt: ask for any examples)**
11. Please recount a story/narrative about your service which has made an impression on you in a positive way.
12. Please recount a story/narrative about your service which has made an impression on you in a negative way.

(Digging deeper...)

13. Do you regularly get access to the knowledge and experience of others and, if so, (a) *whose* knowledge and experience and (b) what is the nature of this knowledge?

14. In your view to what extent does it make sense to draw on and use the knowledge and experience of others?

15. Would you personally share your knowledge/experience with others?

16. If yes, under which conditions?

17. If not, why not?

Final question:

From your point of view, who else should I interview in order to get further perspectives on tacit (hidden, unspoken, embedded, implicit) knowledge within dementia services?

Research Protocol:

Version 3/010714

An ethnographic study of the tacit dimensions of knowledge in the management, organisation, and delivery of services to people with dementia.

Project Summary:

This project will investigate tacit knowledge in two services for people with dementia (one NHS and one Local Authority) [REDACTED]. For the NHS component the project will focus on memory services provided by an older people's mental health team ([REDACTED]) and the management of these services. For the local authority component the project will focus on a respite and day service provided at [REDACTED] and the management of these services. To frame the research the researcher will draw on the metaphor of the dementia pathway as a 'journey' on which are points where people with dementia may enter or exit. These points also represent intersections where organisations intervene in the lives of people with dementia and their families. Each point provides a lens through which to observe tacit dimensions. The dementia pathway provides access to points of service delivery and negotiation, and is therefore considered a good place to observe the 'reality' of essential tacit knowledge.

Ethnography is the method that has been chosen. The study will entail very detailed overt observations of verbal and non-verbal communication, interactions, human expressions and behaviours within frontline services, and in meetings related to the management of services. Alongside the observational work semi structured interviews will be conducted with frontline health and social care staff and managers to explore the nature and concepts of tacit knowledge.

Background:

Organisational and management research has produced a general consensus that the most valuable *intangible* resource of an organisation is knowledge, and that *tacit* knowledge specifically provides a unique organisational advantage because it is complex, rare, idiosyncratic and therefore difficult for other competitor organisations to imitate. What underpins both the activity and productivity of an organisation is essentially unseen "*hidden in the intangible assets of an organization, and it entails the knowledge of what the firm does, how it is done, and why it is done that way*"(Zack, 2003: cited by Curado, 2006:4).

This represents a perspective on organisations known as the *Resource Based View of the Firm* (RBV) and it refers to the bundling of strategic assets considered to be critical in determining sustainable competitive advantage and ultimately organisational performance (Porter, 1991; 1996; and Michalisin, Smith and Kline, 1997; 2000).

In organisations this tacit or personal knowledge resides in individual employees and includes expertise, know-how, "rule of thumb" approaches, hunches, intuitions, and subjective insights. This individual tacit knowledge belongs not to the organisation but exclusively to individuals, used by them voluntarily in their daily work for the organisation (Lytras and De Pablos, 2009). In practice, however, employees may be unable to articulate the content of this highly intangible form of knowledge, making it difficult to assess its impact on and potential benefit to the organisation (e.g. Stiles and Kulvisaechna, 2003). In health and social care organisations not only staff but also patients, service users and carers possess tacit knowledge in the form of knowledge of the experience of living with a particular condition, and the fears and anxieties that may be involved in this reality. This suggests that they are complicit in the creation of knowledge in organisations where they receive care.

The tacit knowledge of employees in health and social care organisations may have particular relevance to the delivery and management of care for people with dementia in terms of managing acute situations, harnessing non-verbal ways of communicating, and acknowledging the embodied, tacit knowledge of people with dementia and allowing this to help to inform care-giving (e.g. Moreno, 1953; Crystal et al, 1989; Carlsson et al, 2000;Kontos, 2003;Kontos and Naglie, 2007, 2009; Edvardsson and Nordvall, 2007; Rossiter et al, 2008; Kontos and Naglie in O'Connor and Purves, 2009; Kontos et al, 2010).

A number of authors have indicated that there are some key challenges associated with investigating tacit knowledge (e.g. Gourlay, 2006; Easterby-Smith and Prieto, 2008) not least those of understanding the nature and processes of tacit knowledge. Nonetheless, research on tacit knowledge in different organisational settings has proved fruitful not only in furthering understanding of tacit knowledge but also in revealing methods that have particular application for such investigations, and which may help in 'surfacing' tacit knowledge (e.g. Ambrosini and Bowman, 2001; Collins, 2001; Habersam and Piber, 2003; Gabbay and Le May, 2004, 2011; Mulder and Whiteley, 2007).

Aim and Objectives:

The overall aim is to generate insight and knowledge about what influence does tacit knowledge in health and social care organisations have on how care for people with dementia is specified, organised, delivered and managed.

The objectives are -

- To identify what tacit knowledge actually is, or might be, in the context of individuals' health and social care practice;
- To explore how tacit knowledge may manifest itself within the work practice of health and social care practitioners/staff, drawing on key conceptualisations of tacit knowledge from other researchers who have conducted empirical work in this area (Ambrosini and Bowman, 2001; Habersam and Piber, 2003; Mulder and Whiteley, 2007; Gabbay and Le May, 2004, 2011);
- To reach conclusions about whether and how we can know that specific practices, behaviours, and gestures equate to tacit forms of knowledge;
- To gain an understanding of the value that is placed on tacit knowledge by health and social care staff;

- To identify ways in which tacit knowledge is managed in services for people with dementia.

Methodology and Methods of Data Collection:

This study involves investigating and making sense of tacit knowledge in the day-to-day interactions and practice of one organisation providing memory services and another that provides day and respite services for people with dementia.

The aim of making sense of typical life of organisations lends itself to the method of ethnography. Ethnography has a credible history as a research method in institutional settings for older people, in health and social care settings for people with dementia, and in mental health settings more generally (e.g. Goffman, 1961; Henderson and Vesperi, 1995; Chatterji, 1998; Hertogh et al, 2004; Holthe et al, 2007; Baumbusch, 2010).

Ethnography is a method which can be said to help to 'close the gap' between research and participants. It amplifies what is *there*, and it gives voice to participants and their experiences. It provides a 'closeness' and type of narrative which is considered difficult or impossible to achieve through other methods such as questionnaires or surveys, or even observational studies. Ethnography invites the researcher to become embedded (to a greater or lesser extent) in the research setting where s/he makes detailed observations of verbal and non-verbal communication, interactions, human expressions and behaviours, alongside semi structured or unstructured interviews.

For this study I will be conducting overt observations and will recognise myself as a player in the research setting. Atkinson and Hammersley (1994) suggest that "*social research is a form of participant observation because we cannot study the social world without being part of it*". I will conduct detailed, in-depth observations in both of the organisational settings, in other local clinics where the team provides memory services to people with dementia, and during home visits conducted by members of the team. The observations will be of practice-specific and informal interactions between people with dementia, their carers, and staff. I will also conduct detailed in-depth observations of management meetings (e.g. team meetings, case conferences) of both organisations.

Semi-structured interviews with health and social care frontline staff and managers will provide a way for me to test out my provisional understandings of what I have observed, and explore in depth the understandings of staff of what tacit knowledge is and whether/how it manifests itself in practice.

Conducting overt observation requires me to announce my role as a researcher to participants. I will wear ID and will verbally inform staff, service users and carers of my role and intentions. However, I will have no control over how staff, service users and carers understand, respond to, and view the researcher role (i.e. what people make of me as I observe and make field notes and whether people will approach me and initiate conversation).

Sampling:

Non probability sampling is considered the appropriate approach for ethnography, and I am specifically selecting theoretical sampling. In theoretical

sampling an optimal case is selected as the fieldwork site where the processes being explored can be **expected** to happen (Glaser and Strauss, 1967).

I will adopt a flexible approach in terms of the sample size in order to reflect the idea of data saturation. Data saturation is a useful idea at a conceptual level but provides little practical guidance for estimating sample sizes prior to data collection. Therefore, my approach is to state that conducting a project over a 12 month period is likely to bring me into contact with between about 120 and 160 potential participants across both sites. Therefore the total *potential* sample consists of:

- All members of staff from the older people's mental health team who are in post during the fieldwork period;
- All members of the social care team at [REDACTED] respite and day service in post during the fieldwork period;
- All managers with management responsibilities relating to the older people's mental health team in post during the fieldwork period;
- All managers with management responsibilities relating to the social care team at [REDACTED] who are in post during the fieldwork period;
- People with dementia being seen at the NHS memory service by any member of the older people's team;
- Carers (this will include a friend, family member, or other relative) accompanying a person with dementia to an appointment with any member of the older people's team;
- People with dementia using the respite or day service at [REDACTED];
- Carers (this will include a friend, family member, or other relative) present at the respite or day service at [REDACTED].

In ethnographic studies it is possible that data saturation (the point at which *"no additional data are being found whereby the [researcher] can develop properties of the category"* [Glaser & Strauss, 1967:65]) is achieved early in the fieldwork, and researchers may withdraw from fieldwork at this point. The ramification of this for selecting a sample size is that the initial sample size estimated may be at variance with the actual sample size depending on when data saturation is reached. To account for this the approach I am adopting is to say that I expect to recruit a sample of 80 people (minimum) but that achieving data saturation may either occur before I reach 80 participants or not until I have reached a larger sample size than 80.

Data Analysis and Synthesis:

In ethnographic research data analysis begins in the very early stages of the research project (even at the pre-fieldwork stages in terms of formulating and clarifying research problems) and continues through the entire journey of the project. It will be important to maintain a degree of reflexivity in order to reflect on the data collection process and what is being produced.

'Making the familiar strange' (Erickson, 1984) is essential to analysis of data in ethnographic studies. This requires continually adopting a critical and questioning attitude towards what is being seen and heard, and Erickson suggests doing this by asking the simple question - "Why is this _____ the way it is and not different?"

During analysis I will draw on analytic concepts that help to make sense of what is happening in the scenes which the data document, and I will also be engaged with theory in the field of knowledge and how theories might help me to illuminate the data. In the advanced stages of data analysis and synthesis I will be attempting to recontextualise the observational and interview data in the context of current thought about tacit knowledge in organisations, and current practice in dementia care.

I envisage using NVivo 9 computer assisted qualitative data analysis software primarily as a way to organise the data, but may also draw on specific applications available in NVivo, such as 'modelling' for presenting data and findings.

Involvement of Patients, Service Users, Carers, and Staff:

I propose convening a mixed group of health and social care staff and informal carers at the midpoint of my data collection (i.e. approximately 6 months into my fieldwork) to whom I will present emergent data and my thoughts and ideas on analyses of these. This will be a way of giving access to participants to my data, and I will invite the group to consider the data and give their input in terms of thoughts and commentary about the meanings they attach to the data. Input from the group will be treated as 'new' data, and incorporated into my data analyses, thus providing an interesting further 'layer' of analysis.

Dissemination of Findings:

The research governance approvals from [REDACTED] council include the condition that the researcher will provide a short report to the council about the research. I will duplicate this report for the NHS trust. I will also provide a lay summary of findings for carers and service users and will request the two organisations to make copies available at the fieldwork sites. I will also make copies available to local relevant voluntary and community sector groups and their members (e.g. [REDACTED]). I will present interim findings at a conference relevant to the topic (2014/15), and I will also present interim findings at [REDACTED] Trust's R&D research event in February 2015.

During the first year following completion of my final PhD thesis, I will produce at least one publication for submission to a peer reviewed journal.

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Appendix D: REC letter of favourable opinion (Ref. 14/NW/0090. IRAS Project ID 140652)



Health Research Authority
National Research Ethics Service

NRES Committee North West - Haydock
HRA NRES Centre - Manchester
3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7827
Facsimile: 0161 625 7299

15 April 2014

Ms Sue Molesworth
Research Associate
North Staffordshire Combined Healthcare NHS Trust
Bellringer Road
Trentham
Stoke-on-Trent
ST4 8HH

Dear Ms Molesworth

Study title: An ethnographic study of the tacit dimensions of knowledge in the management, organisation, and delivery of services to people with dementia.
REC reference: 14/NW/0090
IRAS project ID: 140652

Thank you for your letter of 15 April 2014, responding to the Committee's request for further information on the above research [\[and submitting revised documentation\]](#).

The further information has been considered on behalf of the Committee by the [\[Chair\]](#) [\[Vice-Chair\]](#).

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Rachel Katzenellenbogen, rachel.katzenellenbogen@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [\[as revised\]](#), subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

[Omit this sub-section if no NHS sites will be taking part in the study, e.g. Phase 1 trials in healthy volunteers]

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Advertisement [REDACTED]	1/120813	12 August 2013
Advertisement [REDACTED]	1/120813	12 August 2013
Evidence of Insurance or Indemnity		23 July 2013
Interview Schedules/Topic Guides	2/060913	06 September 2013
Investigator CV: Sue Molesworth		28 January 2014
Investigator CV: Professor Steve Cropper		10 January 2014
Investigator CV: Dr Matthew J. Brannan		16 January 2014
Officer [REDACTED] Research Governance in Social Care		
Participant Consent Form: Staff Interviews	2/190913	19 September 2013
Participant Consent Form: Service Users, Patients & Carers - Observational [REDACTED]	2/190913	19 September 2013
Participant Consent Form: Service Users, Patients & Carers - [REDACTED]	2/190913	19 September 2013
Participant Consent Form: Pictorial Consent Form	1/270114	27 January 2014
Participant Consent Form: Nominated Consultant Declaration	010214	01 February 2014
Participant Information Sheet: Health and Social Care Staff	2/190913	19 September 2013
Participant Information Sheet: Service Users, Patients & Carers - [REDACTED]	2/071013	07 October 2013
Participant Information Sheet: Service Users, Patients & Carers - [REDACTED]	2/071013	07 October 2013
Participant Information Sheet: Simplified Pictorial Information Sheet [REDACTED]	1/270114	27 January 2014
Participant Information Sheet: Simplified Pictorial Information Sheet [REDACTED]	1/270114	27 January 2014
Protocol	2/270114	27 January 2014
REC application 140652/558770/1/854		
Referees or other scientific critique report		11 November 2013
Response to Request for Further Information		15 April 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators

- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/NW/0090	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Professor Ravi S Gulati
Chair

Email: nrescommittee.northwest-haydock@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Nicola Leighton, Keele University
Phil Elliott, [REDACTED]

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