

Stories we tell about dementia

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I declare that the work in this thesis was carried out in accordance with the regulations of the University of Gloucestershire and is original except where indicated by specific reference in the text. No part of this thesis has been submitted as part of any other academic award. The thesis has not been presented to any other education institution in the United Kingdom or overseas. Any views expressed in the thesis are those of the author and in no way represent those of the University.

Signed

Date

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Abstract

The dementias are illnesses which have significant cultural prominence and feature in a wide range of contemporary writing, often as a trope for old age. This thesis examines how stories of dementia are told in fiction and in the clinic. To do this, the work uses Arthur Frank's socio-narratology to examine twelve selected texts in which a key protagonist has a dementia. Three of the selected texts have been written by authors with direct experience of dementia within their family and form a subset of texts, memoir fiction. How stories of dementia are told is considered by examining the clinic as a storytelling venue, the creation of faux medical notes from information in the texts and a Triple Analysis of the memoir fiction using three reading templates. The templates have been created from clinical practice, using the questions posed by Frank's socio-narratological practice of Dialogical Narrative Analysis, and using the parameters of Rita Charon's version of Close Reading drill in Narrative Medicine. The work is informed by autoethnography which uses my position as a clinician and reader to examine how fiction has been used in my clinical practice and how it informs my reading of the selected texts.

The work has led to practical and theoretical outcomes. Alterations to assessment and post diagnostic clinical interviews are suggested which give more emphasis to the person's experience of their dementia. Information leaflets which use the selected texts to offer an alternative means of support and reassurance have been written. How Bakhtin's dialogical position might inform and improve clinical dementia care is explored. The work ends with suggestions about what further work is needed to facilitate the optimum use of this work in the clinical arena.

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Preface

One weekend in January 2014 the BBC broadcast the Radio 4 appeal for the Alzheimer's Society. The core of the appeal was a description of the day-to-day experiences of a forty-eight-year-old man with dementia and suggested that a cash donation of thirteen pounds could change his life by providing increased access to a dementia café. While well-meaning in its attempt to open purses and cheque books, such a portrayal of dementia is iniquitous, dishonest and clinically erroneous. The experiences of a forty-eight-year-old man with dementia will be unlike those of the vast majority of people with a dementia who are likely to be in their eighties, and whose memory difficulties will be compounded by the physical problems of increasing age. Thirteen pounds will not change the life of a person with such a dementia at any age, but dementia presented as tragedy which is ameliorated by hard cash, offers a good fundraising story.

The same weekend *The New Review* article, "New Faces, Fresh Fiction" described Emma Healey's yet-to-be published novel *Elizabeth is Missing* (2014) as 'detective fiction, period detail and dementia meet in a much-courted, multifaceted debut' (*The Observer* 12 January 2014). Healey had based the novel on her grandmother's dementia. Simultaneously *Guardian Magazine* (11 January 2014) ran an edited extract 'Holding on to mother' from Sally Magnusson's *Where Memories Go: Why Dementia Changes Everything* (Magnusson 2014), a memoir about her mother's dementia. Dementia as fiction and dementia as memoir meet as a story of family.

In the 'Do Something' pull-out magazine section of *The Guardian* (11 January 2014) Philippa Perry roused readers to walk more because it would lower the chances of developing a vascular dementia. This is evidence of a slowly increasing narrative, that dementia is at least partly due to lifestyle. In the 'Eat Yourself Smart' section of the same pull-out readers were encouraged to consume high levels of 'super-vitamin B12' because: 'A recent study from Oxford University found that high levels of B vitamins could slow down the onset of Alzheimer's disease.' The article cited no references and Vitamin B12 deficiency has long been cited as a 'reversible dementia' (Waite 2009, Osimani et al 2005). Having consumed the vitamins, readers were encouraged to chew their food for longer because 'a number of studies have linked having no teeth with the degeneration of cognitive function, and higher dementia risk, and one hypothesis was that if you can't chew, there is a reduction of blood flow to the brain.' No references were given in the article but an internet search has located 'Can poor dental health cause dementia?' <Poole 2013 WebMD.com> [accessed 14 September 2015]

On the following Monday (13 January 2014) *The Daily Express* ran one of their regular headlines featuring dementia 'Ten-minute test for Alzheimer's.'¹ Only in the last paragraph of the article on the following page did it state, 'It's important to note that the test is not designed to diagnose dementia.'

Later in the week Michele Hanson pointed out in her column in *The Guardian*, 'A Certain Age' (16 January 2014), 'Alzheimer's seems to be everywhere lately' and went on to question whether the errors she and her friend had made during the previous week amounted to Alzheimer's. The question was a rhetorical one and she

¹ *The Daily Express* and *The Daily Mail* frequently use dementia or Alzheimer's Disease as a banner headline such as 'Britain's Dementia Time Bomb' (7 November 2011). It rivals the weather (*The Daily Express*) and house prices (*The Daily Mail*).

did not wish to know the answer. Michele Hanson is right, Alzheimer's is everywhere. It has been addressed in every cultural medium. Stories about dementia have been told in film,² poetry,³ verse-drama,⁴ television drama,⁵ stage drama (Beckett 1981, Zeller 2015), opera,⁶ cookery book,⁷ and portrayed visually on a Grayson Perry pot.⁸ It is a regular crossword clue.⁹

Stories are told everywhere and about everything; they are what make us human, humane and social. To find such a profusion of dementia stories over one weekend amidst New Year resolutions, retail bargains and portrayed as an illness preventable through assiduous chewing, made me, an NHS clinician, angry and thoughtful. What is it about dementia that makes it so useable in so many different genres and why is the portrayal so often muddle-headed?

This thesis will explore these questions using an NHS 'episode of care' as the underlying metaphor. The preface acts as the presenting problem. Chapters one and two fulfil the assessment process in which preliminary investigations are carried out. The focus in Chapter 1 is how dementia is portrayed in fiction. The rationale and background for treatment is explained in Chapter 2 as the research design. Treatments are delivered in Chapter 3 as the research interventions which are then reviewed in Chapter 4 as research outcomes. Chapter 5 acts as a discharge appointment for review of the care and suggestions for the future.

² *Quartet*, (2012) dir.by Dustin Hoffman (Momentum Pictures 2012).

³ *The Old Fools* (Larkin 1974).

⁴ *Black Daisies for the Bride* Tony Harrison. BBC 1993. Prix Italia Winner 1994.

⁵ *Exile* Screened May 2011. BBC 1 Written by Danny Brocklehurst. Producer Paul Abbott.

⁶ *The Lion's Face*, written by Elena Langer, Librettist Glyn Maxwell. Premier 21 May 2010.

⁷ *Healthy Eating to reduce the risk of dementia*. 100 fantastic recipes based on extensive, in-depth research. 2015 Margaret Rayman et al (London: Kyle Books).

⁸ *Sketchbooks*, Grayson Perry. 2016 (London: Particular Books) A photocopy of the drawing of 'Alty' is shown in Appendix 1.

⁹ Unfortunate condition of Parisian I meant to resolve. *Daily Telegraph* Prize Crossword 27707(24 January, 2015)

This model is drawn from my experiences as a clinician in the NHS working in dementia services and whose greatest professional pleasure was taking a clinical history which was thorough but efficient, and validated the experiences of the person and their supporters attending a Memory Clinic. The professional is combined with the personal through the stories told in the clinic because as well as being a clinician I am also a reader.

Dementia is a global phenomenon, but as a health issue it is most prominent in western developed countries and this thesis is restricted to British and North American fiction. This stance tallies with my experiences as a clinician. Despite working in older people's services in the NHS for over three decades, including a period in London, my experience of people with dementia from the Black, Asian and Ethnic Minorities (BAME) has been limited. Dementia is likely to present with the same neuropathology and symptoms but the meaning the symptoms have, and the way in which they are interpreted, might be different for the BAME communities. I cannot write as a clinician/reader and speak about these groups with an equivalent depth of experience and the limitations of the research are acknowledged. Writers with an Asian background have written fiction in which there is a strong presence of elderly parents and old age, but this arena has largely been one of contested family relationships between generations, rather than family relationships clustering round cognitive decline. An exception would be Rohinton Mistry's *Family Matters* (2002) which addresses Parkinson's Disease, a frequent precursor to a dementia. Similarly, the thesis does not address two significant European novels about memory loss and dementia available in an English translation: Cees Noteboom's *The Following Story* (1994) and J. Bernlef's *Out of Mind* (1984) which act as illness narratives in their portrayal of a person struggling with a diminished memory but not necessarily

dementia.¹⁰ To extend the analysis to include novels in translation would have made an already large body of work too extensive to be manageable for this research. When reading UK and American fiction as a clinician/reader I feel that I have a greater understanding of the likely health care and support systems¹¹ than I do of the various European systems.

¹⁰ I was directed to *The Following Story* by Michael Ignatieff through contacting him to confirm his familial knowledge about dementia.

¹¹ I was fortunate to be awarded a Churchill Travelling Scholarship in 1981 to study elderly health care provision in the USA.

Chapter 1

Dementia and fiction

1.1. Introduction or *Initial assessment*

The examples in the preface indicate the cultural penetration of dementia as an illness about which it is almost impossible to be unaware. They demonstrate the range of discourses and misinformation that roil round dementia but no other illnesses which are equally debilitating albeit in a different way. The stories which tell about dementia as personal tragedy; as an illness which is preventable by a change in lifestyle (or chewing), or as something that can be diagnosed in ten minutes, both inform and are informed by the culture in a circular fashion. This thesis will explore this circularity by investigating stories told about dementia in contemporary fiction and in the clinic.

It will do this by telling a different story about dementia: one which draws on the theory of socio-narratology (Frank 2010) and autoethnography as a research methodology. The stories analysed in this work are of two sorts: selected contemporary fiction and the clinical history as told in an NHS Memory Clinic. Autoethnography draws on my experience as an NHS clinician who was also a reader and who used fiction in practice before ‘bibliotherapy’ became an NHS treatment option. Both theory and methodology acknowledge the role of the self as contributing to the positions of reader and researcher and this is made clear in this thesis by the use of the terms clinician/reader and autoethnography.

The clinician/reader compares the stories heard in the clinic to the fiction that is being, or has been read. The reader/clinician reverses the process and compares the stories in fiction with the stories from the clinic. It is a vacillating position changed by the company the reader keeps. After listening attentively to stories in the clinic,

reading allowed me to ‘pass over into the consciousness of another person, another age, another culture... [and] never come back quite the same; sometimes we’re inspired, sometimes saddened, but we are always enriched’ (Wolf 2008: 7).

Sometimes, however, I would be incensed at the portrayal of dementia: how it was used unnecessarily, how it was usually wrong, how too often it happened to the young, and how the cultural portrayal of dementia in fiction rarely ‘rang true’ with my experiences in the clinic.

This chapter will present the aims of the research, explain the presenting problem with dementia and fiction and then describe the rationale for the fiction selected for analysis. Since this thesis draws on clinical experience as well as fiction the medical understanding of dementia is discussed before moving to how the illness airs in contemporary culture.

1.2. Aims of the research

In this research my aims were to explore stories about dementia in fiction using socio-narratology (Frank 2010) and to make links between the stories of dementia, now widely published, and those told in the clinic as the clinical history as being similarly fictive. To achieve this I used a blended research model of autoethnographic methodology, the socio-narratological practice of Dialogical Narrative Analysis (DNA) and the Close Reading drill of Narrative Medicine (Charon 2008) to examine the two genres of stories, and further, used them to create specific outcomes for use by health professionals. This blended model is united by the involvement of the self in research processes.

Autoethnography is defined by Ellis and Bochner as a ‘genre of writing and research that displays multiple layers of consciousness connecting the personal and

the cultural (2000: 739). In this work it takes a range of forms: vignettes followed by commentary which describe how fiction has been used in my clinical practice and, in Chapter 5, to reflect on the totality of the research process, the manner in which I use a clinical template developed in practice to interrogate three of the selected texts and in my presentation of an alternative understanding of the clinical interview as a story-telling venue. The autoethnographic thread running through the work draws on previous lived experiences, not only as an NHS clinician, but an NHS clinician who read, and used reading to inform clinical practice. Autoethnography is a recognised and accepted sociological methodology which can incorporate this retrospection of the 'dramatic recall' (Sparkes and Smith 2012: 57) because it places the experiences used in a cultural context. In this work the context is how dementia, an illness of old age, is portrayed in fiction and how this relates to the world of the patient and the clinician.

A key social identity of the 'I' in this work is myself as the clinician/reader and reader/clinician. This dual identity is one I have held informally throughout my career but is formally positioned here as integral to this thesis. Labels such as clinician/reader and reader/clinician and those of the patient/reader or supporter/reader are what Diana Fuss calls 'I-slots' (1989: 35) assigned for 'terminological convenience' (ibid: 34) and are not fixed positions but 'fluid boundaries' (ibid: 34). Reading, she argues, creates 'social vacancies' that are filled in different ways by different individuals who never 'just read' but 'always read *from somewhere*' (ibid: 35 Original italics). I read as a serious reader until I read about dementia whereupon my 'I-slot' shifts and I cannot help but read as a reader/clinician. The subjectivity of reading and the flexibility of the 'social vacancy' filled by 'the reader' need to be borne in mind when recommending fiction

about dementia in the clinical space. Although potential readers of the suggested fiction may be attributed labels such as patient, supporter or trainee health professional their 'I-slots' are inherently varied and not their only 'subject positions' and are likely to generate alternative readings of the same text dependent on where they are in the trajectory and experience of dementia. Being a reader, Fuss argues, is socially mediated and implies identification with the assigned category. While I was at ease with my dual identity, my 'I-slot(s)' as a reader/clinician, the people attending a clinic may not feel ready to absorb the assigned 'I-slot' role of patient or supporter, for instance, defiantly stating in the clinical interview 'I am his wife/husband *not* his carer'.

The serious reading of fiction is integral to my sense of self. In this work the focus is on fiction in which a key protagonist has, or is diagnosed with a dementia. Using Arthur Frank's socio-narratological practice of Dialogical Narrative Analysis (DNA) to analyse the selected fiction combines elegantly with autoethnography because both practices demand the active involvement of the self, as reader and researcher to creating the understanding of the stories told. The understanding of the 'dementia fiction' created here is the result of over two decades of involvement with clinical stories in memory clinics and a life time of reading. Socio-narratology offers a theory of how stories shape us and are shaped by us and the practice, Dialogical Narrative Analysis (DNA), for analysing them. DNA and autoethnography are used concurrently throughout the work and in the final summary chapter. Frank, a sociologist, does not cite autoethnographic methodology in his key socio-narratology text *Letting Stories Breathe* (2010) but it is inherent to the theory and demonstrated in the manner in which he uses exemplar stories, which range through myth to illness narratives, including his own, and his experiences as a story teller. The practice of

DNA has been developed into a reading template which is used to question three selected texts to examine, not their narrative structures, but 'what might really be happening' in the novels. This creates a congruency with clinical practice because it is the question which all clinicians should be asking in any consultation.

Frank does draw on the work of Rita Charon in *Letting Stories Breathe* (2010). Charon is a practising US physician who uses fiction in her medical teaching. She has developed a clinical humanities specialism by which she aims to use narrative skills honed through reading fiction to develop an awareness of the stories the patient tells the clinician 'to understand what they mean, to attain rich and accurate interpretation of these stories, and to grasp the plight of the patients in all their complexity' (Charon 2006: 3). For Charon the story told in the clinical space is not a mere routine medical process but dynamic and 'able of its own' (2006: 108) to alter what happens between the clinician and the patient. In her book *Narrative Medicine* (2008) she presents a narratology appropriate to medical practice and has developed a Close Reading drill for fiction which she teaches to trainee health professionals in the strong belief that such an analysis strengthens 'the cognitive and imaginative abilities that are required for the person to take in and appreciate the representation – and therefore the reality – of another' (2008: 113). This drill is used in relation to the three selected texts also analysed using the clinical and DNA template.

Together the three themes of the research: autoethnography, socio-narratology and Close Reading create an integrated and mutually supportive research framework for understanding both fictional and clinical storytelling. They inform the key research intervention, the Triple Analysis which uses reading templates created from my clinical practice, DNA and Close Reading to examine three of the selected

texts which are written by authors who have familial knowledge about dementia. Faux medical notes have been created from these three texts which offer a further means of interrogating the texts and testing their clinical veracity.

1.3. Why the portrayal of dementia in fiction is important

This thesis is predicated on a key tenet: that fiction is a significant cultural medium and that it has the capacity to elicit change. Fiction is part of the cultural landscape, a space where complex issues can be raised and debated. It does its work through reading, a cultural accomplishment now almost universal in the West which can ‘transform attitudes, affect emotions, enlighten, indoctrinate, subvert, seduce or corrupt’ (Furedi 2015: 31). It can ‘change minds’ (Sutherland 2013: 202) and help us live our lives and, according to *The Daily Telegraph* headline on 4 July 2013 ‘A life of reading may protect against dementia.’¹²

If fiction is accepted as a potentially powerful force on how dementia is portrayed it becomes relevant when considering the issues of reading and dementia care. Both are dominated by women. *The Woman Reader* (Jack 2012) quotes a 2004 survey of reading habits revealing that men’s favourite novels were ‘essentially novels of ideas that explore, sometimes among other concerns, essentially intellectual questions in which alienation, free will and angst are central’ (ibid: 286) whereas what was important to women in a novel was that it ‘took the reader on an emotional journey that found resolution in a way which mapped onto their own lives and life crises’ (ibid: 287). Similarly a 2005 BML/Arts council survey of reading

¹² The paper from which this headline was drawn ‘Life-span cognitive activity, neuropathologic burden, and cognitive aging’ (Wilson. R. et al. 2013. *Neurology*, Jul.23; 81(4):314-321) suggests a much more equivocal stance of ‘habitual participation in cognitively stimulating pursuits over a lifetime might substantially increase the efficiency of some cognitive systems so that a relatively greater neuropathological burden would be required to impair functioning’. Reading was only one of the activities studied which included ‘seeking or processing information’ and included letter writing and visiting a library.

confirmed that 40% of people read, with the highest readership of women between 55-64 years of age and into their 70s and who felt that reading was a good way of gaining new knowledge and perspectives. This is the same demographic of people who are likely to be involved in dementia care. As Alberto Manguel has pointed out, reading has allowed women 'to find voices similar to their own, to discover their plight was not unique, to find in the confirmation of experience a solid base upon which to build an authentic image of themselves' (1996: 235) and claim reading as a social currency (Bloom 2008), something which is evident in the growth of book groups. These are predominantly, although not solely, a female domain and in my experience of two, the membership profile of each matched the group who are the most likely to be providing support and care to an elderly relative. One in three people will care for a person with a dementia in their lifetime (Department of Health 2013) and the hierarchy of preferred family support of women before men first identified in the 1970s is still extant (Lee et al.1993). Although men do provide care, 70-80% of home care for elderly people is provided by women (some estimates say 90-95 %). Daughters remain the preferred carer, followed by daughters-in-law who are more likely to be carers than sons, and sisters more likely than brothers. 'Thus the commonly used term "family care" is a euphemism for women's work' (Cruikshank 2013: 125). Similarly professional carers provided by social care and nursing agencies are overwhelmingly women and those cared for by women are predominantly women. In the age cohort 85 years and above, in which approximately one fifth of people will be expected to develop a dementia, women outnumber men 2:1 (Office for National Statistics 2013). Dementia is a gendered problem although rarely addressed as such. Such a bold statement becomes important when considering the role of fiction and its readers discussed earlier. It can

be extrapolated from these positions that fiction portraying dementia has extra relevance for women, who make up the bulk of readers of fiction, and are the predominant carers of people and family members with dementia. In an illness with such cultural penetration and saturation coverage, the portrayal of dementia in fiction ought not to be cavalier. If fiction is to make meaningful the range of resources Sutherland claims, it should, at the very least 'notice reality' (Tallis1998: 213) and resonate with the experiences of the general reader and the clinician/reader.

The following section describes the fiction selected for analysis in this work. The selection of texts does not aim to be comprehensive but representative of fiction encountered prior to, and during the research process. The texts vary in the manner in which they address the condition, ranging from the pragmatic and instructive to the allegorical where dementia is a cipher for the work of memory. They are varied in their style but are united in addressing dementia as central to the narrative through a character that will be, or has been, diagnosed with a dementia.

1.4 . Fiction selected for analysis

The twelve texts selected for analysis all feature central characters that have, or are diagnosed with a dementia. They fall into three main categories: didactic fiction, literary fiction, memoir fiction and stand-alone texts. Didactic fiction is written by the author to inform and educate. Literary fiction comprises texts in which a dementia is used to explore memory and the past in an elegiac rather than educative manner and includes prize winning texts. Memoir fiction is written by authors who have experienced first-hand a dementia in a parent. Stand-alone texts include short stories and a crime thriller which places the progression of a dementia as central to the plot.

Scar Tissue (Ignatieff 1993) provides the starting date for inclusion as a selected text because it was the first novel to fictionalise a family dealing with the diagnosis of a parent with ‘premature senile dementia’ (ibid: 54). The rationale for the end date is that it marked the end of my clinical practice in 2013 when I no longer listened professionally to stories about dementia. Most of the texts were published after 2000, the watershed moment in dementia care when acetylcholinesterase inhibitor (ACI) medication became available on an NHS prescription to help ameliorate the symptoms of dementia. This heralded a Department of Health campaign to raise dementia awareness and increasing access to ‘memory clinics’.

1.4.1. Memoir fiction

Four of the texts: *Scar Tissue* (Ignatieff 1993), *The Corrections* (Franzen 2001), *Grace and Mary* (Bragg 2013) and *The Story of Forgetting* (Merrill Block 2008) follow the course of the disease from diagnosis until death and form a subgroup designated here as ‘memoir fiction’. The texts have been written by authors who have been open about their familial knowledge of the disease and their use of it as source material, although they have done this in different ways. Ignatieff’s personal involvement with the disease was revealed in an academic paper (de Falco 2012) and he has since confirmed this in a personal communication. The memoir fiction texts are subjected to a range of analytical lenses in Chapter 3.

The Corrections (Franzen 2001) is a long and complex novel, a literary family saga in which Alfred Lambert’s developing dementia is the uniting narrative thread through which everybody is changed and the understanding of their lives ‘corrected’. Franzen has written extensively about his family experience of a dementia in his non-fiction writing. In ‘My Father’s Brain’ (2002) he describes receiving the autopsy

report of his father's brain and reflects on the life of his father, Earl Franzen, who developed a dementia and eventually moved into full time nursing care. In a subsequent essay 'On Autobiographical Fiction' (2012) Franzen denies that his novels are autobiographical:

In thirty years, I don't think I've published more than twenty or thirty pages of scenes drawn directly from real-life events that I participated in. I've actually tried to write a lot more pages than that, but these scenes rarely seem to work in a novel. They embarrass me, or they don't seem quite interesting enough, or, most frequently, they don't seem quite relevant to the story I'm trying to tell. Late in *The Corrections*, there's a scene in which Denise Lambert — who resembles me to the extent of being the youngest child — tries to teach her demented father how to do some simple stretching exercises and then has to deal with his having wet the bed. That actually happened to me, and I took a number of the details straight from my life. Some of what Chip Lambert experiences when he's with his father in hospital also happened to me.

(*Farther Away*, 128)

The Corrections (Franzen 2001) is not a memoir about his father but the resemblance between Alfred Lambert and Earl Franzen is obvious. Franzen's description of his father as an 'intensely private person, and privacy for him had the connotation of keeping the shameful content of one's interior life out of public sight' (Franzen 2002: 24) accurately describes Alfred in the novel. Similarly, he describes his mother as:

Task by task, she took charge of their life. And so, although my father's "long illness" was a crushing strain and disappointment to her, it was also an opportunity to grow slowly into an autonomy she'd never been allowed: to settle some very old scores.

(*How to Be Alone*, 25)

This is an apt description of Enid Lambert's participation in the events of the narrative in *The Corrections* (Franzen 2001).

In an interview with Stephen Burn for 'The Art of Fiction' in *The Paris Review* Franzen describes how the purpose of literature is 'to connect with that which is

unchanging and unchangeable, the tragic dimensions of life' and that the literature he was 'interested in and wanted to produce is about taking cover off our superficial lives and delving into the hot stuff underneath.' Franzen does his revealing in *The Corrections* (2001) through 'hypervivid characters, the inter-locking novella's structure, the leitmotifs and extended metaphors' (Paris Review 207) by which he gets to 'aggressively inflict painful knowledge on one character after another' to create a black and 'somewhat angry comedy' (ibid.).¹³ *The Corrections* (Franzen 2001) is not anodyne schmaltz. Comedy in the text is present but fleeting. There is a humorous episode involving Chip, the errant son, leather trousers and salmon fillets but the main comedy in the novel comes from Enid Lambert's social pretences. Alfred's position is written as tragic as his illness leads him into predicaments of almost unbearable poignancy and 'speechless trouble' (Weinstein 2015: 111). Franzen states in his Paris Review interview, '*The Corrections* was pre-occupied with the unreal, wilfully self-deceptive worlds we make for ourselves to live in' yet it is realist fiction. Franzen's position is paradoxical; he denies an absolute parallel with his parents even though 'it became all the more true in *The Corrections*. Precisely then, when I needed to focus all my attention on writing a novel, my parents were falling apart'. He went on to explain:

those Lamberts just kept getting larger and larger. Alfred and Enid were always Alfred and Enid, their voices taken from life. My parents were *not* Alfred and Enid, but on bad days they could sound like them.

(*The Paris Review*, 207)

Such a comment suggests, if not a truth, then a parallel experience, the engineering of literature whereby direct experience is reassembled into fiction.

¹³ <<http://www.theparisreview.org/interviews>>207[accessed 18 January 2015]

Melvyn Bragg, like Franzen, has shared his experiences of a parent with a dementia in an interview, *Proud to be my mother's boy* (*Guardian* Family section 11 May 2013). At Dartington (13 July 2013)¹⁴ he described *Grace and Mary* (Bragg 2013) as using fiction 'to tell the truth about this extraordinary condition' and to get 'as near the truth as I can' and gave a candid account of his mother's dementia which was close to the events in *Grace and Mary* (2013). In the interview he describes 'the first click' of the dementia and the start of her 'inexorable decline'. Despite having carers coming into the house to help, and the installation of a downstairs bedroom, Mrs Bragg refused to use it 'trudging upstairs when everybody's back was turned' (*Saturday Guardian* 11 May 2013) and she could not be maintained safely at home. A trip, leading to a broken ankle, was 'the beginning of her going into hospital, and from there to a nursing home, and by that time her memory was deteriorating' (*ibid.*), a course familiar to health and social care services.

Once in care Mary, in *Grace and Mary* (Bragg 2013) is not always easy to visit. Nor was Mrs Bragg, who her son described at Dartington as "not a settled personality at all, not for a moment".¹⁵ In his *Guardian* interview he recalled that:

She would slip out of character and could be quite harsh with me, with the nurses — sending us away. Sometimes she'd forget I'd been there half an hour previously. 'What are you doing here?' she'd say. 'You never come to see me.' When I'd start to explain, she'd say: 'Well, you've seen me now, so cheerio.'¹⁶

He used the same situations in *Grace and Mary* (Bragg 2013: 75, 100, 143).

Talking openly about his mother at Dartington Bragg appeared as unruffled and unhurt as John is in the novel. In his interview Bragg describes finding most difficult

¹⁴ Ways with Words Literary Festival Dartington, Devon, UK 2013

¹⁵ Direct quote from notes made at the Dartington lecture.

¹⁶ Angela Wintle, 'Proud to be my mother's boy', *The Guardian*, 11 February 2013, Family section, p.3.

his mother's 'lapses into normality', leading to him question whether she could 'see the wreckage' as she confided once to her son, 'I won't get better, will I? They should put us down.' which he uses in the text (Bragg 2013: 75). This experience is shared by many relatives. Such flashes of insight are heart rending and moved me profoundly when I encountered them in clinical practice. They are a reminder that the issue in dementia may not always be one of forgetting, but of being unable to articulate ones needs, thoughts or desires and inform an alternative understanding of dementia discussed in Chapter 4.

In *Grace and Mary* (Bragg 2013) John fleetingly contemplates easing his sleeping mother's progress towards death, 'Should he not help her find a way to go, to die?' (ibid: 247). Of the selected texts only the dementia memoir fiction addresses the very end stages of dementia and death, presumably because it has been observed first hand. It is a stage of the disease hidden from public view, largely managed in nursing and care homes, and likely to be witnessed only by those with direct familial or regular contact. Visiting a person at this stage of the disease can be hard work and unrewarding, as it was for Melvyn Bragg in real life, John in *Grace and Mary* (Bragg 2013), Chip and Enid Lambert in *The Corrections* (Franzen 2001) and the narrator in *Scar Tissue* (Ignatieff 1993) but is an essential part of bearing witness to the ravages of the disease in somebody who is cared about.

Stephan Merrill Block, the author of *The Story of Forgetting* (2008) has used his web page <<http://www.stefanmerrillblock.com/bio/origin.html>>[accessed 24 September 2014] and author's notes to explain his familial link. His grandmother developed a dementia during his childhood and came to live in the family home. Merrill Block observed dementia at close quarters but as a child he would not have had the responsibility for his grandmother's care and for this reason he is not

included in the more detailed analysis of dementia memoir fiction. In his author's notes he cites Franzen's 'moving and sharply insightful essay 'My Father's Brain' that forever changed the way I think of Alzheimer's, explicating its emotional complexities, bizarre paradoxes, and creative possibilities' (Merrill Block 2008: 311). *The Story of Forgetting* (Merrill Block 2008) has the most complex structure of all the texts. The narrative voices of Seth and Abel tell two stories separated by time which eventually coalesce. Overlaying this is the allegorical tale of Isidora 'a land without memory, where every need is met and every sadness forgotten' (ibid: 13). The presence of Isidora in the structure of text becomes more prominent as the narrative progresses, mirroring the grip dementia has as a shared reality recedes. In the text the implications of a land without memory are exposed.

The three key memoir fiction texts do not solely track a dementia from first symptoms to death but address other areas of life and in this way reflect the lives of non-fictional supporters or carers who are unable to devote themselves solely to the caring role. *The Corrections* (Franzen 2001), as well as being a family saga exploring the 'subterranean damage wrought upon one's family by the hard life of a rigid husband and withdrawn father' (Weinstein 2015: 108), is a big American 'state of the nation' novel which satirises many aspects of American culture ranging from restaurateurs and high-end cooking, big pharma, higher education and literary theory. *Scar Tissue* (Ignatieff 1993) is a philosophical text addressing stoicism and the nature of the self and *Grace and Mary* (Bragg 2013) explores the stigma of illegitimacy. Just as the novels are not only about dementia, patients and their supporters are not solely about diagnosis, but have lives, concerns and aspirations beyond the clinic.

1.4.2. Didactic fiction

A second group of texts, *Forgotten* (Lewis 2010), *Remember Remember* (McHaffie 2010) and *Still Alice* (Genova 2009) address dementia directly and are written with the overt aim of informing the reader about the condition. They are categorised in this thesis as ‘didactic fiction’. Susan Lewis writes ‘topic fiction’ on contemporary issues such as ‘saviour siblings’ and domestic violence under the rubric ‘Real Drama: Real Issues’. In the letter to her readers at the beginning of *Forgotten* (Lewis 2010) she hopes she can ‘reach someone in a way that will make them feel less isolated or afraid of something life has thrown their way’ (Lewis 2011: ii) and invites her readers to contact her if they wish to comment on the book. In *Forgotten* (Lewis 2010) David Kirby, a Member of Parliament, marries for a second time, becomes forgetful and is diagnosed with a dementia. He makes plans to travel to an assisted suicide clinic in Switzerland but is struck down by a cerebral haemorrhage before acting upon them. The message in the text is one of highly romanticised unconditional love and support, whereas my experience in the clinic suggests that when dementia occurs in second marriages, without the emotional glue and weathering of a long and stable partnership, dementia may be particularly tricky to navigate.

Hazel McHaffie, who trained as a nurse, also writes ‘topic fiction’ and has previously published novels on medical ethics and in *Remember Remember* (2010) addresses dementia. Doris Mannering is an elderly lady who has kept the secret that her daughter is adopted. The text presents as a fictionalised textbook of dementia care as it describes clinical set pieces such as receiving the diagnosis, medical review, decisions about extra care support at home, and an eventual move to permanent care. Specific assessments are quoted in full and what McHaffie considers

good care practice is labelled, promoted and demonstrated. McHaffie, describes the 'Absolutes', 'all the things you should never do with someone who has Alzheimer's' (McHaffie 2010: 23). Doris' daughter acknowledges these as being impossible 'when there is no off-duty, no annual leave, no retirement' (ibid: 25) and feels that 'If I hadn't heard of the commandments I'd have been spared this additional layer of guilt at least' (ibid: 24). This may be helpful and confirmatory to a struggling supporter of a person with a dementia. Although the 'Absolutes' or 'commandments' do reflect good practice regarding communication ¹⁷ they are not documented anywhere as a prescriptive list and the manner in which the 'Absolutes' are presented in the text suggests a false legitimacy.

The third 'didactic fiction' text is *Still Alice* (Genova 2009) in which Dr Alice Howland, the William James Professor of Psychology at Harvard University finds herself struggling to find words and loses her way home when out running. She is eventually diagnosed with early onset Alzheimer's Disease. The narrative describes Dr Howland's gradual decline and navigation through the changing dynamics of professional and family relationships which the diagnosis imposes on her. The novel was self-published by Lisa Genova after she had contacted the American Alzheimer's Association marketing department who had reacted positively. 'Realizing that I'd created something that the Alzheimer's Association thought was valuable, that could help and educate the millions of people trying to navigate a world with Alzheimer's, I felt an urgent responsibility to get the book out immediately' (Genova 2009: 300).

¹⁷ There are obvious rules regarding physical care and verbal abuse but these are laid down in quality and commissioning guidelines. Most health professionals and voluntary sector guidance suggest broad approaches rather than any 'Absolutes'.

1.4.3. Literary fiction

A third group of dementia fiction texts is 'literary fiction' which comprises *The Wilderness* (Harvey 2009) and *The Garden of Evening Mists* (Eng 2012). These are books which have been on short or long lists for major literary prizes. *The Wilderness* (Harvey 2009) was on the Orange Prize short list in 2009 and *The Garden of Evening Mists* was on the Man Booker short list in 2012. *The Corrections* (Franzen 2001) and *Scar Tissue* (Ignatieff 1993) could also form part of this group. *The Corrections* (Franzen 2001) won the US National Book Award in 2001 and *Scar Tissue* (Ignatieff 1993) was shortlisted for the Booker Prize for Fiction and the Whitbread Novel award in 1993. They are categorised differently, not only because of the familial link. Memoir fiction follows the course of the dementia until death whereas the selected literary fiction takes a stage in the progression of the disease to explore memory and the nature of the self in time through the past and anticipation of the future. *The Wilderness* (Harvey 2009) portrays a relatively early phase of the disease in a successful architect, Jake. The story tracks his decline over four years and the novel ends with Jake still sentient and active. However, as 'he searches through an archive of other one-day thoughts and decides whether to guard them or dispose of them' (Harvey 2009: 328) Jake has moved from a functioning and useful memory to one located in immediacy and fantasy.

The Garden of Evening Mists (Eng 2012) is written in the first person. It is an ironic and complex position because it uses the most lyrical and elegiac language of all the selected texts and features Judge Teoh who has been diagnosed with an unusual early onset dementia, Primary Progressive Aphasia (PPA), which, in its early stages affects language, rather than memory function. The text describes how Judge Teoh creates a garden as a permanent memorial to her sister, who had been in

a Japanese POW camp in the Second World War. The garden will become a substitute for Judge Teoh's anticipated inability to articulate or remember anything about her sister as her dementia progresses, but she will be able to experience the garden. Despite fearing what is ahead 'The prospect of being locked inside my own mind terrifies me' (Eng 2012: 339) the creation of the garden offers Judge Teoh a way of managing the future with 'So many things to do. I will be kept busy in the coming weeks and months' (ibid: 347).

1.4.4. Stand-alone dementia texts

Three texts stand alone. Two are short stories and the other a crime thriller. They are used in this work because they demonstrate a particular telling of a dementia. 'These are not my clothes' in Jackie Kay's collection *Reality, Reality* (2012) is told as an internal monologue by Margaret, a resident in a care home, who is hoping that her favourite carer will be able to buy her a red cardigan. The text describes two days of Margaret's life and access to her internal thoughts and desires which she does not express verbally. The nature of Margaret's condition is not made clear and the reader remains uncertain about how to respond because her reasoning and world view, in which a garden seat is able to speak, becomes increasingly strange. This leaves the reader unsure about whether the red cardigan, which is so fervently desired, has ever existed. In comparison the description of the social structure within the home makes the reader very sure that it will never materialise.

Margaret has increasingly sinister experiences:

No whingeing today, eh? She tugs my hair. No crying, no complaining?
Nope, I say, moving my head elegantly out of her way and shaking it,
proudly tilting my chin, so that it is up in the air and my head is a little back,
No certainly not. We are fine today because our lawyer is arriving at noon.
Come again? Says the nurse, looking, I must say a little apprehensive. You

heard the first time, I say, using my deep voice. You better get a smart suit, lady, because you are going to court!

(*Reality, Reality*, 36)

The reader hopes that it is her memory loss which drives the unreliable narration and that she is sinking into fantasy but scandals about the quality of care in residential and nursing homes remind the reader that Margaret's unreliable reality may be more truthful than we may wish to consider. When, as a clinician, I tried to promote 'These are not my clothes' (Kay 2012) as a teaching tool for care-staff it was deemed by the NHS management to be too inflammatory. The rationale for my suggestion was that it could, at the very least, remind care staff that small acts of care and compassion, such as placing Margaret's chair where she could see the bird table, become significant in a restricted life. Instead, for Margaret it is the garden bench which is in sight. It becomes hyper real and a substitute for social contact which acknowledges her as a person:

Maybe the bench is reading a book. Maybe the bench is reading *Madame Bovary* — that was the name of a book I once read, *Madame Bovary*. It was by Flaubert. Maybe the bench is French.

(*Reality, Reality*, 23)

'The Pink Ribbon' in one of A.S. Byatt's collections of short stories (2003) takes a fragment of time to give an insight into the position of an elderly spouse:

James turned the television on to distract her gaze and cover the sound of the door opening and shutting. There was a picture of childish flower-drawings and regulated grassy hummocks. There was smiley music. There were portly coloured creatures, purple, green, yellow, scarlet, titupping and trotting.

('The Pink Ribbon' 235)

His wife Mado has retreated into the égarement of dementia. In the story a carer arrives. James, who still parses *The Aeneid* for pleasure, leaves the house to go shopping and buys the Telletubby doll, Dipsy, for his wife. That Mado had been

working for British Intelligence when they had first met, and he is now asked whether the doll is for a grandchild, adds pathos unmatched in the selected texts. This small act encompasses the seismic changes that a dementia demands for the person with it and those around them. It is a text suffused with loss and yearning and articulates the description of living with a person with advanced dementia which a wife described to me in the clinic as being a 'widow of the living dead'. The story draws on the mythical Irish Fetch to provide a symbiotic link to all stories of ethereal callers from the grave, but most powerfully to the dementia of Dame Iris Murdoch. In *Iris* (1998) John Bayley announced to the world that his strange, but brilliant, philosopher and novelist wife, Iris Murdoch, who wrote sentences of great length but immaculate construction, had been diagnosed with Alzheimer's Disease and now spent her days enjoying the antics of small, brightly coloured humanoid dolls who communicated in a barely comprehensible 'language'. It is a view which appears to have overtaken all her other attributes in any discussion about her and her writing. It is not possible to read 'The Pink Ribbon' (Byatt 2012) without making reference to John Bayley's use of the children's television characters, the Teletubbies, to entertain his wife. Bayley writes that although Iris Murdoch could no longer make sense of some one-time favourite palindromes 'she will watch the animated cartoons on children's TV with something approaching glee. They can be a great stand-by at ten or so — the trickiest time — till eleven in the morning' (Bayley 1998: 61).

The final text, *Turn of Mind* (LaPlante 2011) has been selected for analysis in this thesis because, like 'These are not my clothes' (Kay 2012) and *The Garden of Evening Mists*, (Eng 2012), it uses the first person and allows the reader to explore the experience of a dementia. *Turn of Mind* (LaPlante 2011) is a crime thriller which uses a 'call and response' narrative to let the reader inhabit the world of Dr White

and enjoy, but be increasingly worried by, the mismatch between what she says and what she thinks. Dr White, a hand surgeon of renown, has recently been diagnosed with Alzheimer's and is the prime suspect in the murder of her best friend. Through fragmented memories the story of the crime and the 'whodunnit' is revealed.

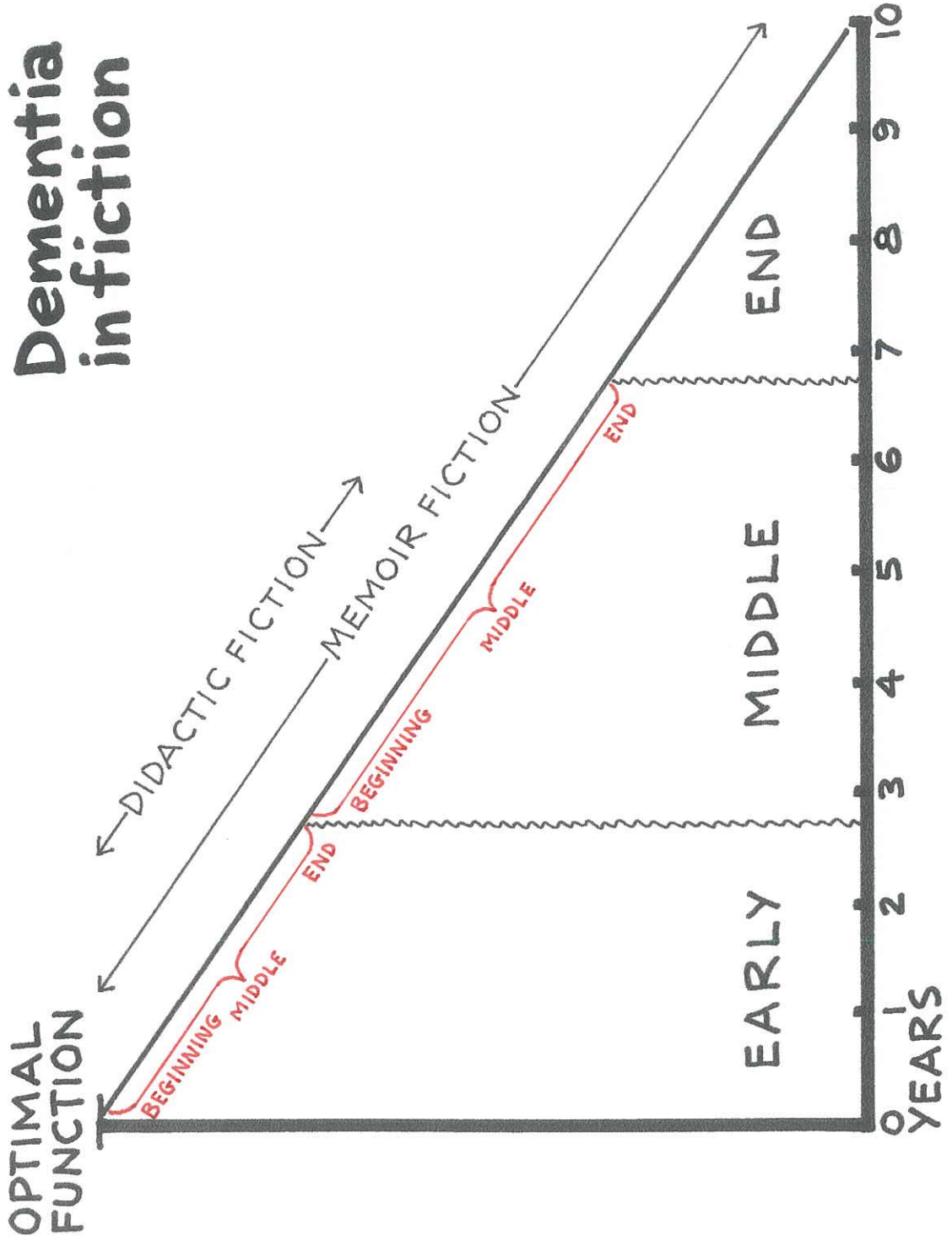
LaPlante is not the first to use impaired memory as a plot device in crime fiction. Alzheimer's Disease is significant to the plot in *The Various Haunts of Men* (Hill 2004), *Devices and Desires* (James 1989) and *Started Early, Took my Dog* (Atkinson 2010) but she is the first to use the progressive decline of Alzheimer's Disease as the plot.

The selected texts tell twelve different stories of dementia in a range of categories. Although they have been divided into three main categories: memoir, didactic and literary fiction other options would be possible. Four of the texts *The Wilderness* (Harvey 2009), *Still Alice* (2009), *Turn of Mind* (2011) and *The Story of Forgetting* (Merrill Block 2008) are first novels. An alternative category could have been texts which take early onset dementia as the core narrative which would include *Scar Tissue* (Ignatieff 1993), *Still Alice* (Genova 2009) *The Wilderness* (Harvey 2009) and *Forgetting* (Lewis 2010). In these the dementia develops in a person with considerable professional success or status, thus highlighting the sense of tragedy and loss. The number of people in fiction with an early onset dementia far outstrips the epidemiological evidence but opting for a dementia to develop in a relatively young and successful person adds drama to the narrative. What the fiction featuring early onset dementia does not accurately reflect is the rampant and speedy devastation that it wreaks. Dr Howland continues to offer thesis supervision in *Still Alice* (Genova 2009:184) despite being unable to draw an analogue clock (ibid: 137). From a clinical perspective this seems unlikely. The emphasis in fiction of early

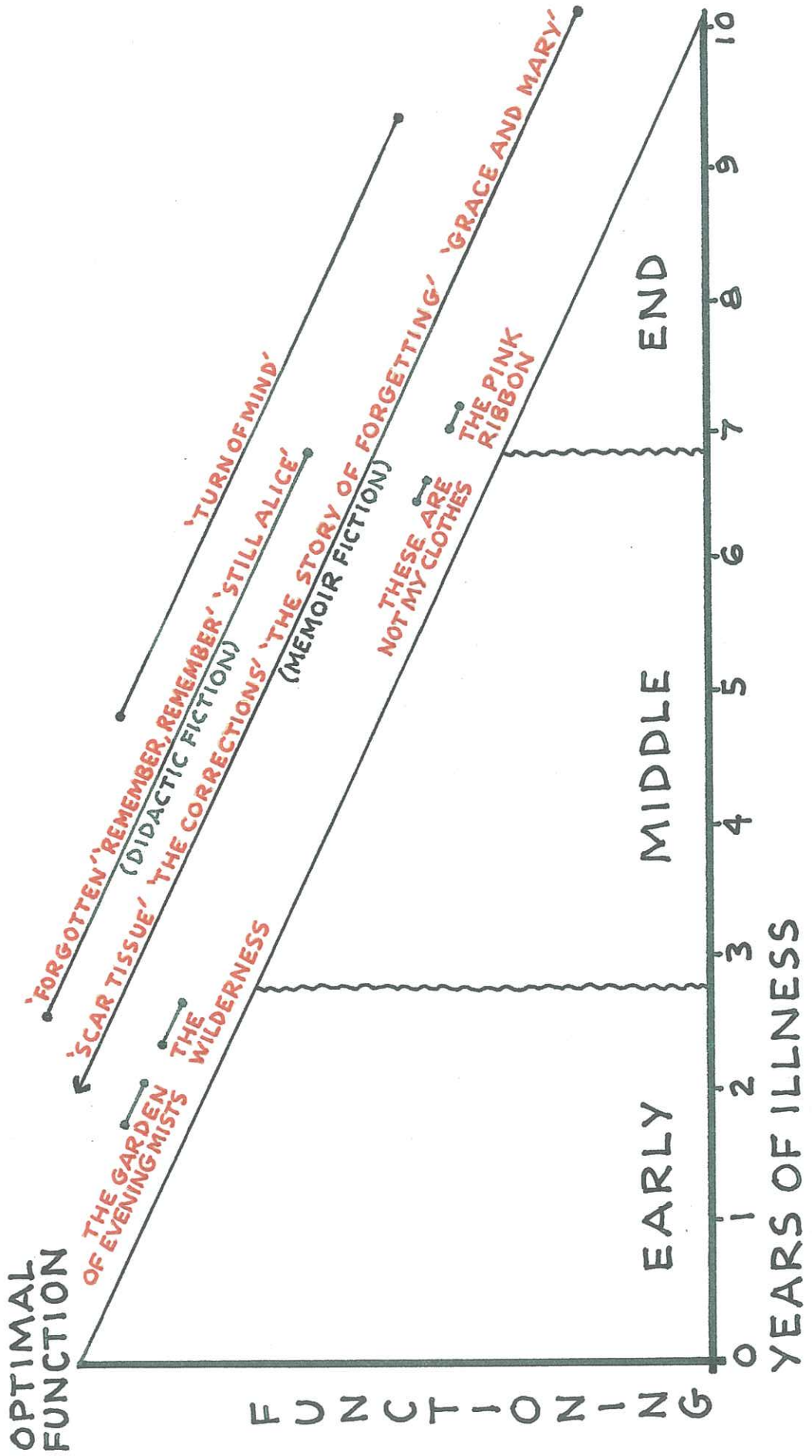
onset dementia means that the reality of the multiple pathologies of old age and frailty do not need to be addressed as they are in *Grace and Mary* (Bragg 2013). Of the novels addressing early onset dementia, only *Scar Tissue* (Ignatieff 1993) offers a valid portrayal of the dementia and the tensions and fragmenting of a family trying to manage the disease. The narrator makes choices which appear ill-advised, notably his obsessional visiting regime (Ignatieff 1993:159) but it is exactly these choices which drive the philosophical thread of the text and engage the reader to reflect: Would I have done that?

Although the selected texts all have a main character with a dementia they do not have equal prominence in this work. The texts act, for the clinician/reader, as the equivalent of the clinic list, the attending patients who share similar reasons for referral but present differently. All are interesting and require attention and consideration but not all patients need further medical investigations. In this thesis further narrative investigations are carried out on three memoir fiction texts but reference is made throughout the work to the other selected texts as exemplars of specific issues. The relevance of the memoir fiction texts is shown in Graph 1 which illustrates the scope of the portrayal of a dementia in the fiction. This is compared with the other selected texts in Graph 2 which demonstrates the limitation of the coverage of the course of a dementia in the other texts. Memoir fiction texts are the only ones to fictionalise the course of a dementia from prediagnosis until death. To pursue the clinical analogy, the memoir texts reflect the reality of the presenting patient in the clinic whereas the other selected texts, though still important, act as case presentations, a snapshot to demonstrate an aspect or issue regarding dementia. There are aspects of a dementia which are tempting to writers and a strong argument is made in the final chapter for it to be viewed as the most narrative of all illnesses.

Dementia in fiction



DEMENTIA IN FICTION



The protean nature of dementia allows the fiction writer to pursue the portrayal of a dementia realistically in *Grace and Mary* (Bragg 2013) and *The Corrections* (Franzen 2001), as metaphor in Isidora in *The Story of Forgetting* (Merrill Block 2008) and myth in 'The Pink Ribbon' (Byatt 2003). All the texts take dementia seriously and empathically to offer what Neel Mukherjee describes as a 'moral energy' derived from their 'capacity to imagine the lives of others' (*Guardian Review* 11 October 2014).

Fiction is not required to be 'truthful' in reflecting the clinical presentation and progress of the disease but if Mukherjee's 'moral energy' is to be present in a text it must have an authenticity which is relevant to the reader. The mismatch between fiction and reality becomes significant when considering fiction as culturally active and as a potential clinical adjunct for patients, supporters and health professionals. 'Truth' and 'reality' in fiction raises complex issues which are discussed by literary theorists such as Fredric Jameson in *The Antinomies of Realism* (2013), and the more culturally accessible *How Fiction Works* (Wood 2008). Jameson (2013) explores the form and legacy of nineteenth-century realist novels of writers such as Zola, Balzac and George Eliot, in which he describes realism in writing as 'a pure form of storytelling with impulses of scenic elaboration, description, and above all affective investment' (ibid: 11). All the selected texts, including *The Story of Forgetting* (Merrill Block 2008) with its meta-fictional conceits, can be viewed as 'social realism' but it is memoir fiction which best fulfils Jameson's criteria for the genre. The scenic elaboration is developed because these texts, in addition to describing the progression of the illness, explore and elaborate other issues to create an emotional involvement with the characters. Raymond Tallis, a geriatrician and literary critic stoutly defends realist fiction as aiming 'to express an uncircumscribed attempt to

notice reality' (Tallis 1998: 213. Original italics). For Tallis a realistic novel need not be compulsively mimetic of the social world but follow a likely and coherent time frame, follow laws of probability and 'seem true' to enable the reader's affective investment. This investment is a 'response to an invitation to draw part of what we know; or to use what we know to imagine into what we don't' (ibid: 212). It is the latter which is important in considering dementia fiction, the reader has to care and be able to empathise with the situations described. Fiction need not be compulsively mimetic but the creation of faux medical notes from the memoir fiction texts described in Chapter 3, suggests they verge on this.

The choice of date for the start of the selection of the fiction means that some texts are inevitably lost to the research, notably Margaret Forster's *Have the Men Had Enough?* (1989) and *There Were No Windows* (Hoult 1944 Reissued by Persephone in 2005) which was originally published during the Second World War and was the first, and is, ironically, the most cogently convincing book about dementia. There have been further novels about dementia published since the selection of key texts: *Elizabeth is Missing* (Healey 2014), *The Night Guest* (McFarlane 2013), *White Lies* (Gatford 2014), *We are Not Ourselves* (Thomas 2014) and *Etta and Otto and Russell and James* (Hooper 2015). Mitch Cullin's 2005 rewriting of an aged and dementing Sherlock Holmes in *A Slight Trick of the Mind* and Alice Lichtenstein's (2010) *Lost* would also have fitted the criteria of inclusion but were identified after the selection had been made.

Merrill Block (2008), Bragg (2013), Franzen (2001) and Ignatieff (1993) use their experiences of dementia as central to the narrative but the dementias they describe are different. The authors of the memoir fiction, have intimate knowledge of 'their' dementia but within this term are many 'dementias' which have different

presentations: Mary's dementia in *Grace and Mary* (Bragg 2013) is a straightforward Alzheimer's Disease in the context of old age. Alfred Lambert in *The Corrections* (Franzen 2001) develops a Lewy Body Dementia (LBD) and Mother's dementia in *Scar Tissue* (Ignatieff 1993) is an early onset Alzheimer's dementia which follows the clinical rule of thumb, that the earlier the dementia begins the more aggressive its course. Understanding 'the dementias' as they are portrayed in the texts rather than 'dementia' is important when considering the potential use of fiction as a teaching tool for trainee health professionals as a research outcome.

1.5. What is dementia?

Despite the evidence suggested in the preface dementia is not new. Descriptions of symptoms which match those of dementia were described by Hippocrates and Galen (Berchtold and Cotman 1998). The Middle Ages used the term dotage to refer to persistent memory loss in old age and is a phrase still in current usage. The eighteenth century favoured the term 'fatuity' and local vernacular has its own terminology. North-east Scotland uses the term 'awfi'-wandered' (Enid Gauldie: Personal communication) and in the 1950s factory workers used the term 'old and silly' to describe dementia in an elderly person (Roger Latham: Personal communication).

The roots of the word dementia hold the key to further complications of usage. Eric Partridge (1990) gives the oblique stem as "demen" to mean mad, to deprive of reason and a 'departure from sanity'. The Shorter Oxford English Dictionary (SOED) gives the first usage of dement in 1545 as a verb to mean 'to put out of one's mind, drive mad or to craze' (SOED 1983: 515) and in 1560 as an adjective to mean 'insane'. The term dementia derives from Pinel's use of the word demence as

‘a species of insanity characterized by a failure or loss of the mental powers’ (SOED 1983: 515).

Prior to Alois Alzheimer’s case study of Frau Auguste D. in 1901 (translated into English in 1907) severe forgetfulness had no formal taxonomy. Although the terms dementia and demented might be used, they encompassed mental illness and did not relate specifically to memory loss for which the term senility was most frequently used. It was Kraepelin’s new 8th edition of his psychiatric text book, published in 1910 which first named ‘Alzheimer’s Disease’ as a ‘particularly serious form of senile dementia’ (quoted in Cheston and Bender 2003: 35). As a specific diagnostic label it failed to make any significant impact and the label of senility for ‘human muddle’, a term used by Victorian writers, such as Charles Dickens and Anthony Trollope, remained in use until the 1970s.

The early link between dementia and madness is still present in the current culture. In the UK people with a dementia are cared for by old age psychiatry services whereas in other European countries they are treated predominantly by neurologists. Phrases such as ‘I was almost demented with...’ imply a degree of unreason rather than loss of cognitive powers. Such confusion is epitomised in the use of the word in titles such as *Confessions of a Demented Housewife* (Greene 2008) which narrates the frazzle of being a minor celebrity and *Demented* (Fleming 2004) in which a series of cartoons explores the life and frustrations of being a woman. In *These Demented Lands* (Warner 1998) the word is used to suggest the near psychosis of the drug and alcohol fuelled inhabitants of a mythical Scottish island. These examples may be individually unimportant but they inform the cultural currency of dementia.

Dementia is not a specific disorder or disease but a syndrome, a set of symptoms, associated with progressive loss of memory and other cognitive and intellectual functions which last more than six months and have not been present since birth. The word implies an inevitable decline, ‘de’ meaning undoing and ‘mentation’, the agency of the brain.

There are over thirty specific and rare progressive dementias; Judge Teoh’s diagnosis of Primary Progressive Aphasia (PPA) in *The Garden of Evening Mists* (Eng 2012) is one of the rarest. The most common dementia is Alzheimer’s Disease¹⁸ which has led to what Libon et al. (2006) have called the ‘alzheimerization of dementia’ as the term ‘Alzheimer’s’ is used colloquially as a generic diagnosis to describe any memory loss in the same way that ‘rheumatism’ and ‘arthritis’ are used to explain the creaks and groans of muscles and joints. However, as Margaret Lock (2013) points out the disease has a “disputed history” (ibid: 7) full of ‘divinatory practices’ (ibid: 9) and is an ‘elusive phenomenon, particularly in light of recent findings in both epidemiology and neuroimaging. In short it is a stubborn conundrum’ (ibid: 11). Jellinger (2010) argues strongly for abandoning the word dementia for a less perjorative term such as ‘cognitive impairment’ or ‘cognitive disorder’ but dementia and Alzheimer’s are so culturally entrenched that it is difficult to see this happening.

¹⁸ The commonest of the dementias are Alzheimer’s Disease (AD), vascular dementia (VaD), Lewy Body Dementia (LBD) and frontotemporal dementia (FTD) and are the illnesses most likely to be referred to when the talk is of ‘dementia’ but should more correctly be ‘the dementias’. AD is acknowledged as the cause of 55% of all dementias, VaD, which includes a mixed AD/VaD group, accounts for 20% of diagnoses. LBD is 15% of dementia diagnoses and FTD only 5% While FTD comprises only a tiny proportion of diagnoses, what clinicians refer to as ‘frontal features’ frequently present as part of the common dementias as Behavioural and Psychiatric (or Psychological) Symptoms of Dementia (BPSD). The dementias involve significant changes to the brain and the frontal lobes are not immune to shrinkage or small infarcts (Waite et al.2009: 9).

In comparison the Department of Health (DoH) has a very specific definition of the disease. As a government department which initiates and monitors the provision of services it informs the current model of dementia and the parameters in which commissioners and clinicians need to work. For the DoH in 2013, dementia is:

a syndrome that can be caused by a number of progressive disorders. It can affect memory, thinking, behaviour and the ability to perform everyday activities. Alzheimer's disease is the most common type of dementia. Other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Dementia mainly affects older people, although there is a growing awareness of cases starting before the age of 65. After 65, the likelihood of developing dementia roughly doubles every five years.

(Dementia: A State of the nation report on dementia care and support in England, 4)

What is interesting to the clinician is that it includes the words 'can affect' whereas practice presumes that it does.

The cultural and fictional portrayal of dementia suggests that it is inevitable and concomitant with ageing. However the epidemiology demonstrates that dementia is predominantly a disease of old age. The prevalence of dementia, that is, the proportion of people in the population with the disease is:

1.4% for those people aged between 65-69 years
4.1% for those people aged between 70-74 years
5.7% for those people aged between 75-79 years
13% for those people aged between 80-84 years
21.6% for those people aged between 85-89 years
32.2% for those people aged between 90-94 years

(Dementia Care, 403)

Statistically, only one third of people over ninety have a dementia which would not be obvious from reading fiction. The incidence, that is the number of new cases arising each year in the population, presents a similar picture:

0.11% for those people aged between 60-64 years

0.33% for those people aged between 65-69 years

0.84% for those people aged between 70-74 years

1.82% for those people aged between 75-79 years

3.36% for those people aged between 80-84 years

5.33% for those people aged between 85-89 years

7.23% for those people aged between 90-94 years

(*Dementia Care*, 403)

Not everybody with the disease has been, or will ever be, diagnosed, a clinical phenomenon equivalent to the ‘quiet madness’ of ‘discrete psychoses that had always managed to fit in well with society, never exploding into spectacular symptomology, never disintegrating into breakdown or crisis’(Leader 2011:11). With a ‘quiet dementia’ people may live apparently limited, but highly predictable lives which make no demands on new learning or skill acquisition, playing to their strength of a well-preserved recognition-memory. The person and their supporters gently adapt to this changing shape of memory which is not problematical. Only when there is a disruption to the pattern of life, such as a bus stop being moved, a local shop closing or, most frequently, an admission to hospital, is the extent of the dementia revealed. Once the person’s fragile recognition system is disrupted by the change it often becomes surprisingly difficult to return them to their sustaining familiarity. Such disruptive events are represented in memoir fiction. Mary in *Grace and Mary* (Bragg 2013) is admitted to hospital after a fall, as is Alfred Lambert in *The Corrections* (Franzen 2001) after he falls from the ship during Enid’s much

anticipated autumn cruise and Mother in *Scar Tissue* (Ignatieff 1993) after the sudden death of her husband.

Although readers may be convinced that early onset dementia is rife, the figures demonstrate the tiny proportion (0.11%) of people presenting with symptoms before sixty five years. The clinician is aware that, contrary to the cultural message, we are likely to end our life without a dementia. It is not inevitable. It is not becoming more common. There has been little change in age specific dementia rates. The total number of cases of dementia is increasing because of the ageing of the population and people with a dementia are surviving longer because of improvements in care. The proportion of elderly people in institutional care is unchanged since the Victorian era. About one third of people with a dementia are likely to be living in institutions, now called care or nursing homes. A person with a dementia living by themselves, despite the maximum support and best endeavours of the family and the community, is likely to need 24 hour residential care as did Mary in *Grace and Mary* (Bragg 2013) and Mother in *Scar Tissue* (Ignatieff 1993). Of the selected fiction it is only the memoir fiction which tackles the family trauma of this rite of passage.

The four main dementias and symptomatology are described using examples from the memoir fiction texts in Appendix 2. Each dementia has a slightly different course in the early to middle stages as behaviour, language and memory functioning change. By end-stage dementia there is no significant difference between the various forms and formal diagnosis becomes less relevant. This late stage is one of physical frailty which leaves the person bedridden, incontinent, curled in a foetal position, not verbally communicative and needing support in all the activities of daily living (ADLs) including feeding. It is a stage of dementia largely hidden from public view.

During this stage there are relatively few physical demands on the body and this phase can be very prolonged, a ‘plateau’ of frailty which takes its toll on supporters and visitors. People rarely die from a dementia they die with a dementia, usually from a secondary infection such as broncho-pneumonia.

Melvyn Bragg’s portrayal of Mary in *Grace and Mary* (Bragg 2013) is the most honest and clinically accurate picture of end stage dementia in a very elderly person. He describes efficient and supportive care in a home where Mary is gently encouraged, washed, nourished and genuinely cared for by people from her own local community and visited regularly by her son John. All the memoir fiction texts describe the trials of visiting a parent in this frail state. The narrator in *Scar Tissue* (Ignatieff 1993) sits by the bed of Mother, as ‘she recognised me as an infant recognises its mother. When she was bedridden and unable to speak, I could extend a finger close to her hand and she would take it’(Ignatieff 1993: 165). As John visits Mary he knew ‘there would come a time soon when all she could do was drowse and make soft, short sounds. He would put his head close to hers and take her cold hands in his. Her eyes would open but mostly find no focus, just look ahead’ (Bragg 2103: 247) as touch becomes an essential part of communication and a substitute for spoken language. In contrast to John, Enid Lambert manages the prolonged period of visiting Alfred by her need ‘to tell him, while she still had time, how wrong he’s been and how right she’d been. How wrong not to love her more, how wrong not to cherish her’ (Franzen 2002: 653).

Memoir fiction addresses the progression of the illness whereas didactic fiction emphasises the diagnostic process. This is more readily available to research by the author and both Susan Lewis and Lisa Genova acknowledge the help of specific units for their writing. The diagnosis of a dementia is always provisional and can

only be confirmed at post-mortem. It is a diagnosis of last resort. The gravity and life changing impact of the diagnosis means that every other possible diagnosis is excluded first. Particular attention is paid to evidence of depression. In the older person depression can present as memory difficulties or pseudo-dementia (Payne 2015) and the clinical history is crucial in clarifying the differential diagnosis. Depression is very treatable whereas even with ACI medication the symptoms of dementia are, at best, temporarily ameliorated. Because there are no reliable biochemical or readily available pathological markers for the disease a diagnosis is driven by the diagnostic triangle of the clinical history, current presentation and the scores on psychometric assessments. Each works together to increase the reliability of the diagnosis.¹⁹ The didactic fiction texts focus on the psychometric assessment and include the questions asked. In *Forgotten* (2010) Lewis describes David's visit to the psychologist and Lisa's response to watching him struggle with apparently simple tasks and the realization of the extent of their difficulties:

It didn't seem possible to be where she was now, in a car returning from a test that might render David's future null and void when it was less than six weeks ago that they'd married, surrounded by friends and loved ones and with, they thought, only happiness in store. It was as if she had crash-landed into someone else's world.

(*Forgotten*, 362)

In *Still Alice* the tests administered by the neuropsychologist to Dr Howland are:

Stroop, Raven's Progressive Matrices, Luria Mental Rotation, Boston Naming, WAIS-R, Picture Arrangement, Benton Visual Retention, NYU Story Recall— were familiar to her. They were designed to tease out any subtle weakness in the integrity of language fluency, recent memory, and reasoning process.

(*Still Alice*, 68)

¹⁹ If circumstances dictate that an assessment should be curtailed, for instance, due to physical frailty, it is the clinical history which would be collected at the expense of the other elements.

In comparison to the robust neuropsychological work up for Dr Howland the assessment of Mrs Mannering in *Remember Remember* (McHaffie 2010: 165) seems somewhat cursory and difficult. This reflects a truism of clinical practice, that the younger the person at presentation, the more extensive the neuropsychological assessment. Detailed psychometric assessment, which is challenging to both the self-esteem and energy of the patient, is about answering clinical questions which cannot be answered elsewhere and must add to the information needed for diagnosis. Most often a standard psychometric assessment such as the Addenbrooke's Cognitive Evaluation (ACE-R) or Folstein Mini Mental State Examination (MMSE) is sufficient.²⁰ Psychometric assessment is dependent on the agreement and cooperation of the patient. Mrs Mannering in *Remember Remember* (McHaffie 2010) is not compliant with Mr Coulthard, the Psychiatric Community Nurse who is visiting her at home, and McHaffie presents the assessment from Mrs Mannering's point of view. For Mrs Mannering the assessment interview is enmeshed with concerns about her lost purse and resentment towards her well-meaning daughter who has just moved in to care for her, and a wish for social standards to be maintained for any visitor. Her responses to direct questions such as 'Where are we now?' and 'Now can you spell pencil backwards?' elicit an evasive challenge to Mr Coulthard of 'I don't know. Do you know?' (ibid: 166) and 'I don't know. Can you?' (ibid: 167). Responses such as these alert the clinician to the degree of insight and awareness of the patient. In comparison to Mrs Mannering David Kirby in *Forgotten* (Lewis 2010) and Dr Howland in *Still Alice* (Genova 2009) enter the psychometric assessment fully aware of the implications and repercussions.

²⁰ See the clinical history template in Chapter 4

The educative message of the didactic fiction texts is clear and the documentary realism of the practices the authors have observed help the reader to anticipate what **might** be expected in an assessment. However such detail has the potential to leave patients and supporters dissatisfied if their experience of the assessment does not match the fictional portrayal because memory clinics vary in their assessment procedures and personnel.

1.5.1. Dementia: literature review

Dementia is currently defined as a distinct set of clinical and pathological features. The goal of diagnosis is to identify methods of treatment and access to appropriate support. This bio-medical model, which emphasises the neuro-degenerative properties of the disease, is dominant and fuels the decline narrative of ageing in the media which places dementia as an inevitable part of that process. This is not new, and has been present since Pythagoras and Aristotle. Pythagoras writes that in the last stages of life ‘the system returns to the imbecility of infancy’s first stage’ and Aristotle that ‘there is not much left of the acumen of the mind which helped them in their youth, nor of facilities which served the intellect, and which some call judgement, imagination, power of reasoning and memory. They see them gradually blunted by deterioration and see that they can hardly fulfil their function’ (Cited in Payne 2015: 78).

It is not surprising therefore that the dementia theorists offering an alternative model have had such a difficult and unsuccessful time disentangling the link between the inevitability of dementia and ageing which is further complicated by a new diagnosis of Mild Cognitive Impairment (MCI).²¹ Attempts to re-construe dementia

²¹ This is a diagnosis which recognises that the person is experiencing memory problems but these are not having any significant impact on every-day life. It hangs between normal ageing and early dementia. Approximately 1/3 of people with this diagnosis will develop a dementia (Peterson 2004).

have been undertaken by clinical psychologists such as Rick Cheston and Mike Bender (2003), Dawn Brooker (2007) and researchers Nancy Harding and Colin Palfrey (1997). They draw on the work of Tom Kitwood to argue for a humanistic, rather than a solely medical, understanding of dementia. Tom Kitwood not only questioned some of the scientific evidence that was being produced, describing it as a 'paradigm in disarray' (1997:34) but was the first to try and explain the variety and range of presentations and progression of the disease as potentially being dependant on the individual and their social context. This humanistic approach broadened the understanding from solely bio-medicine to include the psychological and social environment which interacted with neuropathology to create the condition of dementia. Kitwood's premise is that a person with a dementia needs to be recognised primarily as a person with needs which are highly individual. This is achieved by the bestowal of 'personhood' by which he means 'standing or status that is bestowed on the human being by others in the context of relationships and social being' (ibid: 8). It implies respect, trust, and a valuing of the person with a dementia throughout the progress of the disease.

Patient-Centred Care is a mantra in many areas of health care, particularly in services for people who are frequently disempowered by traditional methods of service delivery such as children, people with learning disabilities, patients with mental health diagnoses and older people. There is no firm definition of the term but three key themes are inherent to it: that there is patient involvement and participation in care, there is a meaningful relationship between the person receiving care and the person or people delivering it, and the care takes place in a culture which supports their positions. For people with a dementia active involvement in care may be difficult and the term Person-Centred Care is preferred which acknowledges that

most people do not receive their full time care in hospital but in care homes where the term 'patient' is inappropriate. It is seen to be synonymous with quality although, as Brooker (2003) has pointed out, the rhetoric behind the practice may be questionable. Person-Centred Care was coined by Tom Kitwood during the 1990s when formulating the socio-psychological model of dementia in which problem behaviours are viewed as the result of a malign social environment rather than changes in neuropathology. In a malign social environment those people surrounding the person with a dementia are unbending and unaccepting of alternative ways of understanding and reacting to the world.

Gilleard and Higgs (2000) move beyond the 'personhood' of Kitwood and re-construe dementia more widely as a loss of social agency in the midst of changing attitudes towards ageing. The stress on dementia risk reduction strategies such as exercise, singing, volunteering, taking ginkgo bilboa, and 'use it don't lose it', reinforce a message of personal responsibility that fits with current health and social care policies. Age becomes something to be deconstructed into a 'compendium of risky but potentially avoidable medical conditions' (ibid: 171) in which Alzheimer's is treated as understandable, remedial and preventable. This position is illustrated by the rise in memory clinics, medications, the 'what's good for your heart is good for your head' mantra, exercise, activity and best-selling books such as *100 simple things you can do to prevent Alzheimer's and Age-related memory loss* (Carper 2011). The profusion of memory training techniques, apps, downloads and brain-training computer programmes move memory training, which had previously been the remit of health professionals, into the market place. Douwe Draaisma (2013) is explicit about marketization of forgetfulness:

Anyone who still has the memory of a twenty-year-old at the age of seventy is not entirely normal. For commercial reasons, older people are invited to take a different view. The marketing that has grown up around memory encourages the shifting of forgetfulness from normal to pathological, from something that goes along with growing older to a symptom-because of symptom points to sickness and therefore to medicines, therapies, training courses, curative herbs, supplements and all those other items for sale in the forgetfulness market. Those who sell into that market want to see their customers to see themselves as patients.’

(The Nostalgia Factory, 51)

Such a position has immense cultural ramifications for service delivery and for the individual. It changes the nature of the contract people have when seeking help for their memory difficulties

1.5.2. Dementia and culture

As the examples in the preface demonstrate, there is a complex cultural discourse about dementia which extends beyond health. Questions need to be asked about why dementia, rather than heart failure or respiratory problems, which have an equivalent impact on independence, has the cultural saturation it does. Each age appears to have a ‘signature illness’ which typifies its fear of mortality. Prior to the industrial revolution outbreaks of acute epidemic diseases, such as plague, were the predominant fears. Outside these circumstances, death was largely through respiratory illnesses such as pneumonia and influenza. In the nineteenth century ‘King Cholera’ was the most feared deadly disease²² and killed across the social spectrum. It is consumption, later called tuberculosis (TB), which draws the most direct comparison with dementia in terms of public fear and presence in fiction. TB did not respect class or education and nor does dementia. The number of years of education and a continued engagement in cognitive activities delays rather than

²² C.N. Trueman ‘Diseases in Industrial Cities in the Industrial Revolution’ <historylearning site.co.uk> [accessed 31 January 2016]

prevents dementia.²³ Money might have offered the TB sufferer some time in a Swiss sanatorium but it remained a killer. People dreaded the spots of blood on the handkerchief in much the same way that people dread a significant memory lapse.

Helen Bynum (2012) documents the changing nomenclature and shifts in understanding of TB, most notably its bacterial causation. Once causation was identified, consumption became known as tuberculosis but despite the change in name, the disease ‘remained a family tragedy to be dealt with inside the family circle’ (ibid: 109) much as dementia remains today, despite the rhetoric of care. However, as she points out:

In the middle of the 19th century consumption had to compete in the popular imagination with the acute fevers and above all the attention grabbing epidemics of cholera that tore through the new industrial cities wherever they burgeoned. Yet consumption gained a heightened visibility through poetry, art literature and the stage. By the century’s end a new leading public enemy had been formulated.

(Spitting Blood, 94)

Her phrase ‘new leading public enemy’ can be transferred directly to dementia in the twenty first century. The plethora of government papers about dementia on the Department of Health website, the visual, radio and print coverage, extra funding for research, the talk of defeat and winning the battle against dementia and the race for a cure is the language of warfare in which the enemy is dementia. Susan Sontag identified such language in relation to the diagnosis and treatment of her cancer in the 1970s and as a response wrote one of the most important essays of the twentieth century, *Illness as Metaphor* (Sontag 1979).

²³ Extended years of education only offer a small reduction of risk of dementia (Eclipse Collaborative Members. ‘Education, the brain and dementia: neuroprotection or compensation’. *Brain*.2010.133. 2210-2216)

This essay was written as a response to the diagnosis and treatment of her cancer before the availability of mass screening and scanning when cancer was viewed as ‘the wages of repression’ (ibid: 22) and the person culpable ‘as one of life’s losers’ (ibid: 50). She takes a more autobiographical stance in her later essay *Aids and its Metaphors* (1989) published a decade later in which she acknowledges that she wrote *Illness as Metaphor* ‘very quickly, spurred by evangelical zeal as well as anxiety about how much time I had to do any living or writing in’ (1989: 99). The purpose of it had been, ‘Not to confer meaning, which is the traditional purpose of literary endeavour, but to deprive something of meaning’ (ibid: 99). It was, she admits ‘not just a polemic’ but an exhortation.

Sontag argues that two ‘master’ illnesses, TB and cancer have been ‘spectacularly and similarly, encumbered by the trappings of metaphor’ (ibid: 5) and as a result of their aetiology being poorly understood were viewed as ‘intractable and capricious’, ‘mysterious’ (ibid: 5), and an ‘insidious, implacable theft of a life’ (ibid: 5) which resonate with how dementia is currently viewed. Like TB and cancer, dementia ‘arouses thoroughly old fashioned kinds of dread’ (ibid: 6) which can lead to a withdrawal of, and from, any social capital. Sontag compares the two illnesses, TB as an illness of a single organ whereas cancer is a disease of lethal growth. Unfortunately dementia combines aspects of them both; it is an illness of brain tissue whose ‘outreach is the whole body’ (ibid: 12), is ‘measured, incessant, steady’ (ibid: 12), whose ‘symptoms are deceptive’ (ibid: 13) and ‘cannot be reversed’ (ibid: 16). TB, Sontag argues, was a ‘disease of the sick self’ whereas cancer ‘is the disease of the Other’ (ibid: 69), a phrase which exemplifies dementia. Her observations about cancer and their relevance for dementia are most telling in the phrase ‘died after a

long illness'. With the addition 'bravely borne' it remains the obituary euphemism for cancer, standing alone it signals dementia.

Illness as Metaphor has been resoundingly critiqued in terms of its lack of empiricism and frank wrongness, notably by Barbara Clow in 'Who's Afraid of Susan Sontag? or, the Myths and Metaphors of Cancer Reconsidered' (2001) but Sontag wrote the initial essay in a different cultural climate in which the development of a cancer was seen as blameworthy and linked to psychological traits, in particular the repression of emotion, for which a key treatment option was psychotherapy. It now reads as an archaic treatise in which full-blown metaphor-rich prose sweeps the reader along. Sontag's argument is that illness is not a metaphor and that 'the most truthful way of regarding illness — and the healthiest way of being ill — is one most purified of, most resistant to, metaphoric thinking' (Sontag 1978: 3). The metaphors of which she is so disdainful are the metaphors of warfare — which are also used in headlines about dementia. Now it is dementia rather than cancer which is seen as the disease that 'doesn't knock first before it enters' (1978: 5). The twentieth century grand narrative has been that science and medicine hold the key to cure all illnesses, and in many areas it has delivered but the dementias, and most neurological illnesses, remain stubbornly resistive in terms of understanding, aetiology and efficacious treatment.

Dementia does not appear, yet, to have accrued the degree of blame which Sontag feels was attached to cancer and its victims. However in her later essay 'AIDS and its Metaphors' (1989) she identified the '*necessity of limitation*' (ibid: 164. Original italics) epitomised in 'programs of self-management and self-discipline (diet, exercise). Watch your appetites. Take care of yourself. Don't let yourself go' (ibid: 163) which is identifiable in the developing cultural turn of gerontology. There

is a rise of interest in the ‘co-production’ (Realpe and Wallace 2010) of health in generating engagement in a personal responsibility for how one ages: keep fit, keep blood sugar and cholesterol down and activity up, keep engaged and in control of one’s illness. In the BBC Radio 4 programme ‘How to live with dementia’ Dr Jennifer Bute, a retired GP who was diagnosed with a dementia in her mid-50s describes it as ‘a challenge, not a death sentence’ and that ‘You live with dementia, you don’t suffer it’ (*The Guardian* G2 26 June 2015). She is active in managing her dementia by producing leaflets for her children and friends to help them cope, has bought a satellite navigation system for driving and uses Facebook for communicating with friends and family because it uses short sentences and a picture of the person with whom she is interacting. She also finds singing helpful, ‘it’s like a work out.’ All of these are positive methods of dealing with a dementia in the early stages and are part of the ‘help-yourself’ approach. Once again, the exemplar in the media is an early onset dementia.

What dementia has accrued is a metaphor of flood and engulfment. This began in 1982 with the Health Advisory Service report *The Rising Tide* after which Department of Health and government publications have been given more anodyne titles. The predominant metaphor now for dementia is that of ‘burden’ which is used with reference to the economy, the NHS, and to families. The experience of the person with dementia is largely missing. My argument would be that it is too painful, the devastation that dementia eventually wreaks on the self is not describable other than in fiction or mediated and presented through the experiences of the still sentient carer.

In *Aids and its Metaphors* (1991) Sontag reinforces the position of the signature illness, ‘It seems that societies need to have one illness which becomes

identified with evil, and attaches blame to its ‘victims,’ *but it is hard to be obsessed with more than one*’ (1991:101. My italics). Dementia is currently that ‘one’ because of the demographic shift: the increase in the proportion of old and very old people with co-morbid illnesses for whom the risk of dementia increases. The reality is that most dementias present like Mary’s and Alfred Lambert’s in the memoir fiction; Mado and Margaret in the short stories and Doris in the didactic fiction, all elderly people who are dependent on others, physically and mentally for survival. All dementias have the potential to be a tragedy because it is an illness which impacts on families and has a relentless downward path which extends for up to a decade. It is a disease which is difficult to manage even with optimum resources of finance, determination and organising energy but even more so if any one of these elements is compromised or simply unavailable. What memoir fiction offers is access to how the disease has impacted on other families and that dementia can happen to anybody.²⁴

1.6. Dementia in non-selected fiction

The fiction which has been selected for detailed analysis places the dementia of one of the characters as central to the narrative. However in considering the power and usefulness of fiction in shaping the cultural understanding of dementia there are many texts which mention it *en passant* or feature a minor character with a dementia. Such small but frequent mentions in texts across a wide range of writing offers subtle, but nonetheless powerful, reminders about its presence and provides evidence that fiction is at work influencing and being influenced by culture. That dementia crops up so frequently in novels, the dominant literary form for representing worlds not necessarily available to the reader, is beyond epidemiological explanation. Its

²⁴ That the ‘anybody’ includes Harold Wilson, Enid Blyton, Ronald Reagan, Iris Murdoch, Margaret Thatcher, Max Bygraves, Gene Wilder and Jimmy Hill can give some reassurance to people attending the clinic that they are among significant company.

ubiquitous presence across a range of writing genres reinforces the belief that it is an inevitable part of ageing and roots it as the contemporary signature illness.

Alzheimer's Disease is now named rather than being alluded to but this overt, and often inaccurate, use of the term 'Alzheimer's' to describe any memory lapse leads to an increasing portrayal of dementia as comic whimsy.

This section does not to provide a comprehensive list of texts which mention dementia which is ever expanding. A *Distant Reading* (Moretti 2013) analysis seems likely given the amount of fiction in which dementia does feature²⁵ and a 'dementia canon' seems likely to develop. The aim here is to provide examples from a range of genres which illustrate the range of ways dementia is used in texts and which inform the argument about the narrativity of dementia in Chapter 5.

Observations about old age and failing memory are a part of story-telling. Although dementia was not named in fiction until the relatively late in the last century, failing memory has been a part of fiction which addresses relationships between people. It appears in fiction as early as 1726 when Jonathan Swift describes the *struldbrugs* in *Gulliver's Travels*:

At ninety they lose their teeth and hair, they have at that age no distinction of taste, but eat and drink whatever they can get, without relish or appetite. The diseases they were subject to still continue without increasing or diminishing. In talking they forget the common appellation of all things, and the names of persons, even those who are their nearest friends and relations. For the same reason they never can amuse themselves with reading, because their memory will not serve to carry them from the beginning of a sentence to the end; and by this defect they are deprived of the only entertainment whereof they might otherwise be capable.

(*Gulliver's Travels*, 233-4)

²⁵ Ninety three novels which mention dementia have been collected during the course of working on this thesis.

Despite being written over two centuries ago he has accurately captured life in a contemporary care home and with a brutal disregard for sentiment, the cognitive and mental decline of a dementia, although without naming it as such.

At the beginning of *Wuthering Heights* (Bronte 1847) it is apparent to the reader that the servant Joseph has a problem with his memory or at least a poor attention span. This is what Rose Tremain would describe as ‘human Muddle’ (2012: 16). The term ‘muddle’ is very helpful clinically when discussing the situations of early memory loss prior to a diagnosis as it is a benign but sympathetic term. In *Merival* (2012) Tremain gives her physician a cook who can ‘no longer be trusted to perform his culinary tasks with any real skill or competence. Last week, Cattlebury sugared a meat pie and fried a herring in molasses’ (ibid: 16). The ‘no longer’ suggests a decline in functioning from previous competence. Bronte and Tremain, writing over a century apart, place the person with the memory problems as a servant, and thus ‘other’ through their class, not their cognitive performance. Contemporary fiction about dementia inverts this by emphasising the real and potential decline of cognition in the portrayal of dementia amongst the (relatively) young and successful. Of the twelve selected texts five feature a professional — an MP, a judge, an architect, a Harvard Professor, and a surgeon — robbed of their intellect in their prime. They gradually become ‘other’ through their loss of cognitive power reflecting the cultural shift in the role and preoccupation with the self in the twenty first century.

A century after decline in function is mentioned by Bronte and two centuries after Swift’s description *There were no Windows* (Hoult 1944) was published. In the text dementia is never named as other than ‘senility’ which is denied by the main

character Claire who knows 'I'm old, but I'm not old in the way they are. I'm not senile' (ibid: 262). The progress of her 'senility' is clinically accurate for Alzheimer's disease and she requires increasing amounts of support from the people around her. Claire remains in denial about her memory problems in contrast to Barbie Batchelor, the impoverished missionary in *Towers of Silence* (Scott 1971). While Claire's memory problems remain un-named and un-diagnosed, but recognisable as a dementia, Barbie herself realizes 'My memory,' she said aloud, turning back in, 'Is not What it Was' (ibid: 184). Following this recognition she descends to a state of 'other' not only in social standing but one in which she no longer recognises Sarah, the one person who had been consistently kind to her, and to whom 'She felt she had to say something important but she could not remember what' (ibid: 422).

Like Barbie, Marigold in *Ending Up* (Amis 1974) is aware of her memory difficulties but vows 'To hide her condition from the others, especially Bernard, as best she might, and as long as she could' (ibid: 65). As is clinically likely, the other elderly house-sharers in Kingsley Amis' dark satire are very aware of her cognitive losses and navigate round Marigold's predicament with varying degrees of sensitivity. Such peer-on-peer surveillance continues in Deborah Moggach's (2004) more contemporary novel:

"We followed her down the street," said Jean. "She stood for ages outside the Mervali Tiffin tea rooms, leaning on her stick."

"Perhaps she just fancied a cup of tea," said Douglas.

"No, there's something odd about her." Jean refilled Olive's glass.

"Yesterday we saw her in the Old Town. We were having lunch, a simple *thali*, quite delicious. We often eat pavement food, don't we Doug? It's

perfectly safe.’ She lowered her voice. ‘I’m sure it’s Alzheimer’s, early stages.’”

*(These Foolish Things, 156)*²⁶

The increasing range of fiction relating to the lives of older people which Elaine Showalter has called the ‘geriatric genre’ (*The Guardian* 30 October 2013),²⁷ means that not just memory loss, but the specific naming of Alzheimer’s Disease has moved firmly into the main stream of topics available for fictional comment. While the person with dementia may eventually move into the space of the ‘other’, the mention of it in fiction reflects the ordinary speculation and anxieties of the reader.

The possibilities for fiction suggested by Furedi and Sutherland earlier in the chapter are developed by Showalter (2005) who promotes the view that the novel developed because readers enjoy reading about their own world and seeing aspects of their lives portrayed fictionally. The novel acts as a social commentary allowing the reader to measure ‘the gap between what I lived and what I read’ (Showalter 2005: 2). From such a position it is inevitable that dementia has such prominence in contemporary fiction. That it can also be used to address the big issues of all fiction: power, inclusion and exclusion make it a narrative necessity in novels with any pretence to contemporary realism.

‘Geriatric fiction’ is about elderly characters and some is written by authors who would themselves be designated as ‘elderly’. Penelope Lively, Jane Gardam, P.D. James, all use characters well past retirement and each address the issues and fears of a dementia. They are able to do this do with a sense of authorial legitimacy but the depiction is uncompromising. In *Last Friends* (Gardam 2013) Lucie

²⁶ Made into the film *The First Exotic Marigold Hotel*. Dir. John Madden. 2011.

²⁷ In a review of *Half the Kingdom* (Segal 2013).

describes her old friends Olga and Faery as ‘senile, though. Serves them right for being so patronising at school’(ibid: 128), a view tempered later in the novel by Dulcie’s challenge to the inevitability of dementia as reason for any sort of aberrant behaviour, ‘it isn’t senility, Anna, and it isn’t spite or resentment because we’ve laughed at him all these years. It’s simple, determined rejection of us, of the very, very few last friends’ (ibid: 182). The author is as old as her protagonists, reflecting and reminding the reader that the aged person can be as judgmental but clear minded as the reader.

In contrast, Penelope Lively hints at the start of cognitive problems as Henry ‘known for his fluency and spontaneity – not for nothing had he been in demand as a speaker on both sides of the Atlantic’ (Lively 2011: 20) gives a disastrous academic lecture:

Henry began to speak. And as he did so he realized with horror that he could not remember the names of the late eighteenth century prime ministers. The Elder and the Younger. Elder and Younger *what? Name.* The name? He spoke; he avoided, he danced away from the crucial word, he sounded odder and odder, he skirted, he fluffed, he knew that it was becoming obvious. And then at last the name surfaced: Pitt, Pitt, Pitt. He flung it out, triumphant, but too late: the puzzled faces before him told him that.

(How It All Began, 25)

Most readers will be empathic to Henry’s situation, willing him to find the word in reasonable time, although the clinician/reader fears the worst.

Dementia is hinted at or named in fiction with a frequency which is not representative of the demography of the disease and draws on outmoded and incorrect connotations of the disease particularly when used in titles. *These Demented Lands* (Warner 1998), as discussed earlier, refers to psychosis rather than cognitive decline. In *Confessions of a Demented Housewife* (Greene 2008) it is used

to describe everyday harassment of someone seeking celebrity. Within this genre of (very) light fiction dementia is present in a parent 'who'd still been running his building business when Alzheimer's had whispered in his ear and taken the files out of his hands' (Sandy 2014: 377) but any problems it poses are solved by having the parent already receiving full time residential care. In this way dementia can be portrayed as potentially adding to (predominantly) female harassment but have no significant impact on the round of business building, shopping and socialising. The signifying of a dementia and being looked after in a care home is a means of grounding the fiction in a world recognisable to the reader and subtly fuel the perception that dementia equals old age. Dementia appears in space, en route to Mars (Weir 2014: 246). Ian Rankin uses it repeatedly in his crime fiction to add grit to the backdrop and indicate a contemporary additional incidental stressor to that of crime solving for Rebus who 'thought of his own father, fighting hard against dementia' (Rankin 2011: 163).

Care homes are a rich source of fictional material and feature in the selected texts. Like monasteries and boarding schools they resemble 'closed communities' and 'total institutions' described by the sociologist Erving Goffman in *Asylums* (1961). Within such highly structured institutions are inherent rivalries and cliques which drive the narrative. Susan Hill has featured dementia care homes in at least two of her crime novels (2004, 2011) and sets one (2004) within a dementia care home in which elderly women have gone missing. The matron of the care home acknowledges that 'Dementia was not pretty. The best anyone could do was damage limitation and safe confinement, as well, of course, as provide clean, bright surroundings, decent food and friendly care' (ibid: 8). She also writes: 'Running a care home for fifteen people with a dementia had trained Carol Ashton to be patient

and firm, in a way as a teacher of small children – the two jobs she thought, had much in common’ (ibid: 36). Such fiction confirms the stereotypical response to dementia.

As the Care Quality Commission assesses, and visitors and relatives searching for an acceptable care home know, the smell of a home is the first indication of the care provided. It is used to indicate deteriorating care in *Lionel Asbo* as Grace Pepperdine’s care home first smelled of ‘deodorant and cabbage; by 2011 it smelled of urine and mice’ (Amis 2012: 133). Hill, in comparison, uses smell as indicative that a home is superior because the home uses ‘disguising smells of the polish or the flowers to mask the stench’ (Hill 2004: 79). What the inclusion of odour does is to consolidate realism in the novel.

Novels, written before the publication of *Iris* (Bayley 1998) and featuring care homes such as *At the Jerusalem* (Bailey 1967) and *the prince of west end avenue* [sic] (Isler 1995) could originally be read as realistic novels but can no longer be so. They portray residents who might be disgruntled, or made unhappy through physical frailty, but they are all sentient. The production of Hamlet mounted by the residents in Isler’s care home would be unthinkable now when 80% of people in care homes have dementia.²⁸

The prospect of dementia and the possible need to either provide or receive care feature in the fiction of late middle aged novelists to an unexpected degree. Julian Barnes (2004) offers a condensed picture of dementia in ‘Appetite’ a short story about growing old. ‘When it all began, I thought, well it’s better than some things he could have got. Worse than others, better than some’ (ibid: 169).

²⁸<Alzheimer’s Society <https://www.alzheimers.org.uk/statistics>> [accessed 30 November 2015].

Eventually there are visits to the care home, 'He has his good days. Of course, he has bad days, too but let's not think about them for the moment' (ibid: 161). Dementia is a persistent theme in *The Sense of an Ending* (Barnes 2011). In his memoir *Nothing to be Frightened of* (2009) he airs with objectivity his response to his mother's dementia which he describes as:

a dementia of alternating kinds: one in which she still believed herself in charge of things, constantly ticking off the nurses for imaginary mistakes; the other, acknowledging that she had lost control, in which she became a child again, with all her dead relatives still alive, and what her mother or grandmother had just said of pressing importance. Before her dementia, I frequently found myself switching off during her solipsistic monologues; suddenly, she had become painfully interesting. I kept wondering where all this stuff was coming from, and how the brain was manufacturing this counterfeit reality.

(*Nothing to be Frightened of*, 10)

It is this manufacturing of the 'counterfeit reality' driven by a failing memory and an increasing inability to articulate the internal world which is so tempting for writers and encourages my view that a dementia is the most narrative of all illnesses.

Other established late middle-aged male novelists, Howard Jacobsen, Martin Amis, David Lodge, Alan Hollinghurst and Ian MacEwen have written novels which feature a person with a dementia. Amis and Jacobsen use dementia as dark satire whereas Hollinghurst in *The Stranger's Child* (2011) is more benign in his portrayal of George Sawle who, as a young man had been party to the creation of a poem which had become famous, despite, or possibly because of, the death of the author in the First World War. Now aged and increasingly confused and pursued as part of a research project he 'looks a bit mad' and his 'heart drugs react badly with his dementia' (ibid: 454). His dementia drives a theme of unreliability of memory in story-telling and academic analysis running through the text. The unreliability of

memory in dementia makes it a tempting plot device in detective fiction. It is central to *Started early, Took my Dog* (Atkinson 2010) and in one of the selected texts *Turn of Mind* (LaPlante 2011).

The presence of dementia in the mid-life fiction of Amis and Jacobsen where it is not necessary as a plot device, suggests the possibility of a more complex meaning: possibly that of mentioning dementia as the preventative hex of ‘if aired then it won’t happen’. If Amis’ assertion that “writing fiction is writing what you don’t know you’re worrying about” (Ways with Words, Dartington 10 October 2003) it would explain the presence of Grace Pepperdine whose ‘bonce is going’ (Amis 2012: 105) and is astonishingly young to develop a dementia. She has been given a diagnosis of ‘that german lurgy that rots you [sic] brain’ (ibid: 105) which leads to her placement in a nursing home in the north of Scotland lest she starts ‘babbling. Might say...something she’ll regret’ (ibid: 106). In this satirical state of the nation novel Grace Pepperdine is used to not only to demonstrate the dangers of an unreliable memory but also the issue of agency. Grace is placed, despite the best intentions of her ‘good’ grandson, at the whim of the lottery-winning jailbird and thug, Lionel.

In *Zoo Time* (Jacobsen 2012) Guy Ableman, wonders whether the behaviour of Poppy, his wife’s mother, is due to ‘the drink or do you think it could be early onset dementia?’ (ibid: 119). In the portrayal of the Guy Ableman’s parents, ‘the Dementievas’, who are ‘advancing into mutual dementia’, Jacobsen may be addressing his own fears that ‘we go senile in a way that reflects our natures’ (ibid: 217). At the end of the novel when Poppy is confirmed as having early onset dementia, he remarks “Dementia made the worst of everything, didn’t it? Dementia left out the nice parts’ (ibid: 352).

Whereas Amis and Jacobsen use dementia, Ian McEwan, rather more like Barnes, draws on dementia to reinforce the cultural placing of the narrative. In *Atonement* (McEwan 2001) Briony describes the diagnosis and course of her vascular dementia:

the route map: loss of memory, short-and long-term, the disappearance of single words— the simple nouns might be the first to go— then language itself, along with balance, and soon after, all motor control, and finally the autonomous nervous system. Bon voyage!’

(*Atonement*, 354)

Briony’s knowingness of her dementia can be read as the atonement of the title, but the dementia creates unreliability of the narration and thus her degree of atonement. His use of dementia in *Saturday* (McEwan 2005) although unnamed, is much more straightforward. Henry Perowne visits a care home where:

His mother no longer possesses the faculties to anticipate his arrival, recognise him when he’s with her, or remember him after he’s left. An empty visit. She doesn’t expect him and wouldn’t be disappointed if he failed to show up. It’s like taking flowers to a graveside — the true business is with the past. But she can raise a cup of tea to her mouth, and though she can’t put a name to his face, or conjure any association, she’s content with him sitting there, listening to her ramble. She’s content with anyone. He hates going to see her, he despises himself if he stays away too long.

(*Saturday*, 125)

It is a lyrical and literary portrayal of dementia but it is nevertheless one of dementia as additional domestic harassment.

The fictional theme of a parent with a dementia is reprised, but with much more tenderness and realism, in David Lodge’s *Deaf Sentence* (2008). Lodge’s retired professor of linguistics, Desmond Bates manages the progressive dementia of his fiercely independent father with frustrated tenderness.

Within the current culture inevitable cognitive decline is increasingly viewed as inevitable. This mistaken perception of inevitability means that cognitive decline/dementia presents in the culture as both a reality, and as a spectre of imminent gloom, hovering over the extending years of retirement. If contemporary and realist fiction is viewed as offering a legitimate commentary on the world in which we live, where in western culture the old are the commonest citizen, then it is likely that dementia will be increasingly visible in fictional texts. That it is also present in other genres of writing is indicative of the cultural penetration of the illness and its acceptance of dementia as a trope for old age. The cultural obsession with ageing and the attributes of a dementia, its length and all-encompassing impact on cognition and memory, the body and ultimately the self, mean that it acts as a *donné* for writers across many genres, including non-fictional dementia memoirs, the profusion of which suggests commercial and publishing exploitation of the illness.

The dementia memoir began with *Iris* (Bayley 1998). The graphic detail in which he charted Dame Iris Murdoch's decline of memory and language into what she described to Peter Conradi as 'sailing into darkness' (ibid:179) is hinted at by her in the penultimate paragraph of her last novel in which Jackson says, 'I cannot remember. At the end of what is necessary, I have come to a place where there is no road' (Murdoch 1995: 249) which suggests, to me, that she may have been aware of her failing powers. John Bayley's description of his wife's deteriorating cognition, and his sometimes angry response to it, was praised by the Alzheimer's Society as helpful in promoting awareness of the disease. However it was published before her death and raises ethical issues regarding her consent which were voiced vociferously in a biography (Wilson 2003) and by Christopher Vassilas who felt that there was a

‘sense of prying uninvited into her private life’ (2003). Bayley went on to write two further memoirs about the end of her life.

Television documentaries, such as ‘Me and My Mum’ (Channel 4: 2006), raise similar ethical concerns. While acknowledging the campaigning earnestness of the documentaries, the editing and lack of real time filming does not reflect the relentless demands of sensitive care and support. The clinician/reader reads or views the material knowing stalwart and loving care is not unusual and could be matched by examples taken from patients and their supporters in any dementia review clinic. ‘Celebrity’ memoirs about dementia, such as *Where Memories Go: Why Dementia Changes Everything* (Magnusson 2014), *How Many Camels Are There in Holland?* (Law 2013) and *My Bonnie: How dementia stole the love of my life* (Suchet 2010) tend to be deeply rooted in the specifics of care provision for a relative, in a particular situation, at a particular time and place. Law’s memoir, published in 2013 is the most egregious example of exploitation and refers to her mother’s dementia some twenty years before. This pre-dates acetylcholinesterase inhibitor (ACI) medication and the development of specialist services. It is hard to see what the purpose of publication might be other than commercial.

Whereas Julian Barnes referred to his mother’s dementia in his memoir about death Linda Grant turned her experience of care and support of a parent with a dementia into novel length memoir. The comma in the title *Remind me who I am, Again* (Grant 1998) encompasses the repetitive questioning of a person with dementia which supporters find hardest to tolerate. Feeling that she has no money, Grant’s mother phones her daughter requesting her cheque book:

‘Send me my cheque book.’
‘I can’t, I’ve told you. I haven’t got it.’

The familiar routine begins. The phone slammed down then a minute or two later rings again.

‘Linda, it’s Mum. I can’t find my cheque book. Have you got it?’

‘No, we just had this conversation.’

‘When?’

‘Two minutes ago.’

‘We didn’t.’

‘Yes we did.’

‘Well never mind that. I want you to send me my cheque book.’

‘I can’t. I haven’t got it.’

‘Please, please I’m so hungry.’

It goes on for two days. The phone calls every hour or so as if they had never occurred before. I go out for a while.’

(Remind me who I am, Again, 169)

The narrator in *Scar Tissue* (Ignatieff 1993) also finds his mother’s repetitive questioning wearisome ‘At first I try to count the number of times she asks these questions. On the first day I lose track at sixty three’ (ibid: 44) as do the Lambert family in *The Corrections* (Franzen 2001) who find Alfred’s constant querulous pleas for help difficult to manage, ‘he calls your name even when you’re not here’ Denise complains to Chip (ibid: 634).

Families anticipate that it is physical care which is likely to be the biggest challenge but it is repetitive questioning and sleep disturbance which is likely to cause carers and supporters to relinquish care (Zarit and Zarit 1982, Goode et al 1998). A possible reason for the non-appearance of repetitive questioning in fiction is because the depiction of a search for reassurance hundreds of times a day would halt any narrative as it halts the life of the carer/supporter. It does so, not only in terms of wearisomeness, but because it demands the recognition from the carer/supporter that they are unable to offer comfort and succour to the person and can only stand by, impotent in observing torment.

Rebecca Solnit extends the memoir to one of personal survival in her collection of essays and stories *The Far Away Nearby* (2013). The core of the text is the manner in which she deals with her mother's memory loss. It starts with a gift of apricots in 'the summer when a new round of trouble began' (ibid: 5) and ultimately leads to her mother being placed in permanent care 'staffed by hosts of angels and saints performing miracles for the benefit of the disintegrating beings in their charge' in an environment of 'gracious bedlam' (ibid: 226), a phrase which aptly describes some of the nicer care homes.

Barnes, Bayley, Solnit and Grant are all established authors who have written in a range of genres before creating a memoir. Andrea Gillies (2009) reversed the process. Unpublished until she wrote her memoir about the care of her mother-in-law in the rural north east coast of Scotland *Keeper* won the Wellcome Book Prize in 2009. She has now produced two works of non-dementia fiction.

Cancer (Diamond 1998), stroke (McCrum 1998), mental illness (Jamison 1996) have robust autobiographies and memoirs to offer an alternative to the medical discourse about illness. Francesca Martinez has used her experience of physical disability in stand-up comedy at the 2014 Edinburgh Festival and in her memoir to challenge the cultural orthodoxy of a 'party of high falutin consultants [who] take turns to pick words out of a tombola brimful of polysyllabic sibilants designed to induce pant wetting dread at the every sound or sight of them' (Martinez 2014:18). The argument is not that dementia has no comedic value. Jeremy Hardy used his mother's dementia and death as comedic capital in his stand up material (*Ways with Words* 12 July 2014) and there is an inherent, but black, comedy in many situations reported by patients and their families. Dementia in comedy is seen through the lens of the 'other' rather than it being a direct articulation of experience and any laughter,

although ostensibly ‘with’, is actually ‘at’. Jacky Fleming has a cartoon collection called *Demented* (2004) which documents, with wry humour, the lot of being a woman. That the title should be editorially acceptable is indicative of a cultural female self-deprecation and the position of dementia in that culture. It would be unimaginable to envisage a book of cartoons entitled ‘Palsy’ about the lot of men. Memory loss is a standard joke in *The Oldie* magazine and Alzheimer’s Disease features regularly in *Private Eye* cartoons two of which are presented in Appendix 3.

There is very little ‘life writing’ or autobiography of dementia because the disease process precludes it. What autobiographical writing about dementia is available is largely done by people with an early onset diagnosis (Taylor 2007) (De Baggio 2003, 2007) (Davis 1989), (O’Brien. Date not specified) and does not reflect the experiences of the majority of people presenting in the clinic. A diagnosis of a dementia which is followed by an autobiography and international career on the lecture circuit (Bryden 2005, 2012, 2015, 2015) makes me as clinician/reader uneasy because it does not match the expected progression of the illness. The Alzheimer’s Society website <www.alzheimers.org.uk> [accessed 8 October 2014] did not have any autobiographical writing as recommended reading. The Reading Agency suggests a broader category of Personal Stories which includes memoir <readingwell@readingagency.org.uk> [accessed 18 May 2016].

Dementia portrayed through illustration and strip cartoon format was first used by Raymond Briggs (1998) who charted his mother’s dementia in a graphic memoir. It is also the medium used in *Tangles* (Leavitt 2011) and *Can’t we talk about something more PLEASANT?* (Chast 2014). Chast charts the decline of her aged and ill-matched parents with a meticulous and resonant honesty. There is an added poignancy and respect as the drawing moves from comic strip illustrations to ones

drawn from life as her mother edges towards death. In their delicacy and tact they offer a pictorial equivalent to the sensitivity of John watching his mother's death in *Grace and Mary* (Bragg 2013: 161). Chast's final drawing of her mother (Chast 2014: 122) mirrors the description of Mother's death in *Scar Tissue* (Ignatieff 1993) but lacks the grotesqueness of his description in the second sentence of the novel:

I do not want to be eternally condemned to think of her as she was in those final moments, when we held her hands, my brother and I, and she fought for life and lost, her mouth stretched open, gasping for breath, her eyes staring sightlessly up into the lights

(*Scar Tissue*, 1)

To have both parents in simultaneous decline, one from dementia and the other in failing physical health, is a common scenario, sometimes referred to as a 'brain and brawn' partnership in the clinic. Less common is Mrs Chast's railing against care and the defeatist attitude of her spouse which is akin to that of Enid Lambert in *The Corrections* who 'try as she might, she couldn't get him interested in life' (Franzen 2001: 5). Mrs Chast wants only 'positive thinking!!! Not a bunch of people standing around singing "Kumbaya"' (Chast 2014:150). Despite describing the vagaries of the US health care system, Chast's memoir is the one I would be happiest to have placed in the waiting area of the memory clinic and to recommend to family members struggling to provide care for parent(s) whilst also trying to earn a living. Paco Roca uses the graphic novel in *Wrinkles* (2015) to tell the story of Ernest who is admitted to a care home because he suffers from Alzheimer's Disease. The bleak visual portrayal of AD symptoms, and the 2nd floor of the care home as an equivalent to one of Dante's circles of hell, uses flashbacks, the ellipses of memory and total bewilderment in a dark portrayal of life there. The apparent companionship of Emile, who steals and teases to make his own boredom less intense, does not ease the horror for the reader.

Dementia appears in travel writing: William Dalrymple (2005: 13) uses it to add local colour in his description of Delhi. More frequently in this genre it is the progression of a dementia as a metaphor for a journey which drives its presence. The most obvious use of dementia in this way is in Michael Jacobs' *The Robber of Memories* (2012). This charts a journey in Colombia which is interspersed, when there is a mobile signal, with telephone calls to a London hospital where he is trying to manage the care of his dying mother who has a dementia. En route Roberts has a chance meeting with Gabriel Garcia Marquez, who was then suffering from Alzheimer's, and makes a visit to the Yarumel district. Here there is a 'hot spot' of people with an early onset dementia whose symptoms occur by the age of forty seven which genealogical studies have linked to a mutation on chromosome 14 in a single Basque settler in the 1750s (ibid: 196). The text hovers between a regular travelogue describing the landscape, people and adventures, including his capture and release by FARC rebels, and a meditation on memory. Together they create a somewhat unnerving read and a questionable motivation in which the role of dementia feels exploitative but roots the text as contemporary.

Any writing which considers age is culturally positioned. Although the thesis does not address ageing per se the majority of patients attending the memory clinic were aged over 75 years and the stories told in the clinic were from this age cohort. A gerontological understanding was part of my experience as an 'old-age clinician' in the NHS and in my role of developing and managing a memory service I was influenced by the structural constraints of critical gerontology and their impact on the commissioning of services. Despite being within Older People's Mental Health Services, the service was commissioned with the requirement that it was demonstrably 'ageless' which posed difficulties for some younger people presenting

at a clinic in which signage, letterheads and the telephone response script referred to older people.²⁹ Whilst managing the service I was also a clinical psychologist within it, and my practice was with the person, and influenced by a more humanistic approach to ageing. Models of gerontology have an influence on clinical practice which is carried out in a politicised health culture.

1.7. Gerontology

The current view of old age is more politicised than in the past largely because of a complex fusion of demography and economics. The increasing numbers of people aged over 65 years constitute a significant ‘grey vote’ which is electorally important.³⁰ The same group are simultaneously viewed as costly consumers of NHS resources but important in terms of the retail power of the ‘grey pound’. This leaves the current judgement about age a confused mixture: personal responsibility for managing ones ageing, a veneer of cultural and societal respect and a perception of relative affluence despite 16% of pensioners living in poverty.³¹

Gerontology is vast, fragmented and rife with contested concepts, not least the combination of the words ‘old’ and ‘age’. Historians of old age have pointed out that ‘old age’ is an ‘imprecise term whose meaning is still vague, its reality difficult to perceive’ (Minois 1989:1) and as such a ‘capricious arabesque’ (ibid: 304) which is reflected in the debates of ageing studies. There exists an extensive terminology of ageing used by gerontologists, dating from the first coining of the word ‘geriatrics’

²⁹ We tried to solve this by holding specific clinics for people presenting with possible early onset dementia but it was an uneasy compromise.

³⁰ 78% of those aged 65+ voted in the 2015 General Election compared with 43% of 18-24 year olds ‘If you want young people to vote, give them the handbook’ David Shariatmadari (*The Guardian* 2 November 2015.)

³¹ <www.ageuk.org.uk/money-matters> [accessed 28 October 2015]

by Ignatz Nascher in 1909, 'Ageing Baby Boomers', 'young old', 'old old'³², 'deep old age' (Featherstone and Hepworth 1993: 385), Third and now Fourth Agers which provide 'quite a syllabus of stagey fictions' (Gullette 2004:180) which 'jams us onto tiny separate terrains constructed by a dominant culture' (ibid:192). The lived experience and expression of ageing from age sixty is inevitably going to be contradictory and fragmented because, unlike cohort tags such 'baby boomers' which are largely restricted to a generation or decade, ageing from aged 60 has the potential to last 50 years.

The demographic shift towards an increased proportion of elderly people sets both the political and economic agenda for the field of gerontology and raises ethical and moral issues. Peter Townsend's seminal study of old people in the East End of London, first published in the *Sociological Review* in 1955, and as a Pelican book in 1963³³ was an isolated landmark. Prior to the 1970s old age was little studied. *Old Age* (de Beauvoir 1972) documented the historical position of ageing and then analysed the lived position of the elderly (predominantly, but not solely, from a French perspective). It is a relentlessly negative text which claims that 'Society looks upon old age as a kind of shameful secret that it is unseemly to mention'(ibid: 7). She mentions dementia as 'the mental illness of the aged that has been longest known' (ibid: 555) and with prescience anticipates the work of Tom Kitwood (1987) and the concept of a malign social psychology by asking whether 'the clinical picture of senile dementia may be an artifact [sic], due in the majority of cases to shortcomings in the treatment' (ibid: 560). *Old Age* (de Beauvoir 1972) presages the work of the critical and cultural gerontologists in the following decades in her view

³² I will continue to use the term 'young old' and 'old old' where required as this was the terminology used whilst in practice. Alternatives such as 'deep old age' (Featherstone and Hepworth 1991: 385) to suggest the transition to frailty remain contentious.

³³ It was required reading on my Social Administration course as an undergraduate in the early 1970s.

that ‘the individual is conditioned by society’s theoretical and practical attitude towards him’ (ibid: 15) a use of the pronoun which dates the work more obviously than the information in the text.

Gerontologists have studied the political and social agendas using two predominant paradigms: structural versus functional (alternatively labelled constraint versus choice) which, whilst both relevant, have been largely insulated from each other. The constraint model has been studied as ‘critical gerontology’ by W. A. Achenbaum (1995) in the US and as ‘social gerontology’ by Phillipson and Walker (1987) in the UK. For scholars and researchers under this rubric, the underpinning belief is the social critique that the:

major problems that ageing people encounter are not the inevitable result of biological senescence, nor of unfortunate decisions, but are constructed through social institutions and through the operation of political and economic forces.

(Ageing, Meaning and Social Structure, 2).

It emphasises structural mechanisms of social inequality such as pensions, housing, and the distribution of resources between generations and groups as key to understanding contemporary ageing.

In comparison, the choice model focuses on the interpretation and meaning in later life. The coining of the term ‘Third Age’ (Laslett 1989) alongside the work of Mike Featherstone and Mike Hepworth (1990), Mike Hepworth (2000), Andrew Blaikie (1999) and Bill Bytheway (2011) has gradually promoted increased interest in how ageing is viewed in the wider culture and examined texts, media and the arts including popular music (Jennings and Gardner 2012). It led to an emerging interest in the everyday experiences of older people which was not linked solely to health

and potential frailty and led ultimately to the model of 'positive' or 'successful ageing' promoted by Katz (2000). The template for taking the clinical history presented in this thesis in Chapter 3 is a response to this. It anticipates that the person remains active within a social world and frames questions about the changes the person might be experiencing by asking, 'Have you stopped going out or doing the hobbies you used to enjoy?' rather than 'What can't you do now?' and 'Do you feel fit and well today?' rather than 'What is wrong with you?' As western populations live longer healthier lives policy discourse and socio-political interventions are increasingly organised around the choice model of an active successful ageing which involve health, wellness and productive citizenship (usually in the form of volunteering). Laslett (1989) coined the term 'third age' to counter aged-based discrimination by emphasising the possibilities of productivity, health and activity. However, I would argue that the possibilities of a third age have been over emphasised, dependant as it is on financial resources and physical health. It has pushed stigmatisation and marginalisation on to the fourth age where there is an increased polarity between the two ages in health and social care practices in relation to risk and frailty.

Dementia offers a prime example of how two paradigms of ageing are clearly interrelated. It can be argued that one of the reasons that dementia is so dominant in the cultural discourse is because it challenges both the constraint and choice paradigm in a way that other conditions more prevalent in older people do not. The length of illness, occurring in an intact body and its closeness, particularly in the early stages, to the benign changes of function associated with age means that it has a vacillating position between the two models which leaves the culture unsure where

to place it. In short, the messages about dementia are mixed. The texts discussed in this chapter reflect these multiple versions of the illness.

The differences between two working models of ageing are more apparent in scholarship than practice where they co-exist as drivers for formulating government policy and service delivery. The constraint model has informed the development of mental health services for older people and latterly the development and promotion of memory services whereas the choice model has been important in extending the therapeutic developments in memory services such as the ‘Making the most of your memory’,³⁴ and ‘Memory Matters’³⁵ groups for individuals and carers in which memory strategies and best practice for supporters was encouraged.

In contrast to the constraint and choice models, Chris Gilleard and Paul Higgs promote a cultural approach which is where this thesis has its strongest roots. By culture they mean ‘the various and complex systems of meaning that constitute everyday life’ (Gilleard and Higgs 2000: 2). Despite the jocularity of greetings cards such as ‘Adventure before Dementia’, life-style magazines trumpeting a narrative that seventy is the new sixty, headlines such as ‘Work is the new retirement.’ (*Prospect* Pensions Special report July 2015), promotion of films with cut price day-time viewings for the ‘grey audience’ and Showalter’s identification of positive ageing in ‘geriatric genre’ fiction, Gilleard and Higgs, realistically, but gloomily, point out, that regardless of the school of gerontology:

no organisations seek to portray old age to the individual as either an aspirational commodity to choose or a socially valued process to join. Old age lies sullen and unchanging – represented as the end of the social; a point in life after which further choices are irrelevant.

³⁴ The title of the group I ran.

³⁵ Memory Matters <www.memorymatterssw.co.uk> [accessed 25 November 2015] is a Community Interest Company (CIC) providing memory support sessions for individuals and groups to ‘benefit cognition and quality of life’.

(Cultures of Ageing, 4)

They suggest there is no significant authoritative voice or grand narrative about ageing in the wider culture other than the narrative of inevitable physical decline, which increasingly appears to include cognitive decline. This goes some way to explaining the manner in which ageing and in particular dementia is addressed in fiction.

This chapter has focussed on the two main themes of the research: fictional stories of dementia, what dementia is and what it may mean in the current culture. The following chapter reviews the theory and methodology underpinning this work.

Research Design or Assessment: preliminary investigations and treatment rationale

2.1. Introduction

This chapter describes the key theories and methodology at play in this work: socio-narratology, Narrative Medicine and autoethnography. As an episode of care this chapter fulfils the purposes of a second out-patient appointment where the rationales of treatment options are discussed.

The interdisciplinary elements of research design are illustrated in Diagram 1 (p.75). The selection of material has been examined in Chapter 1. This chapter focusses on the theories and methodology which inform this thesis. The key theoretician for this work is Arthur Frank a sociologist who has examined a range of illness narratives, including his own, and in *Letting Stories Breathe* (Frank 2010) extends his theorising beyond these narratives to all forms of storytelling. Crucial to Frank's thinking is that who we are and what we experience is defined by the stories we tell ourselves and others. His work is influenced by Mikhail Bakhtin and Rita Charon. Bakhtin was a Russian literary and cultural theorist, folklorist and semiotician whose work was translated and became readily available in the West in the 1980s. Over the course of his writing Bakhtin developed concepts which have been absorbed into literary theory of which dialogue will be considered here in most detail. Rita Charon is a clinician who has developed Narrative Medicine as a branch of medicine in which 'a narrative vision is required in order to offer compassionate and effective care' (Charon 2006: 13). In her TED presentation(4 November 2011)³⁶ she talks about the development of Narrative Medicine and describes herself as

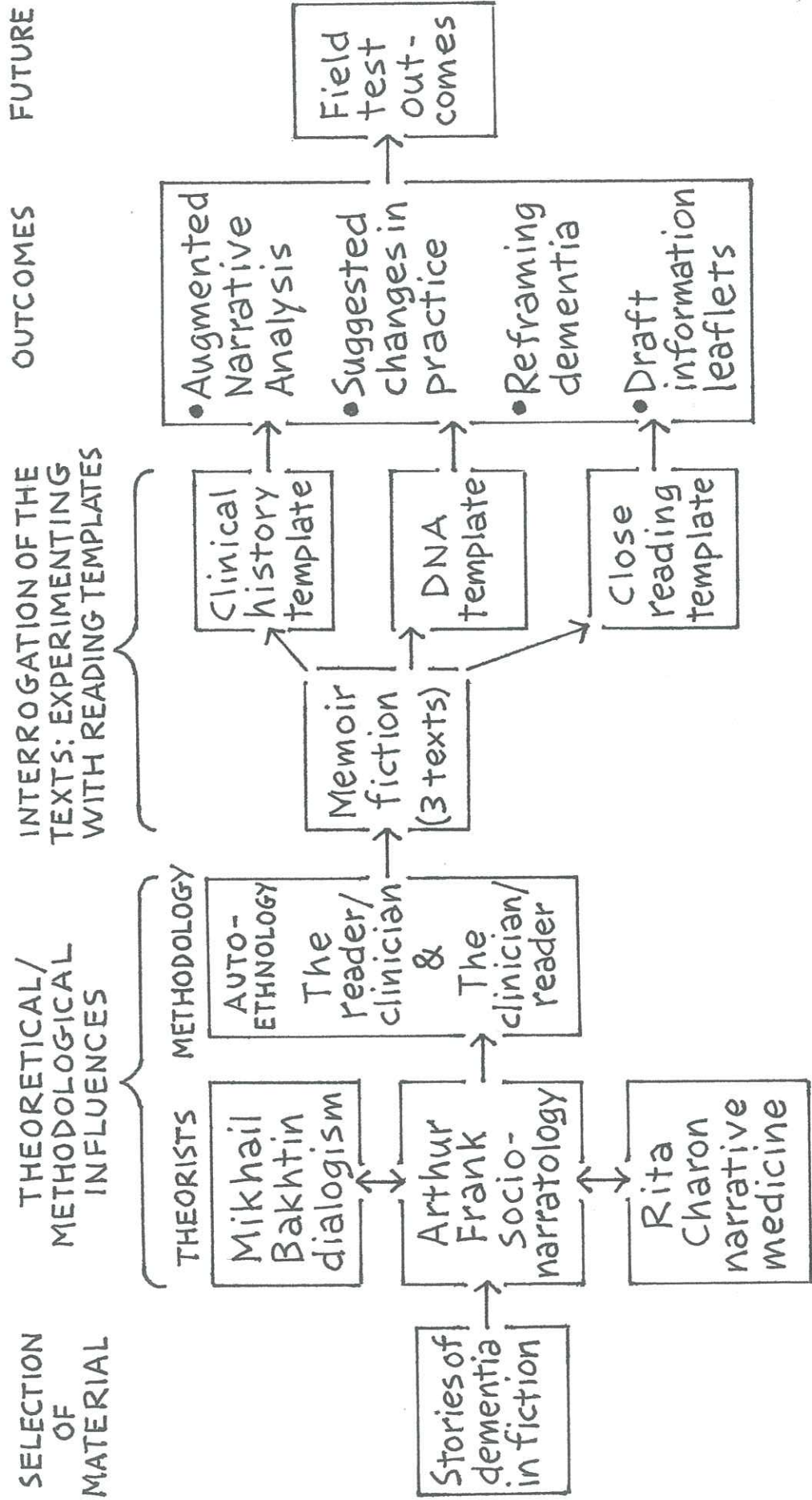
³⁶ Available on Youtube [accessed 6 May 2016].

coming to medicine because she was a life-long reader and ‘as a reader what I did in the office was to pay exquisite attention to the narratives they [patients] gave me’ and whose clinical practice has been ‘fortified by what to do with stories’.

The research methodology of autoethnography uses retrospective examples of fiction at work in the clinical space. The theory and methodology inform the research interventions and capitalise on the vacillating experiences of the clinician/reader and the reader/clinician. The clinician/reader interrogates the clinic as a story telling space where the focus is not the content of the stories told there but how they are told as the clinical history, how they are heard, recorded and put to work in the medical notes which are then examined as a text. This allows issues of authorship and ownership of medical notes, their partiality and closeness to fiction to be considered. In comparison the **reader**/clinician uses a form of literary reverse engineering by which a fictional story of dementia is examined in detail through testing its ability to fulfil the information required in a clinical assessment to create a clinical history and faux medical notes for key characters in the memoir fiction. This tests the clinical veracity and authenticity of the three memoir texts.

The same texts are analysed using three templates for reading: the Memory Service Assessment for history taking developed as part of my clinical practice, Dialogical Narrative Analysis (DNA) from socio-narratology and one developed from the Close Reading of Narrative Medicine. I have called this the Triple

RESEARCH DESIGN: STORIES WE TELL ABOUT DEMENTIA



Analysis. The implications of the research outcomes for clinical practice are discussed in the final chapters of the thesis.

This interdisciplinary research draws on different aspects of narrative practice and fulfils the criteria of ‘analytic bracketing’ (Holstein and Gubrium 2012: 9) in which neither the ‘what’ nor the ‘how’ of story-telling practice is privileged as I, the researcher, manoeuvre around the interplay between the two. In this work, the manoeuvring is done using the theory of socio-narratology to challenge dementia fiction and autoethnography to ground my experiences as a clinician/reader in the research endeavour.

In sociology, narrative enquiry tends to focus on personal stories — especially their content, themes, and structures where the ‘attention centers on transcribed material, often gathered through interviews’ (Holstein and Gubrium 2012: 3). This research does not use interviews or the verbatim stories told by patients³⁷ but emphasises how those stories are elicited and collated in the clinic as a story telling venue. Exploring how dementia narratives are shaped by the context of the clinic leads to a greater understanding of how the individual enters the clinic as an individual and leaves a patient, how professionals maintain boundaries, and how institutional power is demonstrated in the development and maintenance of medical notes. The clinic defines the structure for the way the story of a person’s possible dementia is told.

In a work which addresses story telling in a clinical space Michel Foucault’s *The Birth of the Clinic* (1973)³⁸ has to be acknowledged. His analysis of the medical gaze, ‘*le regard*’ and the power relations of a ‘non-reciprocal situation’ (Foucault

³⁷ Although this research uses the experience of working with patients no patient or service is identified and the research has not been subjected to NHS research ethics procedures.

³⁸ English edition. First published in France in 1963 as *Naissance de la Clinique* (Presses Universitaires de France)

1973: xv) inherent in clinical medicine are accepted as informing practice and the space where it is carried out. The focus of this research is in the clinic where stories of dementia are told within an intimate environment but the clinic sits within a web of relationships and hierarchies such as NHS commissioning teams and corporate bodies which are tasked with delivering the national and local strategies for dementia. Within this matrix of relationships many other stories are told about dementia ranging from reports on the status of the waiting list, accreditation, press coverage and in-house newsletters to patients, all of which have an impact on the work of the clinic.

The research has an unconventional frame but Geertz (2000 Quoted in Flick 2014) has argued for research which draws on:

ways of thinking that are responsible to particularities, to individualities, oddities, discontinuities, contrasts, and singularities', because in a world of pressed-together dissimilarities variously arranged [...] there is nothing for it but to get down to cases, whatever the cost to generality, certainty or intellectual equilibrium.

(An Introduction to Qualitative Research, 531)

The particularity of this research is that it is interdisciplinary mixing clinical practice and literary analysis, and contrasts clinical outputs and fiction. The research interventions, and in particular the creation of faux notes, are singular and made possible through my personal circumstances. Within this research model there is a cost to certainty but it creates outcomes which have general relevance for clinical practice and dementia care. The research uses unorthodox methodologies and tools as suggested by Lury and Wakeford (2012) who encourage 'devices' such as lists and anecdotes as being legitimate resources for interdisciplinary research arguing that such devices provide a pivot between theory and practice. Although such 'inventive' practices reflect novel ways of creating knowledge and offer an

alternative heuristic they can be prone to the dangers of the scattergun and the aim is to avoid this by using a single theory, socio-narratology and a methodology, autoethnography, which are broad enough, and forgiving enough, in research terms to encompass the range of research interventions and offer an argument about the stories told about dementia in fiction and in the clinic.

Socio-narratology is particularly apt for underpinning this work. It encourages curiosity and inquisitiveness about stories and is presented as a means of ‘movement of thought’ (Frank 2010: 74). Because it does not say ‘*these are the rules; here are the steps to implement these rules, follow my direction or suffer rejection*’ (ibid: 74) it is not prescriptive and can cope with a degree of playfulness and innovation in the research methodology. It is elaborated by Arthur Frank in *Letting Stories Breathe* (2010) as the culmination of his sociological work exploring illness narratives. Mikhail Bakhtin is placed adjacent to Frank in the diagram of research because Bakhtin’s dialogical position is central to the epistemology of Frank’s theory of socio-narratology. Similarly Rita Charon’s is placed alongside Frank because her ‘new frame for clinical work’ (Charon 2006: 13) which ‘makes the case that narrative training in reading and writing contributes to clinical effectiveness’ (ibid: 107) through her specific drill of Close Reading reflects Frank’s position that stories are actively at work in the culture. Frank, Bakhtin and Charon share a central tenet that fiction has cultural relevance: Bakhtin in promoting an ethical and cultural understanding, Charon as a tool to influence the practice of medicine and Frank in viewing stories and their telling as central to being human because they ‘affect the terms in which people think, know and perceive’ (Frank 2010: 48).

Research rarely presents itself as fully formed. This has been an emergent model which mirrors clinical practice and uses an NHS ‘episode of care’:

assessment, treatment and evaluation, as its structural model. The research has used knowledge and resources gained through my clinical career and combined them with a theory and methodology which can accommodate the position of the self as clinician /reader and reader/clinician. Using socio-narratology which roots stories in an active social world, and autoethnography as a research method which values the role of the self, offers both a retrospective and prospective lens. Retrospective because I have used autoethnography to re-understand what might really have been happening when I used fiction in practice and prospective because I have combined clinical experience and narrative research to develop research outcomes. The theory and methodology combine to facilitate the exploratory nature of the research and suggest practical possibilities for the real world, the culture in which patients, their families and health professionals live.

2.2. What is socio-narratology?

Socio-narratology is the culmination of Arthur Frank's work as a sociologist and is explicated in *Letting Stories Breathe* (2010). It follows *At the Will of the Body* (1991) which dealt with his own response to serious illness and the transformations which take place in the medical encounter as the person moves into the role of patient. In *The Wounded Story Teller* (Frank 1995) he describes how disease becomes 'the story, the common bond of suffering that joins bodies in their shared vulnerability' (ibid: xi) and how people who are ill 'need to tell their stories, in order to construct new maps and new perceptions of their relationships to the world' (ibid: 3). *The Renewal of Generosity* (2004) extended his interest in narrative to include health professionals and their patients.

Frank proposes socio-narratology as a way of thinking and studying stories so that it is possible to 'learn to live better with stories that surround and circulate

through our lives' (Frank 2010: 1). As a method of narrative analysis it does not search for themes in stories but instead asks what the story does. They act:

in the sense, of providing information but more significantly, stories give form — temporal and spatial orientation, coherence, meaning, intention and especially boundaries — to lives that inherently lack form. How stories inform lives can be a gift or a danger.

(Letting Stories Breathe, 2)

This statement suggests that not only do stories inform our lives, our stories are our lives: they are what make us human and shape conduct. The ability of stories to shape experience gives added heft to the need for fictional stories about dementia to have, at the very least, a narrative authenticity because we 'remain caught up in some, forget many others, and adapt a few to fit adult perceptions and aspirations' (Frank 2010: 8). This statement suggests that we use and create stories in our self-construction and is reflected in this research by my positions as a listener and creator of stories as a clinician, autoethnographic researcher and reader. It is Frank's assertion that we have a 'necessary, inescapable, sometimes beneficial but too often imperfect companionship with stories' (ibid: 2) and the goal of *Letting Stories Breathe* (2010) is to improve the quality and terms of the companionship. His tone becomes almost evangelical and is seductive to me as a researcher, for whom being a reader is part of my self-definition. It is the companionship of stories which drives the 'socio' of the theory because, for Frank, it is stories which make life social and connect people. In a thesis which is exploring how stories of dementia are portrayed in fiction and inform the culture and storytelling in the clinic the connective companionship of stories is a useful theoretical premise.

In his early works Frank (1995: 188) made the distinction between the terms narrative and story as 'People tell their own unique stories but they compose these

stories by adapting and combining narrative types that the culture makes available' but in *Letting Stories Breathe* (2010) he uses the terms story and narrative interchangeably and accepts that 'the words *narrative* and *story* overlap so frequently that sustaining this distinction in usage proves impossible' (Frank 2010: 200 Original italics) and the practice will be followed in this work. Although Frank refuses to define 'story' he claims that it is recognizable to any listener or reader, shares key essential attributes, and is active and at work in the culture through its ability to reshape the past and imagine the future. Maintaining such a broad remit for stories allows socio-narratology to be as relevant to stories in the clinic as those on the bookshelf. That it is a theory not restricted to literature, and includes all story-telling genres in their most vibrant and open form, is permissive and beguiling to me as a reader of *Letting Stories Breathe* (Frank 2010) but problematical for the researcher.

The 'narratology' of socio-narratology is less rigorous than traditional narrative theorists such as Bal (2009) or Rimmon-Kenan (1983) who focus on narrative structure and goes beyond the experientiality of Fludernik's 'natural' narratology (1996). Frank opts for a relaxed model of narrative in which he lets stories 'be', that is, breathe. This, he argues, liberates them to take their place where they must to do their work. This is an elusive business and one of the roles of the researcher trying to use socio-narratology to analyse particular genres of story-telling practice is to tie it down.

In addition to his use of Bakhtin's concept of dialogism to underpin socio-narratology and Rita Charon's Narrative Medicine in *Letting Stories Breathe* (2010) Frank collects fragments and concepts such as Pierre Bayard's 'inner library' (Frank 2010: 54) to create a theoretical eclecticism to add intellectual weight to a theory

which can be insubstantial once the seductive rhetoric is peeled away. For instance, he borrows Frank Kermode's metaphor of the ticking of a clock to explain the expectation of causation inherent in narrative (Frank 2010: 25) and then William Labov's (1997) five-part narrative structure⁴¹ to explain why, to become interesting, powerful or useful, stories develop within Kermode's ticking a more complicated form.

Similarly Frank appropriates the term 'habitus' from Pierre Bourdieu as 'narrative habitus' the 'collection of stories that interpellate a person' (Frank: 2010 52). Habitus is a key concept because, like dialogue and dialogism, it is transdisciplinary and pervades 'not just his own [Bourdieu's] discipline but the 'full gamut of social sciences and humanities (Atkinson 2016: 1) to the extent that it is 'pivotal to comprehend the pains and pleasures of contemporary human existence' (ibid: 26). As Reed-Danahay (2005) has demonstrated Bourdieu used a range of words and nuance over his career to explain his defining concept but the most common definition used is 'Systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures ...collectively orchestrated without being the product of the orchestrating action of a conductor' (Bourdieu 1977: 72) . Habitus is tacit, durable, felt as instinctive and not taught but acquired through socialization to become a property which shapes social action. Frank describes it as acting as 'second nature' (Frank 2010: 52) enabling a person to recognize a situation as comfortable or familiar rather than or obscure or strange. It determines 'how a person feels *conducted* to do what they do' (ibid: 52. Original italics) and ultimately provides an analysis of social power, what Bourdieu calls 'capital' operating in any given situation or 'field'. As such it is at play in the clinic.

⁴¹ Abstract, orientation, complicating event, resolution, and evaluation.

Each person in the clinic brings to it their own unique habitus which is rarely articulated, simply understood by all participants. Generally the habitus of the clinician is one of control and an expectation of holding the social and cultural capital which plays out with individual degrees of intensity. The patient and supporter are expected to obey the unspoken rules, what Bourdieu calls '*doxa*', of subservience and a degree of gratefulness that they are being seen. The habitus of the clinic is taken for granted by the clinician and only becomes overt when a patient presents with a set of symptoms which are outwith anything they anticipated. With unusual presentations and stories colleagues confer to combine their clinical experience to decide whether the patient's story fits with someone's clinical experience or the person had been referred to the wrong clinic. Habitus informs the discussion of the clinic as a story-telling venue.

Frank's extension of habitus into 'narrative habitus' is his own adaptation which implies 'the taken for granted corpus of stories that we feel comfortable telling and hearing in any cultural environment and the shared sense of where the stories might lead (Frank 2010: 94). He argues that 'people are disposed to certain stories just as they are disposed to certain foods' (ibid: 52). It involves firstly a repertoire of stories that a person recognizes and feels competent to use which allows a predication of how others will react to a story. In a memory clinic the narrative habitus relates to the shared understanding of what stories may be told there, usually ones of memory lapses or of memory function which is no longer helpful in navigating the world independently. Narrative habitus invokes a person's taste in stories to which they will be open and a sense of what Frank calls 'predictable plot completions' (ibid: 54), that is, 'what we know will happen'. *Turn of Mind* (LaPlante 2011) fulfils this in terms of being both a crime thriller and dementia

fiction. Similarly *The Wilderness* (Harvey 2009) and *The Garden of Evening Mists* (Eng 2012), alongside the memoir fiction, fulfil my narrative habitus, whereas the didactic fiction does not and I find these texts, for reasons that are articulated during the course of this work, a less pleasing and more challenging read as both a clinician/reader and reader/clinician. Within realist fiction there is a preferred narrative of rules, direction and limitations about what leads to what; similarly there is a narrative habitus for dementia in fiction and in clinical story telling. For instance, it appears that in fiction it is acceptable to authors and editors that reference can be made to dementia which grounds the text as contemporary but the portrayal of the end stages of a dementia are restricted to memoir fiction.

Bourdieu explored the work of Gustave Flaubert to illustrate the wider social structures at work in the development of the ‘point of view’ as it relates to habitus within social fields (Reed-Danahay 2005: 10). Reed- Danahay identifies autobiographical undertones in the way that Bourdieu uses Flaubert in the development of his understanding of life trajectory which, Bourdieu would argue ‘comes about not as a result of some inherent unity or identity of the individual who follows a particular path but, rather, as an outcome of the various social fields and their attendant values in the overall economy of symbolic exchanges, in which the person operated’ (ibid: 23). Social fields both create and constrain the habitus of authors because they represent both ‘cultural capital and marketable commodity’ (Moran 2000: 6). All the memoir fiction authors have significant cultural capital, Ignatieff and Bragg as critics and politicians and Franzen as a prize-winning novelist and essayist. They ‘have the potential to be commercially successful and penetrate into mainstream media, but are also perceived as in some sense culturally ‘authoritative’— in other words, they occupy a contested area of cultural production’

(ibid: 6). Frank accommodates Bourdieu's position on point of view within narrative habitus as the range of stories it feels possible to tell. It is, for instance, hard to imagine Franzen, Ignatieff or Bragg writing a Tolkeinesque novel.

The habitus of authors has been explored by Amy Palko (2009) through the work of Stephen King in which she argues that there exists a dramatization of King's habitus at the level of narrative which is centred round the figure of the author-protagonist. More importantly she makes the point that authors exist within cultural, economic, institutional and literary production fields which are invoked when writing and navigating novels to publication. The habitus of each author and the reader expectations of realism in contemporary novels help to explain why young onset dementia dominates in the fictional portrayal. Dementia is a narrative illness but it is the young onset variety which has the strongest narrative drive of drama and tragedy. Lisa Genova, author of *Still Alice* (2009) was a first-time novelist with a PhD in neuroscience from Harvard at the time of publication makes this explicit. She had a grandmother with dementia but chose to portray dementia in a fifty-year old professor 'because we as a culture expect eighty five-year olds to be forgetful' (Genova 2009: 216). She gives Dr Howland a 'straight and narrow shot to diagnosis, both in the interest of providing an example of what should happen and of creating a story that wasn't five hundred pages long' (ibid: 301). As an online columnist for the American Alzheimer's Association her aim was to 'educate and reassure' (ibid: 300) but her fictional portrayal of dementia suggests an unlikely degree of control and insight in Dr Howland, which may well offer false hope to readers. The narrative habitus of dementia fiction is of a dementia which occurs in the young and insight is maintained rather than a prolonged period of stable frailty where the body is alive but the person largely absent. In *Still Alice* Dr Howland continues to teach and

supervise despite being unable to draw an analogue clock correctly (Genova 2009: 137) and Judge Teoh in *The Garden of Evening Mists* (Eng 2012), despite problems with expressive language and writing, eloquently articulates her future which her diagnosis suggests would be unlikely.

Frank uses accrues theoretical concepts from others and develops a novel terminology such as ‘material semiotic companions’ (ibid: 42) and ‘fabrication mechanism’ (ibid: 131) not all of which is helpful for fictional stories. More useful for this work is ‘institutional emplotment’ (ibid: 134) which has relevance for the clinical history because the ‘institutional emplotment’ of individual stories restricts the range of narrative resources people may need. This is certainly true of the clinical history which shoe-horns the narrative into a template and defines the person as a patient.

For Frank, stories exist and are active in a real world; that is where they do their work and have their relevance. The implication is that fictional stories exist not only on the page, but in a web of relationships within the culture. Stories inform the culture and are informed by the culture, a relationship which Frank describes as symbiotic (Frank 2010: 37). This symbiotic relationship creates what Frederic Jameson, the literary theorist and critic describes as ‘the vehicle of polyphony or the recognition and expression of a multiplicity of social voices’ (Jameson 2013: 3). Not only do the selected texts use a multiplicity of literary and social voices, these voices are used to different social purposes and thus become the ‘work’ of the novel.

Fiction as active and at work is not new. In *Fictions at Work* (1995) Mary Talbot extends the argument for the relevance of fiction, which she views as an ‘ideological production’, to explore how fiction makes a ‘crucial contribution to the

constitution and reproduction of social life' (Talbot 1995: 4) and '*at work in society*' (ibid: 5 Original italics), a phrase later used by Arthur Frank in relation to the activity of stories in the world. Talbot draws on Jameson's concept of 'strategies of containment' (quoted in Talbot) which usually take the form of imaginary resolutions to real contradictions or tensions, a term which could describe dementia fiction. Authors using first-hand experience of dementia in their fiction raise the spectre of the essential relationship between reality and fiction. This has been a long standing contentious topic in literary theory (Allan 2001) although James Wood claims that 'fiction is both artifice and verisimilitude, and that there is nothing difficult in holding together these two possibilities' (2008: 2). Although theories differ about how, it seems clear that reality and fiction are persistently meshed. This thesis takes a position more closely aligned with that of Wood because it liberates the use of fictional narratives about dementia to substitute for patient narratives, for instance, in honing assessment skills and the development of patient and supporter information for use in the clinic which are discussed as research outcomes.

Whereas Frank embraces storytelling and can encompass stories in the clinic Talbot focusses on fiction and is useful in considering dementia fiction. For Talbot, ideology has the potential to enter fiction three ways: through the story, the discourse and the significance of the theme. The position of dementia in the culture is evident by the amount of fictional stories told about dementia but no other illnesses. The narratives create a range of potential discourses about dementia, for instance, love being sufficient to conquer all the difficulties of dementia reduces the illness to a manageable sadness rather than the relentlessly grim decline portrayed by Franzen and Ignatieff. The didactic dementia fiction selection, of which *Forgotten* (Lewis 2010) is one, aims to empower the reader by offering increased knowledge and

awareness about the presentation of dementia and the mechanics of reaching a diagnosis through straightforward story-telling. Despite the well-meaning intentions of the authors of didactic fiction who wish to empower and educate readers they are writing with the grain whereas it is writing against the grain, which, Talbot argues, is where fiction as a vehicle for significant empowerment lies. It is texts such as *Half the Kingdom* (Segal 2013)⁴² which use satire and comedy to challenge both how dementia is diagnosed and treated. It resists and contests the dominant discourse about dementia more powerfully than the didactic fiction which follows the implications of the medical model. Nor does memoir fiction resist wholeheartedly the dominant discourse. *The Corrections* (Franzen 2001) and *Grace and Mary* (Bragg 2013) do not challenge it directly but significantly enrich it by placing dementia in believable situations and relationships. This makes them potentially more useful in the clinical space than a text such as *Scar Tissue* (Ignatieff 1993) in which the internality and over-involved relationship of the narrator and his mother, although ‘against the grain’ creates unease for the reader which is likely to make the text difficult to use in the clinical arena.

Part of the discourse of fiction is through the voices of the characters which populate the texts. In the selected fiction examined in this thesis various voices are represented. Three texts use the direct voice of the person with a dementia, *The Wilderness* (Harvey 2009), *The Garden of Evening Mists* (Eng 2012) and most poignantly that of Margaret in ‘These are not my clothes’ (Kay 2012). The most complex narrative voice is in the crime thriller *Turn of Mind* (LaPlante 2011). The voice and position of carers and supporters in dementia fiction is most clinically resonant in *Grace and Mary* (Bragg 2013) and at its most varied in *The Corrections*

⁴² A New York emergency room experiences an ‘epidemic’ of sudden onset Alzheimer’s Disease.

(Franzen 2001) in which each of the siblings has a novella length chapter to develop their voice and tell their version of the story.

As with fiction, a range of voices are available in the clinic to tell their story of dementia. The health professional is working within a medical model and promoting a line which is compatible with relevant local and government policies. Patients and families usually attend the clinic with expectations and hoped for outcomes and a successful consultation, for everyone, is when these are shared. It becomes contentious when an alternative understanding of dementia is pursued, for example, that a specific diet or a canal boat life style is the only acceptable option. Each personal position is informed by experiences, of which fiction may be a part, hence the importance of the portrayal of a realistic truth about the illness. An attendance at clinic based solely on the knowledge about dementia gained from *Forgotten* (Lewis 2010) may set unrealistic expectations that love will be sufficient to see a couple through the diagnosis and aftermath. My clinical experience suggests that this may not always be possible and during the progression of the illness many compromises of what love and care might look like are likely. As Frank points out ‘stories can make life good, but they also make life dangerous’ (Frank 2010: 2).

‘Every text has built into it an implied reader, an imaginary addressee for whom the text was written, someone who can easily supply the necessary information resources to make coherent sense of it’ (Talbot 1995: 151). As a clinician/reader I bring to the dementia texts different resources and expectations to those available to patients and supporters. One of the resources is the knowledge that the concept of dementia is not fixed. It has changed during the course of my career and is currently being reshaped to suggest dementia as the norm if it occurs in late age. In contrast people presenting with mild memory problems which are not

currently creating significant difficulties may now elicit a diagnosis of Mild Cognitive Impairment (MCI). Prior to 2000 these people would never have become patients but now have a diagnosis the equivalent of 'dementia limbo' as it is not possible to detect which third of the people diagnosed with MCI will proceed to develop dementia. Such clinical and conceptual shifts which surround dementia have been not only a response to increasing scientific knowledge and treatment possibilities but driven by demography and the economics of care. As a clinician I recognise that the narrative of dementia as an illness is not fixed yet the diagnosis of dementia is given as if it was definitive and the story is set.

Through his work with illness narratives and his own experiences as a patient (1991) Frank recognised a mismatch between the stories told by clinicians and the stories told by patients and sought a theoretical understanding of the situation in *The Renewal of Generosity* (Frank 2004) where he draws on Bakhtin's concept of dialogue as a means of promoting a more honest and enriched clinical encounter. Frank extends his thinking from illness narratives to more generic storytelling in developing socio-narratology (Frank 2010) but dialogue remains the core concept of the theory. Bakhtin appeals to Frank and Frank to me as a clinician, because both value and promote humanity which in medicine Frank calls generosity.

Not all of socio-narratology as described in *Letting Stories Breathe* (Frank 2010) is totally coherent, or sensible, and useful for this research. What is useful in socio-narratology are the narrative structures he invokes and the practice of Dialogical Narrative Analysis (DNA) which work together to offer a democratic and equalised reading of texts. The usefulness of the narrative structures of socio-narratology which he calls capacities are examined in relation to one of the selected texts

2.2.1. The capacities of socio-narratology and how they work in the selected fiction

Frank describes thirteen ‘capacities’ as the ‘narrative equipment’ (ibid: 27) of socio-narratology which fill the structure of a story, engage and hold the reader to reveal ‘how stories do their work for and on people’ (ibid: 28) and ‘arouse people’s imaginations concerning how their lives might have been different, and the possibilities that still lie open to them’ (ibid: 42). The capacities include familiar categories of narrative analysis, such as character and point of view, to which are added abstract ones such as ‘performative’, ‘inherent morality’ and ‘interpretive openness’. The capacities reveal a major difficulty for socio-narratology in practice, not only because some of them are slippery but because they conflate the position of the reader and the substance of the texts. Frank is likely to argue that the division is irrelevant in terms of the ‘socio’ of the theory and that reader and text function as one in the culture. However further complications arise with them. Frank argues that ‘Stories to be stories, must have a *sufficient* number of these capacities, and sufficiency depends on how the capacities are used, as well as the tolerances of those who receive the story’ (ibid: 28 Original italics). They are described in detail in Chapter 1 of *Letting Stories Breathe* (Frank 2010) but disappear from the text and play no further role in the explication of the theory. Despite these reservations, the capacities, which are listed and defined in full in Appendix 4, are a novel means of analysing how a piece of fiction works. To reveal aspects of a text as it relates to dementia Frank’s capacities (in bold) are explored in relation to one of the selected texts, *Turn of Mind* (LaPlante 2011).

2.2.2. Capacities at work in *Turn of Mind* (LaPlante 2011)

Turn of Mind (LaPlante 2011) is a crime thriller in which Dr White, a renowned hand surgeon is accused of, and eventually committed for, the murder of her good

friend and neighbour, who has been found dead with the fingers of her left hand neatly severed. Dr White is widowed and has recently been diagnosed with Alzheimer's disease. She is cared for at home by a live-in carer and is supported by her daughter, who manages her mother's care and finances. Dr White's son is broadly supportive but less intimately involved. Despite Dr White being young to develop a dementia the *mise-en-scène* is realistic and believable.

Frank's first and key capacity is **trouble**: this is defined by Frank as a 'complicating event' or as 'something goes awry' (ibid: 28). Trouble for Dr White is her dementia and investigation as perpetrator of a murder. This creates a skew and tension in the expectations of the reader, a space of uncertainty and shifting views, as the reader negotiates, through some clever plotting, whether it is the dementia or the murder providing the narrative drive. The trouble permeates current family relationships and retrospectively those with the deceased father/husband. The siblings have slightly different **points of view** regarding their mother, as does the paid care giver to Dr White. Here two capacities, trouble and point of view, create a third one of **suspense**. The question here is not of 'who did it?' but rather 'did she do it?'

The **truth telling** of this text is done through the shift in the voice of the narrative. The narrative is constructed through paragraphs forming a 'call and response' structure by which Dr White comments on events through an internal monologue available to the reader but not to the other characters, which gives the text the capacity of **imagination**. Dr White's monologue moves with subtlety from the first person into second person and ultimately into a third person narrative as her dementia progresses. This allows the omniscience of the narrator to remain, albeit in a more fragmented form. At the end of the novel Dr White is able to use the first

person, 'No I will not go that far. I am not that far gone' followed by 'The person is starting to cry again' (LaPlante 2011: 304). This may mean Dr White's response to her daughter's revelation or the observation of her daughter's response to the revelation. Either way Dr White is left in a dark limbo. The voice of Dr White continues to speak to the reader who is locked into an increasingly empathic state with her. Such ambivalence offers the reader Dr White's subjective view which is read objectively. It is these two capacities of truth telling and imagination working together which gives this crime thriller such power and authenticity.

All the characters respond differently to Dr White's dementia and predicament. The care management role undertaken by her daughter creates rifts between the siblings and exposes the chequered past of the son. The work Dr White had put in to resolve her husband's shady dealings with the law tells the story of a marriage which was apparently robust, but now revealed as cracked, repaired and changed. This is an important story for Dr White, internalised and not reported outwith the family. This story within a story demonstrates **interpretive openness**, as the children are revealed to have been more aware of what happened within the embedded story than Dr White had ever known.

This embedded story impacts on the crime thriller 'reveal' at the end of the book. Through trying to be good, upholding the family status and professional standing, the daughter becomes a murderer. At this point the narrative reverses to the predicament of Dr White who 'knows' who the perpetrator of the murder is but is in no position, through her advanced dementia, either to articulate or reveal this knowledge. Her daughter's actions are complex and ambiguous. She eventually confesses to her mother that she is the murderer but her mother, lost in the égarément of end-stage dementia, in a locked nursing unit, and serving the sentence for the

murder, will never be in a position to reveal this. At this point the reader is in an intense relationship with the text because they, unlike the daughter, have access to Dr White's internal monologue which reveals her position as more knowing than her external presentation suggests which results in the reader becoming more participant in the awful position of the mother.

Some capacities work through the plot, others work through responses to the plot. The capacity of **shape shifting** depends on the emotional location of the reader. The role of the paid carer is one rarely portrayed in dementia fiction but is realistically present in this text. Magdalena is the paid carer who does the 'heavy lifting' of day to day care and monitoring of Dr White. This capacity highlights the tension in the tolerance of demanding behaviour in dementia when managed through payment rather than familial duty or affection.

Turn of Mind (LaPlante 2011) has all the conventional tropes and shape of crime fiction; by the end of the book we must know who did the murder and how. The **resonance** of all previously read crime thrillers pervades the reading of the text but it tells profound truths about dementia through the 'call and response' structure of the narrative.

Two capacities have not so far been mentioned: **sybiotic** and **performative**. They highlight difficulties with using only capacities to analyse stories because they relate not to texts or stories per se but to the nature of story-telling. Sybiotic is described by Frank as 'Stories work with other things — first with people, but also with objects and with places' (Frank 2010: 37) and the most obvious sybiotic is between stories and the people who tell them. This is no more than reading. The capacity 'performative', that is, 'Stories *do* things; they *act*' (ibid: 40), explores what

the symbiotic entails, ‘reporting, convincing, instructing, indoctrinating, recruiting, amusing, generating sympathy or antipathy, or simply passing the time’ (ibid: 40). The same story might perform many of these activities dependent on the context of the telling and the reader. In the context of the clinic the capacities can reveal how fiction might perform as a teaching tool for trainee health professionals.

Frank’s definition of a story is that a ‘sufficiency’ of capacities are in play but because he draws on such a broad base of stories to illustrate the theoretical base of socio-narratology, the examples offered by Frank lack certain capacities and emphasise others.

Some of the selected texts explored in this thesis are more tentative in their use of multiple capacities but they are there in some form. The issue becomes therefore not one of use, but of emphasis. In fictional narratives the relationship between author and reader is more distanced in time and less responsive to the feedback and finessing available to a verbal story teller. It is not merely whether there are sufficient capacities but how the capacities reverberate and resonate with each other that create the activity and vitality of the story.

Turn of Mind is a crime thriller in which the plot twists hinge on the progression of a dementia. It uses more capacities than other selected texts (See Appendix 5) which demonstrates its structural complexity but used alone capacities do not reveal the work of the text. Their utility is as scene setting precursors to orient the reader in answering the questions of Dialogical Narrative Analysis (DNA) which Frank describes as the practice of socio-narratology. The dialogic position permeates socio-narratology but it is through DNA that it becomes overt and its potential usefulness for clinical practice is revealed. Before examining DNA in detail it is

necessary to clarify Bakhtin's concept of dialogism and how Frank uses it, sometimes quirkily, in DNA.

2.2.3. What is dialogism?

Dialogism is an understanding of the world which is 'more than a literary or a purely interpersonal phenomenon: it describes the condition of all verbal interaction and therefore of all conceptual, social and ideological activity' (Renfrew 2015: 95) and offers a moral position regarding social relationships. Bakhtin developed his idea of dialogue in his analysis of the author, hero and characters in Dostoevsky's novels in which he claims that for Dostoevsky the hero is not ' "he" and not "I" but a fully valid "thou" (Bakhtin 1984(a): 63), a 'deeply serious, *real* dialogic mode of address' (ibid.) which 'affirms the independence, internal freedom, unfinalizability, and indeterminacy of the hero' (ibid.). 'Unfinalizability [...], unclosedness [...] and [...] indeterminacy' (Bakhtin 1984: 53) define Bakhtin's dialogue and determine the morality of social relationships because it means the voice of an 'other' counts equally with one's own. It is an idealized position of being able to look 'as it were, in all the mirrors of other people's consciousnesses, he knows all the refractions of his image in those mirrors' (ibid: 53) and demands of the individual a degree of self-awareness and capacity to consider 'all the possible refractions'. The multiplicity of all the refractions is unknowable but the position acknowledges the validity of multiple understandings and demands that the individual should be 'constantly asking: what does this look like to *them*, from where they are? (Frank 2004: 44 Original italics). This phrase and the one Bakhtin uses in arguing that that Dostoevsky 'speaks not *about* a character, but *with* him' (ibid: 63) defines the ideal clinician-patient relationship and good health care.

Bakhtin's use of Dostoevsky's stories to develop a moral position regarding social relationships suggests that all stories can be scrutinised from a dialogical perspective which Frank develops as the Dialogical Narrative Analysis (DNA) of socio-narratology. For Frank a dialogical position implies an 'ethical demand for openness to the difference of the other, both recognizing what is different and also respecting the need to sustain that difference, not assimilate or finalize it' (Frank 2010: 193).

The antithesis of dialogism is monologism, 'the single unquestioned voice' (Frank 2004: 103) which is closed to the response of the other and exemplified in the clinic by the delivery of the diagnosis. The monological position is 'finalised' and meanings are fixed whereas in the dialogic nothing is finalised and no meanings are fixed. Both dialogic and monologic positions are present in the clinic. Diagnosis is almost always delivered from a monologic position which defines and finalises the person as a 'patient with dementia'. Once diagnosed and in the early stages of the disease some patients describe a feeling of being consigned to live only as their diagnosis which is taken as defining them. In this thesis I refer to this position as 'otherness' or 'alterity' whereas Bakhtin calls it 'finalization' and not available for change. Its especial relevance for dementia is because it is an illness defined by relentless change. It has a given trajectory, albeit variable time frame, and a finalized position means that the complex positions of sameness and alterity that the person with a dementia finds themselves in during the course of their illness are not accepted as valid and legitimate. What is available to them is a single voiced monological understanding as 'demented'. The person potentially becomes 'other' when diagnosed yet remains the 'same' in that they are not obviously physically ill, and remain active in a social world, particularly in the early to middle stages which

are the focus of most dementia fiction. The tension, between the otherness and the sameness is explored in dementia memoir fiction. It fuels Enid's frustrations with Alfred in *The Corrections* (Franzen 2001), John's anxieties about how cognizant his mother is of her position in *Grace and Mary* (Bragg 2013) and the narrator's observations about his mother's performance at the dinner party in *Scar Tissue* (Ignatieff 1993).

2.2.4. Dialogism and dementia

Dialogism is crucial to socio-narratology and relevant and for dementia care. For Bakhtin the relational nature of the dialogic position informs all his thinking. He reinforces this with powerful overstatement:

I cannot manage without another, I cannot become myself without another; I must find myself in another by finding another in myself (for mutual reflection and mutual acceptance).

(Problems of Dostoevsky's Poetics, 287)

Such a statement explains the appeal of Bakhtin when considering dementia care. I was taught, and subsequently used to teach, that 'dementia is a social illness' as a glib sound-bite. What I meant by this was that for the person with a dementia, survival and well-being is dependent on relationships with other people and the progression of the illness demands that these relationships will inevitably change. Memoir fiction, because it addresses the complete illness demonstrates why such changes take place and how painful they can be; John loses access to his mother and the Lambert children are moved to a 'corrected' position by Alfred's illness.

Mike Bender (2003), a significant commentator on dementia and the position of their carers cites Bakhtin and dialogism *en passant* when discussing the importance of relationships in understanding and validating the person's experience

of dementia. He construes dialogism as ‘representing what others have told us about ourselves or how others might see us’ (2003: 245) and akin to the cacophony of voices seen in psychosis (Lysaker and Lysaker 2001). This understanding constrains the impact of dialogism for dementia care because it is limited to the person and not the person in relationships and he does not interrogate the potential implication of the dialogic position for dementia care. Bakhtin’s dialogic position, because it is rooted in relations with others, is helpful in promoting care which enhances personal identity, the individual ‘personhood’ of Kitwood and clarifying the essential nature of dementia care. Cheston (1996) argues this should be essentially therapeutic and concerned with enhancement of identity, acknowledging issues of life history and each person’s unique subjectivity and experience.

Carolyn Shields (2007) has examined how dialogism can work in relation to the US education system and her table summarising the differences between traditional schooling and Bakhtin’s “Novel” Approach to education (Shields 2007: 136) is adapted below for dementia care with Medical Model of Dementia Care substituted for Traditional Schooling.

| Traditional Schooling | Medical Model of Dementia Care | Bakhtin's "Novel" Approach to Dementia Care |
|--------------------------------|---------------------------------------|--|
| Promotes disengagement | Minimizes agency | Emphasises agency |
| Focuses on mastery | Focuses on diagnosis | Encourages enquiry |
| Confined by "habitus" | Confined by tradition/habitus | Embraces outsidersness |
| Remains static and boring | Reductive | Increases vitality |
| Is monologic | Monologic | Demands dialogism |
| Requires certainty & absolutes | Offers certainty of diagnosis | Requires ambiguity |
| Requires completion | | Accepts incompleteness |
| Fragments knowledge | | Contextualizes learning |
| Is primarily receptive | | Is active and reflective |
| Focuses on simple explanations | Diagnosis explains everything | Acknowledges complexity |
| Remains fixed and closed | Emphasises only neuropathology | Is open |
| Is hierarchical | Hierarchical | Is relational |
| Fears diversity | Emphasis on progression of disease | Assumes diversity |

(Based on Shields 2007: 136)

The table illustrates how Bakhtin might offer an alternative view of dementia without necessarily contradicting the medical model but working alongside in the practical application of care for the individual.

Bakhtin's relevance for dementia and dementia care is because he is sensitive to authority in discourse. For Bakhtin, words hold no objective meaning, only in the context of the utterance is any meaning revealed. Here the context implies both the physical and the emotional. The utterance may vary in length, complexity or structure. It is a 'unit of communication' and a complete finished thought where rules of power are put into play. Use of the label such as 'the demented' to describe a specific group is indicative of an utterance. The user clearly understands a context which will benefit them and marginalise those, 'the demented', who are outside the power structure. Tone and terminology throughout the course of the disease becomes highly significant. Foucault (1969) and others have demonstrated that terms, language and practices do not emerge by accident, nor are they used in a transparent descriptive way. Instead, discourses shape what is possible to think and say. Because Bakhtin offers a framework for understanding language in context it throws a lens on many interactions and situations ranging from signage, menus, room labels, promotional leaflets, reminder notes and 'communication books' for professionals and supporters of a person with dementia in addition to direct conversations.

Discourses act upon people in particular ways at particular times. While it is clinically important that the diagnosis should be offered with accuracy, sensitivity, and ideally documented as verbatim in the medical notes, the option of the person not to hear it, and for some never to hear it, must remain. Families and supporters find their own way of talking, or not talking about it. That one family should refer to the disease as "silly old Alzheimer's" a phrase not in a text book or taught, is

indicative of the way they chose to minimise its power within the family. That they also chose not to use the phrase outwith the family, although the person with the dementia always did so, demonstrates Bakhtin's relational approach to language in which the word 'Alzheimer's' is vested with multiple social and cultural meanings. In the essay 'Discourse and the Novel' Bakhtin acknowledges that:

there is interwoven within this generic stratification of language a *professional* stratification of language, in the broad sense of the term "professional": the language of the lawyer, the doctor, the businessman, the politician, the public education teacher and so forth, and these sometimes coincide with, and sometimes depart from, the stratification into genres. It goes without saying that these languages differ from each other not only in their vocabularies; they involve specific forms for manifesting intentions, forms for making conceptualization and evaluation concrete. And even the very language of the writer (the poet or novelist) can be taken as a professional jargon on a par with professional jargons.

(*The Dialogic Imagination*, 289)

This extended extract is important because Bakhtin is talking about the genres, the 'specific approaches, forms of thinking, nuances and accents characteristic of the given genre' (ibid: 289). By his citation of the range of professions, it offers a timely reminder that the person with a dementia may well have been one of these roles, and of course, many others. In such roles there is easy access to such genres and an acceptance that the language of the bank is not the same as that of a family supper and that reading *The Sun* is not the same as *The Guardian*. What Bakhtin calls genres might also be seen as registers, and as a dementia progresses, access to the range of registers becomes increasingly restricted. This is most obviously displayed in *Jackson's Dilemma* (Murdoch: 1995) in which the sentence construction and range of adjectives is pared down in comparison to *The Sea, The Sea* (Murdoch: 1978). Changes in both expressive and receptive language are part of the progression of

dementia; language becomes increasingly monoglossic but has a right to be heard from a dialogic position.

Bakhtin used fiction as intrinsic to his theorising. By using examples from fiction to demonstrate the theory the reader is taken beyond the specifics of their immediate environment and returns to it, but in a new relationship with it. Memoir fiction can act similarly. It is rooted firmly in an unromantic social realism and can act, not only as a proxy patient, but also as a proxy environment. Texts such as ‘These are not my clothes’ (Kay 2012) address the total experience of impaired functioning and demonstrate that small choices, such as where one’s seat is placed, become dominant as the horizon of the person’s life diminishes.

2.2.5. Dialogical Narrative Analysis (DNA)

For Frank it is Dialogical Narrative Analysis (DNA) which provides socio-narratology’s narrative scaffold. He describes it as a practice of criticism (2010: 73) rather than a critical method and claims that it offers a heuristic guide, not a specific and final analytical template. The dialogical of DNA refers to the method of analysis not the degree of dialogism in the texts to be analysed. The key concepts of the dialogical position: unfinalizability, unclosedness and indeterminacy are indicated in the breadth and openness of socio-narratology’s capacities, for instance, inherent morality and the questions DNA asks of the texts. They illuminate for stories Frank’s essential dialogical request which he developed from his work on illness narratives; that the reader asks ‘what does this look like to them from where they are?’ (Frank 2010: 44), meaning that the reader has to consider the ‘other’. The capacities and the DNA method of questioning liberate both the analyst and the text from an analysis as solely one of structure to one of revealing multiple but respectful understandings. For any analysis to be dialogical the analyst must be aware that the practice of DNA

produces an understanding, not a definitive statement about a text which allows it to remain open and accessible. This is reflected in the Triple Analysis.

In using DNA with memoir fiction as part of a Triple Analysis the joys and frustrations of DNA are revealed. It increases open reading of the text and sets the scene for the research outcome Augmented Narrative Analysis because DNA respects that texts are understood from a position, a specific horizon, which, for health professionals using texts as part of training, might be one of limited experience. Rereading a text allows the understanding to change with clinical experience. Like texts, people, and particularly patients, fare better when they are understood from a dialogical position, they remain work in progress, never presumed to be wholly knowable.

The DNA of the memoir texts is undertaken from my position of a clinician/reader. The three texts are rich in themes and open to alternative understandings. One of the pleasures of socio-narratology is the permission for some stories to be ‘heard immediately and intuitively, as *belonging* under one’s skin’ (Frank 2010: 53 Original italics). It is clear that *The Corrections* (Franzen 2001) has that position with me as a text ‘that one ought to listen to, ought to repeat on appropriate occasions, and ought to be guided by’ (ibid: 53). This position does not suggest any diminution of worth of other texts, it is simply that it fits my ‘narrative habitus’ the intuitive, usually tacit sense that some story is *for us*’ (ibid: 53 Original italics). An equivalent position arises with patients. Although infrequently discussed all clinicians have patients for whom they feel an indefinable ‘extra’.

DNA, as the critical practice of socio-narratology shares the presumption that stories do not stand alone but in a dialogical relationship, live and interactive, at

work, both with the reader and in the wider culture. It is carried out by the reader asking questions of the text: What does the story make narratable? Who is holding their own in the story, but also, is the story making it more difficult for other people to hold their own? What is the effect of people being caught up in their own stories while living with people caught up in other stories? What is the force of fear in the story and what animates desire? How these questions are answered in relation to the dementia fiction and the stories told in the clinic form a key element in this work.

The DNA provides interaction between the reader and the text through the practice of asking of the text rather than analysing its narrative elements. Such questioning of the text is dialogic because it accepts that the reader answers the questions from a position which is equal to that of the questioner, and indeed the author, and that the responses to the questions are not fixed for all time. The reader's response to the text may vary with circumstances although the capacities within the text remain the same. Answering the DNA questions formalises thoughts an engaged reader might ask of texts which are meaningful to them such as 'what is really happening here?' The questions make the reader implicit and active in the text which grounds the practice of DNA in a real world of readers. Frank's assertion that DNA's 'refusal to accept immediate, common sense understanding, while at the same time having the most profound respect for and curiosity about common-sense understanding' (Frank 2010: 73) opens up, through its questioning, layers of activity within the text and is evidence of Frank covering all bases of understanding. All the selected texts describe the symptoms of dementia in a 'common-sense' manner but it is DNA which reveals the richness of the memoir fiction. The DNA reveals the role the dementia is performing in the texts. It is more than documenting the progression of the illness. The questions challenge the work of the text by asking what it is the

dementia is doing in the text rather than ‘how does it do it?’ which would be asked in a more orthodox narrative analysis. The DNA questions, as they are written by Frank are a challenging mixture of the pragmatic, abstruse and ephemeral but reworded they lead to Augmented Narrative Analysis (ANA) as a research outcome..

For the researcher using stories and DNA Frank claims there should be: a statement of the ‘analytical interest’ (2010: 114). DNA begins with what Frank later calls the ‘animating interest’. For him it was: ‘*Medical treatment too often increases patients’ suffering rather than reducing this suffering; why is this and how could it change?* It is what I return to when I am confused or lost. It is the true north of my compass’ (Holstein and Gubrium 2012: 37 Original italics). My animating interest as a **reader**/clinician was *Why does dementia appear so frequently in contemporary fiction?* a question to which might be added the subsidiary queries, *What work is it doing in the text?* and *Why is it so often wrong?* The animating interest, Frank argues, is what fuels the dialogue at the heart of DNA and is preceded by a standpoint of ‘someone’s personal troubles’ (ibid: 38). He justifies the one-sidedness of the standpoint as:

the recognition that the reports present stories not as transparently accurate descriptions of what is — not as having some privileged understanding — but rather as storytellers’ representations of what they perceive. People’s stories report their reality as they need to tell it, as well as reporting what they believe their listeners are prepared to hear.

(*Varieties of Narrative Analysis*, 38)

The statement of interest is epitomised in this work by the position of the **clinician**/reader hearing the patient tell their story of memory loss and the fear of what it may mean. By using fiction and the clinical history this thesis fulfils Frank’s criteria for narrative research which is dialogic by utilising the position of the

clinician/reader and **reader** /clinician who is proximate both to the texts and to the experience of dementia. It acknowledges that the reader is part of the story and simultaneously made up of their own stories, a position which Frank labels a ‘hermeneutic interpretation’, a ‘commitment to work with one’s pre-judgments, recognizing the need for these but also their inherent danger’ (Frank 2010: 96). It is relevant when considering the use of dementia fiction in the clinic or health professional teaching. I cannot stand outwith my position as clinician/reader when reading about dementia in a text but this position is relevant only to me. The hermeneutic interpretation or response to the text by a patient, supporter or trainee health professional will be an individual one. Dementia texts might offer comfort or confirmation for the reader but also hold Frank’s ‘inherent dangers’ of stories in their stark portrayal of the end stages of the disease. The patient information leaflets about dementia fiction developed from the research take these dangers into account while capitalising on the more positive aspects of a hermeneutic interpretation by using the story to make new connections:

the question of interpretation thus becomes how to enter into dialogue with a story, translating it and discovering unnoticed aspects, whether these are linkages or discontinuities. Interpretation is less a matter of commenting on a story than of retelling it in a varied form to create new connections.

(Letting Stories Breathe, 105)

Frank also suggests a ‘typology of narrative forms’ (ibid: 117).The suggested typologies of the narrative forms of dementia fiction suggested in this thesis can be viewed as dialogic because the typology is not deemed final. It is not definitive or fixed and will be subject to change as new fiction emerges. For Frank ‘the typology builder is always listening for another type’ (ibid: 121) and a prediction might be that there may be a further additions to the typology of dementia fiction such as

‘dementia as normal’ or ‘dementia as whimsy’ which would leave ‘dementia as tragedy’ for that fiction addressing young onset dementia which more actively reflects the contemporary political and cultural discourse.

To complete a narrative analysis that is dialogical Frank suggests studying stories as ‘documents of an effect’ (ibid: 125). This means that rather than coding research material, the researcher thinks about what is being told, what the researcher is hearing, including the gaps and silences. This is a stance which is akin to the taking of a clinical history but the narrative researcher usually needs a tangible outcome as evidence of the thinking.

In addition to his suggestions for ensuring narrative research remains dialogic Frank asks for Five Commitments (Holstein and Gubrium 2012: 34) from the researcher which demonstrate their dialogical position. The first commitment is the understanding that ‘stories are always told in dialogue’ (ibid: 33) as a response to others ‘whether actually present or imagined—and anticipates future responses, including the retelling of the story, with variations’ (ibid: 33). This is not a form of co-construction such as discourse analysis, rather it is the expression of multiple voices through a single voice: ‘A storyteller tells a story that is his or her own, but no story is ever entirely one’s own. Stories are composed of fragments of previous stories, artfully rearranged but never original’ (ibid: 35). Inherent in Frank’s first commitment is Bakhtin’s concept of polyphony. Polyphony is how one speaker’s voice is always resonant with the voices of specific others. This is exemplified in the clinic when a patient might say, ‘My doctor said...’, ‘My daughter thinks...’, ‘My neighbour told me...’ In the clinic the patient tells a polyphonic story whereas the patient’s story in the notes is heteroglossic. Heteroglossia is close to polyphony and often used interchangeably but has a nuance which emphasises how stories are

assembled. Whereas the patient's story may be told polyphonically once in the notes it becomes heteroglossic because it is assembled from what Frank calls 'the generalized others of a speech community, not specific individuals. In any one person's speech, multiple communities interact' (Holstein and Gubrium 2012: 35). Such a community in the notes contains the voices of the patient, family or supporter and the referrer.

The second commitment of the dialogic narrative researcher is to be suspicious of the antithesis of dialogism, that is, monologism. The monological position suggests a closed typicality such as the term 'the demented'. It presents in the clinical arena as a shorthand of expectations when, for instance, developing services and writing accompanying documentation. In the dementia fiction it is most pronounced in the didactic fiction texts which present a much more finalised and certain portrayal of dementia. The dialogic researcher demonstrates the second commitment by witnessing multiple stories which can be heard alongside each other 'thus giving shape to what could become a dialogue' (ibid: 36) fulfilled here by the position of the clinician/reader drawing on stories told in the clinic and selected texts which resonate to suggest alternative ways of reframing dementia.

Frank's third commitment extends Bakhtin's dialogic position into what Frank calls a symbiotic relationship to stories. By this he means that stories have 'provisionally independent lives' (ibid: 36), that is similar stories are called upon repeatedly to tell of experiences which are claimed as legitimate and authentic by the teller. At a trivial level the symbiosis is evident in the culture as the urban myth and in medicine by stories of 'A colleague had a patient who...' Frank's more robust evidence for this position is drawn from his work with illness narratives (Frank 1995) and is reflected in this work in reframing the stories told as the clinical history

as fiction as a research intervention. Frank's position is that as humans we need stories to release experiences which remain inchoate until told. Patients in the clinic sometimes self-diagnose as they tell their story, using phrases such as 'This isn't normal is it?' The talking therapies are predicated on stories existing within a person as something felt, but unable to be articulated. The work of therapy is to enable the articulation whereupon the story becomes accessible to a range of other voices which may offer alternative interpretations.

The fourth commitment addresses unfinalizability which is carried out through 'interpretive plasticity' (Frank 2010: 193) and presupposes an acceptance of diverse views and possibilities in the world. The selected fiction presents dementia in a range of ways which vary in the degree of dialogic intensity. Texts such *The Wilderness* (Harvey 2009) and *The Garden of Evening Mists* (Eng 2012) explore the experiences of early dementia and the responses of people in their social environment to their illness and leave the protagonists with plans and a future available to them. They are not 'finalised' in the manner in which David, Margaret and Dr Howland are in the didactic fiction which has a much more monologic position regarding dementia. An acknowledgement of the dialogic position towards dementia opens up the possibility of an alternative paradigm of understanding and care to that of the monologic 'medical model'.

Frank's fifth and final commitment of the dialogic researcher is not to summarise research findings (Holstein and Gubrium 2012: 37). For Frank the term 'findings' acts undialogically and implies ending rather than an on-going commitment to listening and responding. The term 'outcomes' is used in this thesis as the more dialogic alternative because it implies an ongoing evolving position

rather than answers found from the research data. The Triple Analysis of the texts suggests that the outcomes of any analysis remain provisional and open.

By using DNA the narrative researcher utilises all the Five Commitments into a more codified form of questioning the text. It acknowledges the position of the researcher and the texts which fits with autoethnography, a research methodology in which the researcher is embedded in the research task but makes overt the assumptions inherent in their role within it. In literary theory, interactivity with the text is most obvious in the reader-response criticism of Wolfgang Iser (1974) and Stanley Fish (1980) by which the reader brings their subjective contribution to establishing the 'meaning' of any text. Socio-narratology goes beyond reader-response criticism to engage with both the reader and the text by placing them in a reciprocal and sometimes vacillating relationship with each other. The text is in a dialogic relationship with the reader as much as the reader is in a relationship with the text. The potential of this is that the text becomes malleable and:

No one's meaning is final and no one meaning is final. What counts is two's [sic] meaning, which is enacted through a process of those two creating meanings as expressions of their relationship. In a dialogic framing, no one can ever take him – or herself out of relationships with others.

(Letting Stories Breathe, 99)

Frank recognises that as research practice DNA does not make strong claims about generalizability. Rather, he argues, it is the 'atypical but information-rich cases' (ibid: 114) which highlight different objectives such as narrative versus clinical truth in dementia fiction. The clinician/reader may seek an emphasis on factual truth or at least responsible reportage but a narrative truth of 'ringing true' may be sufficient for many readers. This does not reflect any superiority of

readership by the clinician/reader but is Frank's capacity of 'resonance' at work. In the clinic it is through eliciting atypicality and information richness from the patient's story which suggests the strong link with the clinical history and fiction.

Frank acknowledges key issues about interpretation, particularly in regard to fiction and argues that there is no system of interpretation but an 'interpretive competence [which] can be worked on systematically' (ibid: 88). All stories, he argues, can tell a truth, but they do so by twisting it. Stories do not need to be mimetic but open up a reality to an interpretive competence. A truthful story is one with the least elaboration, as in *Grace and Mary* (Bragg 2013) but good stories elaborate some truth by artful story telling.

In the same manner in which the capacities were examined in relation to *Turn of Mind* (LaPlante 2011) the usefulness of DNA is tested in relation to the selected fiction.

2.2.6. Dialogical Narrative Analysis in practice with dementia fiction

The questions DNA asks are designed to 'encourage thought to move' (Frank 2010: 74) and 'call attention to the particular work that stories have the capacity to do' (ibid: 74) which is to explore '*what is at stake* for whom' (ibid: 74 Frank's italics) in the narrative by exploring what is possible, permitted or responsible. What is at stake in stories of dementia is the degree of self and agency. The 'whom' includes the storyteller, the protagonists in the texts, the reader and others who may be implicated. With reference to dementia fiction this would include authors of the texts, the characters within the texts, patients, families and supporters of people with a dementia.

a) What does the story make narratable?

In forming this question Frank draws on a memoir about the development of two brothers, one developmentally 'normal' and one with Down's Syndrome. He argues that the memoir makes narratable a life which would be vulnerable to devaluation but through the creation of a memoir, becomes 'claimsworthy', 'vivid and morally recognizable' (Frank 2010: 75). In a similar way the dementia texts make narratable stories of people with a dementia, they make the protagonists claimsworthy by making clear that the people with a dementia have been other than how they are presented now⁴³ and remind the reader that the person with a dementia is not finalised, merely shape-shifted. Making dementia narratable is an important response to the DNA question but it does not address the question of 'why dementia?' which is answered by an alternative response: what is made narratable is not merely the disease process but agency.

Within the humanities and social sciences, agency refers to the capacity of individuals to act independently and make their own free choices. It is the status quo for most adults and highly valued in advanced capitalists societies because it 'entails an ability to coordinate ones actions with others and against others, to form collective projects, to persuade, to coerce and to monitor the simultaneous effects of one's own and others' activities' (Sewell 1992: 21). It suggests a degree of power and intention which offers rationality to the way one lives one's life. The certainty of this position declining in dementia explains the fear the illness engenders because it means a person becoming increasingly dependent on those around them who gradually take over decision making, acting in the person's best interests, as proxy or collective agents. Agency is already in the hands Mrs Mannering's daughter in

⁴³ In the mid-1980s this was recognised as a problem and older people were being nursed as if they were 'different'. Goodwin S., Mangan P. 'Cosmic nursing: do old people come from outer space?' *Nursing Times* 1985.July 10-16, 81 (28) 52-3.

Remember Remember (McHaffie 2010) and with the younger wife in *Forgotten* (Lewis 2010). Transitions in agency provide the narrative fuel in memoir fiction which is benign in *Grace and Mary* (Bragg 2013) but ambivalent in *Scar Tissue* (Ignatieff 1993). In the didactic fiction the diminishing of individual agency of the person with a dementia is a source of tension (Genova 2009: 66, Lewis 2010: 365, McHaffie 2010: 125). In the clinic when the legitimate take-over of agency is in the person's best interests, but likely to be challenged⁴⁴ it is sometimes managed by families being encouraged to blame the health professionals using phrases such as, 'The doctor says...'

For the clinician/reader it is noteworthy that no fiction portrays a malign takeover of agency although this does happen occasionally in the clinical setting. *The Corrections* (Franzen 2001) shows Alfred Lambert's agency moving to the proxy agency of Enid and ultimately towards the muddled and dysfunctional collective agency of the wider family. Although the reader cannot envisage the family negotiating collective agency easily it is through haplessness rather than malice. It is hard to imagine the dark satire and apparent callousness of *Housemother Normal* (Johnson 1971) being published now in a culture where the narrative habitus does not appear ready to accept the fictional portrayal of malign intent towards a person with a dementia. The mercilessness of Johnson's portrayal of old age and dementia comes from his reduction of a life to a series of statistics. Rosetta Stanton is:

'age 94
marital status not known
sight 5%

⁴⁴ Simultaneously, the clinician has to be aware when agency is being curtailed and appropriate adult 'safeguarding' procedures put into place.

hearing 10%?

touch 5%

taste 15%

smell 20%

movement 5%

pathology everything everyone else has; plus incipient bronchial pneumonia; atherosclerotic dementia; probable ament; hemiplegia (with negative Babinski response); to name only a very few.

(*Housemother Normal*, 161)

The textual representation of her dementia is graphic and profound. There are a series of almost blank pages with apparent words such as ‘geirweir’ and ‘atodiad’ spread across them followed by a plaintive coherent cry of:

‘ I am
terrible, Ivy

Now I can every
word you I am a prisoner in my
self. It is terrible. The movement agonises me.

Let me out, or I shall die

No, I do

not get any

lighter, Ivy,

I in—

(Housemother Normal, 176)

The text on the page fragments further and is followed by six blank pages. Johnson's use of the printed word presents a visual portrayal of end stage dementia. Although the statistical description of Rosetta is stark the text faces the reader with an involvement in the disintegration of the mind and self of which there is no equivalent in the selected fiction.

The collective agency of an institution overpowering that of the individual is at its most prominent in the short story, 'These are not my clothes' (Kay 2012). The reader is placed in a position of conflict with the text. They do not know the degree of memory loss and veracity of Margaret's strong assertions, but they are aware of her internal sense of agency. It is however, an agency which cannot be acted upon because of her dementia.

The texts which address individual agency are those written from the point of view of the person at the beginning of their dementia. Two texts, *The Wilderness* (Harvey 2009) and *The Garden of Evening Mists* (Eng 2012), explore the impact of the diagnosis on the sense of agency and, more particularly the knowledge and fear that such a loss will engender. The diagnosis galvanises two professionals, an architect and a judge diagnosed with a dementia, to address an aspect of life which sits uneasily with them.

It is the mismatch between the degree of agency and the measured cognitive decline of the protagonists demonstrated by Dr Howland's clock drawing (Genova 2009: 137), Jake's response to the MMSE questions (Harvey 2009: 242), and Judge Teoh's language use in *The Garden of Evening Mists* (Eng 2012) which raise for the clinician/reader issues of the clinical authenticity of the text. When a clinician hears a patient's history they listen for elements which resonate with all the previous histories, a 'clinical intertextuality', to develop a likely diagnosis. The clinician/reader of 'dementia texts' cannot abandon all the clinical stories they have heard and they are placed in an equivalent relationship to a text as they are with a patient. Here clinical, and what Frank calls 'narrative authenticity' (2010: 192) meet. In socio-narratology the concept of narrative authenticity relates not to the apparent 'truth' but to the concept of an 'own story' since 'anyone's story presupposes both other stories and the recognition of other people'. 'People's stories are their own, but people exist only in dialogical relationships, and stories express a relation' (Frank 2010: 192). Clinical and narrative authenticity is not therefore about truthfulness but about clinical and narrative 'fit'.

Authenticity of a story becomes a contested and negotiated position, a 'dialogue and sometimes a contest, between story teller and listeners' (Frank 2010: 12). When addressing a dementia through fiction, the 'authenticity' or fit of the text becomes important both to the general and clinician/reader. Memoir fiction draws on family experiences as source material but is not written contemporaneously. The experience is reinterpreted through the lens of time and a degree of emotional distance. The reader however, reads the text as accurate, told how it happened and as real. This becomes a problem when anticipating the use of dementia fiction in a clinical setting where texts need be handled with the equivalent of a health warning.

What is made narratable in dementia fiction is not merely the progress of the disease, but the variety of responses to it.

b) Who is *holding their own* in the story, but also, is the story making it difficult for other people to hold their own?

Frank describes 'holding their own' as a 'degree of self-regard; someone with sufficient self-consciousness of what is valuable and worthy of respect about him or herself' (ibid: 77). He acknowledges that one person 'holding their own' is likely to be mirrored or at odds with others who are similarly simultaneously seeking to hold *their* own. Frank views an 'enactment of resistance' (Frank 2010: 77) as crucial to answering the question. Such resistance, whereby the disadvantaged get the better of those with more apparent power, such as the trickster in folk tales, and thus hold their own is rarely displayed in the dementia texts, largely because it would place too great a demand on a degree of agency. An inevitably deteriorating condition makes it impossible for the character to hold their own in the end. It is the inability to 'hold their own' which creates the tension in the selected texts. Even when the decline is inevitable the tension lies in how it will happen, and, who will pay the emotional price.

The Wilderness (Harvey 2009) and *Garden of the Evening Mists* (Eng 2012) manage this situation by limiting the narrative to a portrayal of dementia to a period relatively early in the process when the protagonists remain aware and accepting of what may lie ahead. Judge Teoh anticipates a continuance of herself through her garden, 'Even as I am losing myself, the garden will come back to life' (Eng 2012: 348). In *The Wilderness* (Harvey 2009) Jake's memory is being prompted by photographs and he thinks that 'he would like to build something' (Harvey 2009:

328). Both Judge Teoh and Jake manage to hold their own through the anticipation of creating something tangible.

Holding their own can take many forms. In 'The Pink Ribbon' (Byatt 2003) it is the ability to translate Latin which takes on this function. In 'These are not my clothes' (Kay 2012) Margaret appears to lack agency but evidence that she is holding her own is demonstrated by her first person internal monologue which demonstrates that her self-regard remains robust.

In *The Corrections* (Franzen 2001) the 'holding their own' in both protagonists and family members is one of the key narrative drivers. Alfred Lambert continues to hold his own in the emotional war of attrition at the heart of his marriage until the cruise when mental and physical frailty overcome him and any self-regard disintegrates into hallucinations and uncertainty. Enid struggles to hold her own against Alfred and the children while leaving a trail of distress and frustration. Simultaneously each of the Lambert children struggles to hold their own within the extended family of parents, partners and siblings. The narrator in *Scar Tissue* (Ignatieff 1993) tries to 'hold his own' in an enmeshed and over-involved relationship with his mother but his family and professional life eventually implode.

The comparison between memoir and didactic fiction such as *Forgotten* (Lewis 2010) and *Remember Remember* (McHaffie 2010) is most obvious in this DNA question. In didactic fiction there is no nuanced or significant exploration of how the 'holding of their own' shifts within the narrative.

c) What is the effect of being caught up in their own stories while living with people caught up in other stories?

Frank describes this question as asking ‘what stories different actors are caught up in, what actions those stories authorise and even require, and how some stories silence other stories’ (Frank 2010: 80). For him stories produce an ‘embodied assent that requires the incomprehension of other stories that fail to fit the underlying narrative of one’s own stories’ (ibid: 81). In the selected texts the story of dementia is the dominant narrative even when others, such as an adoption in *Remember Remember* (McHaffie 2010) and illegitimacy in *Grace and Mary* (Bragg 2013) run concurrently. In this manner the fictional texts mirror the stories told in a memory clinic where dementia prevails over other issues or stories which might be told. It is the clinician who seeks commonalities in the stories from the clinic and the clinician/reader who does so for the selected texts.

The Corrections (Franzen 2001), *Grace and Mary* (Bragg 2013), *Remember Remember* (McHaffie 2010) and *The Story of Forgetting* (Merrill Block 2008) tell other stories in addition to that of dementia. *The Corrections* (Franzen 2001) is a ‘realist’ novel about dementia with the ‘rough and ready feel of everyday existence’ (Eagleton 2013: 146) in which three siblings have very different views on their parent’s situation which is at odds with that of the spouse. At the beginning of the novel, Alfred is already struggling with everyday tasks. Enid notices and:

seemed to recall that the last time he had painted the furniture he’d done the love seat in two hours. Now he went to his workshop morning after morning, and after a month she ventured in to see how he was doing and found that all he’d painted of the love seat was the legs.

(*The Corrections*, 5)

Any views Alfred has as an individual recede in impact and importance as his dementia progresses and the illness becomes the story of the family. The narrative mirrors my experience in the clinic where many of the alternative stories a family

may wish to tell are effectively silenced initially by the monologism of the diagnosis and at follow up appointments by the management of the progression of the dementia.

The Story of Forgetting (Merrill Block 2008) answers this question of being caught up in stories most fully. The author was twenty-six when the book was first published. His grandmother developed Alzheimer's Disease and eventually came to live with her daughter, the author's mother and Merrill-Block witnessed the changes of dementia from within the household. This is unlike the experiences of the other authors of 'memoir fiction' who write from the view of a caring, but 'visiting from a distance' adult child. Merrill-Block describes writing the book as 'more like remembering than imagining'

<<http://www.stefanmerrillblock.com/bio/origin.html>>[Accessed 24 September 2014]. The text has three narrative threads: a veracious portrayal of an early dementia through the realist stories of Abel and Seth, the story of the imaginary land of Isidora where memory does not exist and there is no awareness of death, and a story about a fictional geneticist. *The Story of Forgetting* (Merrill Block 2008) offers complex readings of dementia, as one of relentless diminuendo of the person, one contingent on clarification of the genetics of dementia, and using Isidora, as symbolic of the change dementia enforces on the person. The realist telling and the fairy tale mimic the change in agency in dementia. The story of Isidora is placed initially in the text with no explanation which reflects the insidious onset of a dementia. Gradually the Isidora fable becomes more prominent fragmenting the text and echoing the relentless domination of a dementia on everyday life. The text is suffused with allegory: Seth's father only watches repeated historical documentaries on the television as a means of dealing with the present, whereas his wife's memory

is eroded to the extent that she recognises neither her husband nor her son. Through multiple subordinate narratives the dominant narrative of the impact of dementia on the life of the family is revealed.

d) What is the force of fear in the story and what animates desire?

This question might work for generic stories but is a complex and challenging question for dementia fiction. Fear might be obvious but desire is less so and Frank (2010) is unclear as to whether it is either fear **or** desire in the story or fear **and** desire. His exemplars are more robust in considering fear. The obvious experience of desire in the context of dementia is in the desire to complete certain life tasks while it is still possible, as Judge Teoh does in *The Garden of Evening Mists* (Eng 2012). Frank acknowledges that ‘Stories make some things fearsome and other things desirable, yet stories do not invent people’s hopes and fears. Stories shape fears and desires’ (ibid: 81) but fear is of something and desire is for something which suggest that the force of fear and desire in the question is about outcomes. The outcome of a dementia is inevitable and the fear is usually less about this than how one arrives at that inevitability. Dementia fiction can:

express these fears but also contain them, in the sense of holding them within visible form. People may not master their fear through stories, but through them they do come to grips with their fears; or, put another way, they hold their own against their fears.

(Letting Stories Breathe, 81)

Frank acknowledges that fears ‘take different shapes in different ages’ (ibid: 81) and draws on the myth of Beowulf as his exemplar to answer this question about the force of fear. In the current culture a primary fear is one of ageing badly through chronic ill health and dependence (YouGov 22 May 2012). Congestive heart failure and osteoarthritis are debilitating physical conditions primarily linked to ageing but

do not have much, if any, fiction written about them in contrast to dementia which is mentioned frequently. The superficial response therefore is that the selected texts, in addressing dementia in full focus, engage with the fear of the disease. The fear is made up of three components which relate to agency: the particular fear about the course of this disease; its heritability, and the prospect of loss of control. The subgenres of dementia fiction deal with each differently. By focussing on the first stages of an early onset dementia in articulate and insightful professional people *The Wilderness* (Harvey 2009) and *The Garden of Evening Mists* (Eng 2012) avoid the worst ravages of the disease and offer the reader a meditation on the role of memory in (re)-forming the past and constructing a future. Judge Teoh asks ‘Now, I wonder if he left me more than just the garden. Did he also leave the answer to the one question I had been asking?’ (Eng 2012: 342) and for Jake ‘Relationships sketch themselves out in his memory — wife, child, children, husband, parent — and form lines that are either snaking towards him or snaking away. And maybe they are not memories but inklings’ (Harvey 2009: 316). These two texts present dementia as a cipher for memory and as an intellectual exercise rather than an illness which invokes only fear.

In contrast, the didactic fiction offers fear reduction through describing the pragmatics and minutiae of the progression of a dementia as set pieces: the initial concerns about memory; raising these with the person presenting with the memory problem; talking to a health professional; referral; diagnosis and then onward care. At each stage the process is explained in the text in some detail, the reader’s hand is held with the tacit message ‘you are not alone,’ and ‘you too can manage this’ with the aim of diminishing fear. The author creates a knowledge base and manages expectations for the reader by illustrating a possible next stage of the process. The

text acts as the equivalent of a series of appointments in the clinic where the next stage of the illness is anticipated and an attempt is made to allay fears and offer, at the very least, some comfort and support.

Two texts directly address the ‘force of fear’ of loss of control and the desire to retain this through the exploration of assisted dying. In *Still Alice* (Genova 2009) the protagonist has a folder on her computer which she uses to self-monitor the progress of her dementia:

Alice, answer the following questions:

1. *What month is it?*
2. *Where do you live?*
3. *Where is your office?*
4. *When is Anna’s birthday?*
5. *How many children do you have?*

If you have trouble answering any of these, go to the file named “Butterfly” on your computer and follow the instructions immediately.’

(Still Alice, 212 Original italics)

Eventually Alice does have problems answering these questions, opens Butterfly then she ‘lay down on her bed next to the former contents of the drawer and closed her eyes, feeling sad and proud, powerful and relieved as she waited’ (ibid: 273). Having followed the instructions she is denied her planned death by the interruption of her husband who offers her a different ‘glass of water and handful of pills’ which she swallows (ibid: 273). Alice continues to live with her dementia apparently oblivious and unconcerned by the apparent failure of her plan. When asked about what information she felt it was crucial to include in the novel in the conversation with the author at the end of the book Genova writes:

people have very strong opinions about the right to end your own life when faced with a terminal illness, and I didn’t want to alienate any readers. But I found that everyone I knew diagnosed with Alzheimer’s under the age of sixty-five had considered suicide. That’s extraordinary. The average fifty-year-old

doesn't think about killing himself, but every fifty-year-old with Alzheimer's does. This is where this disease forces you to go. So I felt Alice had to go there as well.

(*Still Alice*, 301)

The impetus for the planned suicide is self-identified cognitive changes. In contrast, *Forgotten* (Lewis 2010) makes the driver for an exploration of assisted suicide a much more general loss of control or agency. Having been taken to visit a care home

David realises:

he was like a conductor who's lost control of his orchestra; percussion and brass were suddenly colliding with woodwind and strings; pianos were sounding like drums and clarinets like violins. A grim, relentless symphony of tangled sounds and malfunctioning plaques.

(*Forgotten*, 447)

He plans to visit Exit, a Dignitas equivalent, as the solution to his decreasing sense of agency. Whereas John, the husband in *Still Alice* is unaware of Alice's folder and her plans, David raises the issue with his family who feel unable to support him. He has the insight to acknowledge this and seeks other people who might help but the issue is solved by his cerebral haemorrhage.

Although the texts are robust in tackling these issues it does not tally with my clinical experience. The long timescale and pervasiveness of a dementia often means that the person has reached the position which, when clear minded, they anticipated considering suicide before they recognise themselves as being there. A supportive network may promote a false sense of control for the person and defer any acknowledgement that control is lost whereby the person can no longer carry out any plans they may have previously considered. These two texts, through addressing suicide and assisted dying, heighten the awareness of the universal desire for agency in our own lives. When this is lost there is the poignancy of Margaret's predicament

in 'These are not my clothes' (Kay 2012) as she sinks into what the reader half hopes is increasing paranoia, but fears may be the reality of the life lived in care homes.

The texts which address planned and assisted suicide are those in which the dementia takes place in successful professionals. This suggests that it is the imagined loss of power and control in authorial empathy that is driving it into the narrative because it does not occur in the memoir fiction where authors have direct knowledge of the disease. Only John in *Grace and Mary* (Bragg 2013) raises the spectre which Bragg gives to an academic whose mother has a dementia:

It was research or mass euthanasia and most likely culling, she said. 'We are too many.' She had told him that any solution was some way off, that by 2050 between two and three million people in the UK alone would be suffering from Alzheimer's or allied diseases and that it was a crisis in waiting.

(*Grace and Mary*, 161)

The force of fear which memoir fiction does address is the heritability of the disease. This resonates with my clinical experience. For adult children attending clinic with a parent it is the question most frequently asked. Here the focus on early onset dementia in fiction might legitimately raise the issue as the heritability of an early onset dementia is significantly raised to 50% (Wingo, et al. 2011). Paradoxically it does not. In the Dear Reader introduction to *Forgotten* Lewis writes that she desires the novel to 'give a sense of hope and friendship where sometimes there might seem to be only darkness' (Lewis 2010: ii). Covering assisted suicide in the narrative the addition of heritability of dementia may be too dark for her anticipated readership.

All the memoir fiction addresses heritability. *Scar Tissue* (Ignatieff 1993) ends with the son attending a medical appointment following scans and a medical work-

up which he anticipates will confirm a dementia. He manages this consultation by viewing it as a comical charade, 'Getting the Bad News', but is thrown by his medical consultant saying 'It's not what you expected' (ibid: 192). The son's response is to ask Dr L. to 'read the report and not spare me any details. When he finished, I said 'So it's too early to tell?' And he nodded and then he said, 'You look almost disappointed' (ibid: 192).

The narrator in this text is a philosopher who uses intense introspection and exploration of his mother's dementia to ask questions about the meaning of life, identity, the nature of memory and 'What was the margin beyond inheritance?' (Ignatieff 1993: 193). In considering them he has sacrificed his family and now only has the dementia to root him in a conscious reality in which 'The good Dr L. is mistaken. The scans are mistaken. The cells are too small to see. But I know. I feel them inside me. My fate has come to meet me. My voyage has begun' (ibid: 199).

In contrast John, the son of Mary in *Grace and Mary* (Bragg 2013) considers the issue pragmatically but, as with assisted suicide, through the voice of an acquaintance, a 'fanatically fit middle-aged academic' who despite:

workouts at the gym and cryptic crosswords and five helpings of fruit and vegetables a day and, of course, no smoking, meagre drinking, minimal meat, regular sex, six-monthly total check-ups, no coffee and five walnuts for breakfast, it could still strike. Later, possibly, but if, as could well be, it was genetically embedded, then when it saw the opening, it would seize it.

(*Grace and Mary*, 162)

For John it was now a regular feature of life 'that he would encounter someone who was related or close to a sufferer from a form of dementia' (ibid: 162). In an interview Bragg was asked whether he had considered the heritability of the disease:

Yes, and I hate it. My mother could tolerate it, but I haven't got that kind of stoicism. If I reach a certain stage in a few years' time where I think, oh, sod this. I'll take measures.

(*The Guardian* 11 May 2013)

The measures are that he will ask a close friend to reveal any signs of dementia, then he will inform his family of his intentions, sort out his affairs and arrange an assisted suicide. He will not allow legalities to impede him, though he is confident that there will be new legislation in place by then because he doesn't think 'we can continue sending people to Switzerland or the Netherlands' (ibid.).

In *The Story of Forgetting* (2008) Merrill Block uses a literary conceit of an imaginary, but believable, genetic mutation, EOA-23 and a fictional researcher Marvin Shellard to explore the heritability of early onset dementia. Seth seeks to discover the origin of the story about Isidora which had been told to him by his mother who is now lost to a dementia and no longer recognises him. He does this by posing as Shellard's research assistant. This allows him to meet other people with early onset dementia in various stages of personal and cognitive disarray and to navigate some unspoken family relationships. The genetics lead not only to a dénouement but gives narrative space to the message that there is no correct way, and only an individual way, to manage the disease, something that the didactic fiction does not do. At the end of *The Story of Forgetting* (Merrill Block 2008) Seth, 'now a third-year graduate student in Marvin Shellard's Neurodegenerative Studies Lab, I spend my days taking measurements of what can be measured, gathering oral histories, entering data, correlating the findings' (Merrill Block 2008: 309). Despite this empirical stance he is aware that there is an alternative datum of experience:

filling the vast emptiness that stretches around the tiniest pieces of my family's history, trying to fashion a whole in the way we always do, as my

family has done before me, filling the dark, impossible places with my best guesses and also with outright lies, so that they might be filled with something.

(The Story of Forgetting, 309)

This filling with the best guesses is what the most truthful fiction does.

Despite the fictional portrayal, dementia is a disease of old and very old age. My experience suggests that older people are much more sanguine about, or unaware, of their predicament and younger authors write about a dementia through a culturally (mis)guided anticipation and fear. The exception to this is those patients with Huntington's Disease. This is a genetically determined early onset dementia, where there is a heightened risk of suicide after diagnosis is confirmed and the onset of symptoms (Draper et al. 2010) which Ian McEwan addresses particularly sensitively in *Saturday* (McEwan 2005).

e) How does the story help people, individually, and collectively, to remember who they are? How does a story do the work of memory?

This question presumes an approach to stories as functioning actively within our everyday lives. They 'help people to deal with their fears of what change brings, and they express hope for what change might bring' (Frank 2010: 83). Stories are told from a memory which is fallible, as witness testimony and much psychological research confirms (Roediger and McDermot 2000). We recall acts or aspects of an event which have 'recency, salience and emotional impact' (Frank 2010: 83) but without any confirmed accuracy because memories appear to be assembled and reassembled with regard to what they have to do. This is of significance when considering memoir fiction which although viewed here as having a heightened clinical authenticity and relevance it remains fiction: it is storytelling. Frank calls memoir 'the genre of storytelling that self-consciously recollects memories' (ibid:

84) and in memoir fiction the boundaries between ‘what really *happened*’ are blurred, particularly so when the authors use other narratives such as illegitimacy in *Grace and Mary* (Bragg 2013) to leaven the portrayal of the dementia.

In ‘My Father’s Brain’, the essay that begins his collection *How to be Alone* (2002) Franzen writes with a candid clarity about the diminishing of his father’s physical and psychological state as he succumbs to a dementia. After the onset of his dementia in 1990 Earl Franzen, the author’s father, participated in a research project which had as ‘one of the perks for participants [was] a post mortem brain biopsy, free of charge’ (Franzen 2002: 8). Franzen eventually receives the report which prompts the writing of the essay. In it he talks about the narrativity of family events, how his mother’s letters to him were crucial in his reconstruction and the recognition of the fragility of memory. ‘Each succeeding recollection and retelling reinforces the constellation of images and knowledge that constitute the memory’ (Franzen 2002: 9). It is an essay, not only about his father’s brain and dementia but about storytelling and the fictive and constructed nature of experience. Franzen acknowledges ‘This was his disease. It was also, you could argue, his story. But you have to let me tell it’ (ibid: 11) and by writing *The Corrections* (Franzen 2001) he has taken the storyteller rather than the memoirist option. Rather than viewing his father’s brain as meat:

I seem instead to maintain a blind spot across which I interpolate stories that emphasize the more soul-like aspects of the self. Seeing my afflicted father as a set of organic symptoms would invite me to understand the *healthy* Earl Franzen (and the healthy me) in symptomatic terms as well-to reduce our beloved personalities to finite sets of neurochemical coordinates. Who wants a story of life like that?

(*How to be Alone*, 20)

Earl Franzen had been determined to manufacture his own story of decline by reticence and disavowal of problems, ‘What he *wanted* (in the early years, to stay clear; in the later years, to let go) was integral to what he *was*. And what *I* want (stories of my father’s brain that are not about meat) is integral to what I choose to remember and retell’ (ibid: 31.Original italics). Franzen writes: ‘The will to record indelibly, to set down stories in permanent words, seems to me akin to the conviction that we are larger than our biologies’ (ibid: 33). The story of Earl Franzen is reassembled by Franzen as Alfred Lambert in *The Corrections* (Franzen 2001) because ‘how could I not fashion stories out of that love’ (ibid: 36) for whom, after his death, ‘the only stories we could now tell were the ones we already had’ (ibid: 38).

In socio-narratology Frank claims no bounds between the real and the fictive story and it is possible to understand the memoir fiction texts as doing the work of reassembling lives, as Franzen has done for Earl Lambert. It is the reassembling of the life of a parent that gives memoir fiction an authenticity and veracity, and thus integrity, which generic dementia fiction lacks. Franzen, Bragg and Ignatieff, sit as the stories they tell, on ‘both sides of the fence’ (Frank 2010: 85) between memoir and fiction. Fiction begins with creation whereas memoir begins in the given but they are united by the imaginative impulse. The recognition of the fictiveness of memoir fiction raises issues for stories enmeshed in the clinical history and potential problems for the use of fiction as an adjunct to clinical work.

DNA treats stories as ‘memory-in-action’ (Frank 2010: 83). The profusion of dementia stories in fiction and in the wider culture mentioned in the introduction suggests that dementia stories are in action addressing an issue of significance to authors and readers. It is a disease which affects the individual and their position in

the family and social networks and with political and economic salience. It is fiction which allows dementia's role in these arenas to be explored and presented in a palatable form.

For a text in which Bakhtin's concept of dialogism is intrinsic to the argument *Letting Stories Breathe* (Frank 2010) can be at times surprisingly monologic in its assertions. Concepts are utilised from disparate sources and it is hard to create a strong theory of narrative, which in part may be due to its position straddling the worlds of literature, sociology and philosophy. The utilization of story-telling, in all its forms, liberates DNA as an analytical tool to encompass fictional and clinical stories. It provides a democratic means of working with narratives because it acknowledges that within a text are multiple readings and an acceptance that what is told by the teller of the story is not necessarily that which is received by the reader; a stance will become important when considering the place of dementia fiction in the clinical space.

2.3. Narrative Medicine

In the diagram of this research (p.75) Frank, as key theorist is positioned between Bakhtin and Charon as being influential in this work. Charon's Narrative Medicine provides evidence of storytelling at work, and in particular, at work in teaching medicine whereby 'students discover that stories, when read seriously and skilfully, get into their bones and have a say in what they think and what they do and who, ultimately they are' (Charon 2006: 110). In Narrative Medicine health professionals are taught narrative skills through a version of Close Reading and are expected to transfer these skills to the narratives of illness they hear in their practice so that they are better able to hear and understand the stories they are told. This places Charon firmly alongside Frank, as encouraging readers to think not only about, but with

stories and she presents a ‘narratology appropriate to medical practice’ (Frank 2010: 24). From Freud onwards doctors have written case study narratives about patients instead of formal case histories. Alan Ropper (2014), Henry Marsh (2014) and Atul Guwande (2014) are ‘doctor writers’ (Solomon 2016) who have recently written powerful narratives about medicine but they are not practising Narrative Medicine which Charon describes as:

Not so much a new specialty as a new frame for clinical work, narrative medicine gives doctors, nurses, and social workers the skills, traditions, and texts to provide nuanced, respectful, and singularly fitting clinical care to the sick while also achieving genuine contact with their own and their colleagues’ hopes and ideals as health professionals.

(Narrative Medicine, 13)

She argues that it is only through ‘narrative listening’ (ibid: 67) that good medical care and treatment can be offered because ‘the story of sickness comes out chaotically, achronologically, and interwoven with bits of life and the past’ (ibid: 99). The clinical history template used in practice was an attempt to create order from such a story, to allow it to be compared with other stories the clinician has heard, and will hear, in order to identify confirmatory or atypical elements in the story as part of the diagnostic process.

In developing Narrative Medicine Charon proposes:

that health professionals, as a matter of routine, be equipped with the skills that allow them to competently and naturally absorb, recognize, interpret and comprehend the value of all that patients tell. Through training in reading, in writing and reflecting, in decoding these many gestures of life writing, health professionals can readily become dutiful and powerful readers of their patients’ illness narrative.

(Narrative Medicine, 103)

She identifies five narrative features which are active in clinical practice:

‘temporality, singularity, causality/contingency, intersubjectivity, and ethicality’

(Charon 2006: 39) which act as building blocks for clinical understanding because a ‘symptom or disease is indeed an event befalling a character, sometimes caused by something identifiable, within a specified time and setting that has to be told to another from a particular point of view’ (ibid: 41). To develop a narrative competence with patients and be a more effective clinician she promotes her version of Close Reading of texts whereby ‘The close reader deploys full powers of intellect, concentration, imagination, metaphorical thinking, and moral confrontation, fulfilling desires for identity, self-examination, facing up to the challenge, and attaining new clarity about the world and self and other’ (ibid: 125). Close Reading moves the act of reading to being one of the means by which clinicians might be trained because:

A reading theory of the clinic encompasses the dynamics of the relationship between two people, the teller and the listener, but also conceptualises the narrative itself as a dynamic partner in their intercourse, able of its own to alter what happens between them.

(Narrative Medicine, 108)

Charon begins by encouraging her students to hone their Close Reading skills using fictional texts. Gradually these skills extend into the clinic which ‘becomes the literary scholars’ laboratory, while their theories contribute to clinician’s daily work’ (ibid: 109).

Charon’s Close Reading of fiction uses the following headings:

Frame: this locates the text in the world which Charon equates to the historicizing done by historians when considering texts.

Form: this is made up of genre, visible structure, narrator, metaphor, allusion and diction. The main function of form is to inform the reader what the text is about and

its possible influence on them. Genre is the form of the text such as a short story and the visible structure is how the work is divided. Close readers are asked to examine the role of the narrator with regard to their position in the text, their knowledge and omniscience. Metaphor is the fleeting or sustained image which runs through and helps to define the text and allusion to the references in other texts because ‘All texts speak to other texts—they cannot help it’ (ibid: 119) which is a nod towards the dialogic position of Bakhtin although he is never mentioned in *Narrative Medicine* (Charon 2006). Diction is the register in which the text is written. Medical notes contain a range of registers within them which reflect the purpose of the entry. The correspondence to the referrer has a different register to that of the daily record.

Time: Charon divides this category into sub categories of order, duration, story-time, discourse-time and velocity. She argues that such apparent complicating of time is important because it tunes the clinician’s empathy to a patient’s ‘illness time’ and is ‘better able to imagine the day or the hour of the life of the sick person for who she cares’ (ibid: 122).

Plot: is what happens in the story. Although Charon acknowledges that ‘ “Reading for the plot,” of course, has been derided as the thing learned readers do not do.’ (ibid: 123) but as a reader she takes comfort in the permission of Peter Brooks (1984) that plot is ‘a constant of all written and oral narrative, in that a narrative without at least a minimal plot would be incomprehensible’ (ibid: 5). For Brooks narrative is ‘one of the largest categories in which we think. Plot is its thread of design and active shaping force, the product of our refusal to allow temporality to be meaningless, our stubborn insistence on making meaning in the world and in our lives’(ibid: 323).

Charon argues that if clinicians are equipped to read fiction in which the plot is ambiguous it provides a rich training for diagnosing illness.

I do not mean to suggest that there is a straight line connecting Mrs Ramsay of *To The Lighthouse* with the diagnostic criteria for rheumatoid arthritis or Alzheimer's Disease [but that] a similar combination of cognitive, affective, imaginative and characterological abilities are called into play in finding plot in narrative and making a diagnosis in unwellness.

(*Narrative Medicine*, 124)

The order and shape of a plot reveal the 'contours of meaning' contained within it and open the clinician to both the likely and unlikely diagnoses.

Desire: This concept, also used by Frank in DNA is, even for Charon, 'both the most obscure and the most accessible' (ibid: 124).

It powers the production and the consumption of a text and recognizing the satisfactions of reading — Roland Barthes calls them "pleasures [sic] of the text" enhances not only the reward but also the accuracy and our appreciation of the text.

(*Narrative Medicine*, 124)

Despite attempts by Barthes (1975), Charon and Frank to define it, desire remains a concept of abstraction but is known and felt by the reader. *The Corrections* (Franzen 2001) left me satisfied in a way that *Forgotten* (Lewis 2010) and *Remember Remember* (McHaffie 2010)⁴⁵ did not. Of all the selected fiction it was the memoir fiction of Franzen and Bragg which penetrated my 'self' as a reader/clinician. I was transformed by them, they acted as a physical entity and I responded to their veracity about the illness and the manner in which they dealt with the reality and complications of death with a dementia.

In eliciting the clinical history no questions are asked about desire. One of Frank's definitions of a story is that it is about 'what makes people cry and what

⁴⁵ I mark my leap into adulthood when I read *The War Between the Tates* (Lurie 1974) as an undergraduate. Nothing was quite the same again. It has stood the test of re-reading for this thesis.

picks them up (Frank 2010: 82) and yet this is rarely asked in a clinical interview. A question such as, 'What would make a difference now?' could elicit the hopes and fears, the 'desire' of the patient or family. Enid Lambert in *The Corrections* (Franzen 2001) might well reply to this question that it was a cruise or the prospect of a last family Christmas in St. Jude.

Kalitzkus and Matthiesson (2009) are critical of Charon's all-encompassing model for medicine. They clarify the various narrative genres at play in narrative based medicine and argue that complex illness narratives are 'neither applicable nor necessary in daily medical practice', that narrative competence does not come quickly and can lead to 'destabilization and doubt' about one's own practice. While narrative can make a considerable contribution to humanizing health care 'it is not the only thing that counts in medicine' and 'there are patients who are not interested in telling their story nor sharing their innermost feelings, and not every topic raised in a consultation calls for detailed narrative exploration.' The huge agenda claimed for Narrative Medicine by Charon is one to which good clinicians should aspire without, necessarily, the use of literature.

The Close Reading of Narrative Medicine has informed one of the reading templates used in the Triple Analysis of the memoir texts and presents a useful model for listening to stories which Frank acknowledges in *Letting Stories Breathe* and the development of socio-narratology. It informs the development of Augmented Narrative Analysis (ANA).

Frank, Bakhtin and Charon provide the theoretical background to the understanding of fiction used in this work. Charon applies a prescriptive narratology to clinical storytelling which Frank uses to promote his view that stories are at work

on the culture. The theorists acknowledge the active participation of the reader or listener in the story, neither is privileged but viewed as an equal partner. As a reader of stories and as a clinician who listened to stories the research required a methodology which can cope with and absorb this dual position and this is found in autoethnography.

2.4. Autoethnography

Autoethnography is a qualitative research methodology which values context-conscious stories of and about the self and is ‘a form of self-narrative that places the self within a social context’ (Reed-Danahay 1997: 9) and uses ‘personal experiences as primary data’ (Chang 2008: 49). It clarifies my ‘analytical interest’ (Frank 2010: 114) in the research endeavour and establishes a space in which ‘social identities influence the research process, particularly in terms of what, who, and how we study; what and how we interpret what we observe and experience; and how we represent our observations and experiences of cultural life’ (Adams et al. 2015: 19). It acknowledges, even embraces, subjectivity, the ‘I’ of the researcher, as influential in the research endeavour because it:

- Uses a researcher’s personal experience to describe and critique cultural beliefs, practices and experiences.
- Acknowledges and values a researcher’s relationship with others.
- Uses deep and careful self-reflection — typically referred to as “reflexivity” — to name and interrogate the intersections between self and society, the particular and the general, the personal and the political.
- Shows ‘people in the process of figuring out what to do, how to live and the meaning of their struggles’.
- Balances intellectual and methodological rigor, emotion, and creativity.
- Strives for social justice and to make life better.

(Autoethnography, 2)

Adam's definition of autoethnography (2015) clarifies the link between reader of fiction and the clinician using fiction. This informs the observations about the clinic as a story telling space and the clinical history as fiction which leads to proposals about how texts about dementia might be used in the clinical space.

Autoethnography developed during the latter half of the twentieth century as part of the narrative turn of sociology and a response to changes in the conceptualization of the self to one which is more constructed and having a multiplicity of identities. It defines a research approach that 'seeks to describe and systematically analyse (*graphy*) personal experience (*auto*) in order to understand cultural experience (*ethno*)' (Ellis et. al 2011) in which the 'researcher uses tenets of *autobiography* and *ethnography* to *do* and *write* autoethnography. Thus, as a method, autoethnography is both process and product' (ibid: [1]). Both doing and writing perspectives of autoethnography will be used in this research. The doing of autoethnography will be in evidence through the creation of faux medical notes created from the memoir texts and the exploration of the clinic as a story telling venue. Both of these research activities draw directly on my experience as a clinician. The writing of autoethnography will be in the form of vignettes describing different ways I have used fiction in clinical practice throughout my career. The use of the term 'I', which is pronounced in this chapter, is accepted practice in autoethnography. However the dangers of letting the use of 'I' develop into 'self-indulgent introspection' and 'stories about yourself garnished with details' is warned against by Chang (2007: 149) who stresses that however the autoethnography is written, as constructive interpretation, descriptive-realistic, confessional-emotive or analytic-interpretive, it must make sense of how it connects the personal to the cultural through critical reflection. It is the critical reflection, not the anecdote or

story, which provides the understanding or insight. The vignettes are not only stories of ‘what happened’ but stories of interaction with social structures and institutions. Such writing utilises the permissiveness of autoethnography described by Ellis et al. (2011). Retrospection about past experiences or ‘epiphanies’ to illustrate facets of cultural experience meets Reed-Danahay’s key criteria of autoethnographic practice in that it crosses boundaries (1997: 3) between fiction, clinical practice and being a reader.

The boundary crossing of autoethnography means that the research becomes personalised, and although it demands ‘unusually rigorous, multi-layered levels of researcher reflexivity, given that the researcher/s and the researched are normally the same people’ (Short et al. 2013:1), it allows the researcher to speak from the heart as a socially-conscious act. Vignettes and commentary have been used by Humphreys to describe a career change and offer an honest scrutiny of the personal exposure that they entail. In the paper he describes the ‘false starts, discarded material, rejected themes, and feelings of despair and disappointment as well as insight, creative breakthrough, new understanding, inspirational moments, and all the other emotions associated with ethnographic research’ (2005: 845). In early thinking and drafts I had used the term ‘privileged reader’ to describe my position as a clinician/reader without quite grasping the interpretive intensity of a phrase so redolent of power and ill-fitted to a thesis in which the dialogic understanding of stories is paramount.

Such weaving of theoretical analyses of texts and situations has led to a degree of self-discovery and leaves me regretful that I did not make stronger connections about how knowledge, particularly the knowledge gained about patients in the clinical history, is socially constructed and how my role as the instrument of the data collection was central to its creation. The methodology not only accommodates the

past and epiphanic moments⁴⁶ but also movement in the present by acknowledging that in the process of writing and re-writing a story is likely to change. Through an iterative process writing the vignettes has moved from autobiography and reminiscence to a much more focussed account of how fiction had been used. In doing so it prepared the way for thoughts about how fiction **might** be used. The permission autoethnography gives for research creativity allowed me to ‘play’ with available resources in the creation of the ‘faux notes’ from memoir fiction texts discussed in the following chapter. This opened the way for the development of the DNA and Close Reading templates which mimic the format of the clinical history and subsequently to the innovation of Augmented Narrative Analysis (ANA) as a research outcome.

Because an auto-ethnographic approach is not necessarily linear it can absorb the retrospective element of this research. Lydia Turner acknowledges that ‘Autoethnographic writing has often encompassed the kinds of experience we might not ordinarily talk about publicly. Autoethnography has been a vehicle for sharing, thoughts, feelings and experience, which might only be witnessed by those close to us, or perhaps kept to ourselves’ (Short et al. 2013: 215) and involves a degree of risk. The close fit between the clinical history and fiction could **never** have been either expressed or explored openly in the medical and managerial structure in which I was managing and practising. Although in the clinic there were glimpses of fictionality they had to remain as unseen and unexplored. The immersiveness and power of the research method is evident in *Contemporary British Autoethnography* (Short et al. 2013). The examples validated my experiences of returning to study,

⁴⁶ That the clinical history had strong links to fiction was a key moment in the research process. It makes a strong argument for battle hardened clinicians to have some NHS sabbatical thinking time to stand back from practice.

challenged my professional experiences and facilitated engagement with the situations and the lived lives described. The selections reflected the position of researchers who ‘sometimes begin projects with personal experiences that we want to understand more fully, deeply and meaningfully’ (Adams 2015).

Autoethnographers not only try ‘to make personal experience meaningful and cultural experience engaging, but also, by producing accessible texts, she or he may be able to reach wider and more diverse mass audiences that traditional research usually disregards, a move that can make personal and social change possible for more people’ (Ellis and Bochner 2011:[14]). The production of draft information leaflets as one of the research outcomes extends my personal experiences of reading to create the ‘accessible texts’ suggested by Ellis. Although they are unlikely to make significant changes in the lives of people with a dementia and their supporters they are written with the view that fiction may offer support and confirmation.

The potential vastness of the autoethnography is reminiscent of the scope of Frank’s concept of story and raises similar difficulties when putting it into research practice. Anderson (2006) counters this by suggesting Analytical Autoethnography by which he means specific strictures of autoethnographic practice: explicitness about the group being studied and an immersion in it, combined with a commitment to a theoretical understanding of the social phenomenon being studied.

Ellis et al. robustly counter the critics of autoethnography (2011: [36-40]) and it has developed an increasingly respectable place in qualitative research as a method which ‘utilizes the researcher’s autobiographical data to analyse and interpret their cultural assumptions’ (Chang 2008: 9). These data are expected to be treated with ‘critical, analytical, and interpretive eyes to detect cultural undertones of what is recalled, observed and told’ (ibid: 49) which transforms the work from

autobiography into autoethnography. Even with this caveat, Ellis and Bochner (2000) point out that autoethnographers vary in the emphasis between the ‘auto’, the ‘ethno’, and the ‘graphy’ and that ‘exemplars of autoethnography fall at different places along the continuum of each of these three axes’ (quoted in Chang). The thirty nine ‘varieties’ of autoethnography (Ellis and Bochner 2000: 739-740 quoted in Chang p. 47) including, ‘auto-pathography’, ‘experiential texts’ and ‘impressionistic accounts’, suggests that anything written using personal experience can be construed as autoethnography. Carolyn Ellis has drawn on personal narratives, memoirs, confessions, anecdotes and an account of teaching a course in autoethnography to create a novel *The Ethnographic I. A Methodological Novel about Autoethnography* (2004) in which autoethnography is described as:

research, writing, story, and method that connect the autobiographical and personal to the cultural, social and political. Autoethnographic forms feature concrete action, emotion, embodiment, self-consciousness, and introspection portrayed in dialogue, scenes, characterization and plot. Thus, autoethnography claims the conventions of literary writing.

(*The Ethnographic I*, xix)

In the novel she intentionally combines fictional and ethnographic scenes about a course she has not taught ‘but could have’ (ibid: xx) and draws on Frank’s early work *The Wounded Storyteller* (1995) to make the distinction between ‘thinking *with* a story and thinking *about* a story’ (Ellis 2004: 197). The dichotomy is somewhat artificial in practice. Ellis suggests that thinking about a story involves three ways a narrative can be analysed: narrative, thematic, structural whereas thinking ‘with’ asks questions such as what *is* the story doing and what *might* it do? Frank encourages thinking ‘with’ a story through the practice of DNA.

The research design presents ‘layered accounts’ of autoethnography ‘which juxtapose fragments of experience, memories, introspection, research, theory and

other texts [which] reflect and refract the relationship between personal/cultural experience and interpretation/analysis.’ (Adams 2015: 85). Using such a wide range of modalities increase the lines of sight and interpretation which look behind the scenes of practice to reveal what may lie beneath. This work demonstrates the increasing acceptance of the role of the self in medical writing and reflective practice and in using the self as a reader examines the closeness of the clinical history to fiction; a discovery made through the creation of faux medical notes from one of the memoir texts. This was one of the ‘revelatory synchronicities that enable us to live our lives more vividly’ (Breakwell and Hammond 1994: 8) and a position which is valued in socio-narratology. The vignettes aim to demonstrate how fiction has been used to add another dimension, ‘vividness’, to clinical settings. They are autoethnographic writing but limited in terms of autoethnographic rigour: strong on the ‘auto’ but less so on the ‘ethno’ because of the retrospective and serendipitous use of the methodology. They do not fulfil the key elements of Analytical Autoethnography (Anderson 2006) proposed to reinsert rigour into the methodology. Data were not collected in situ, field notes are not available and participants have not signed up to the research. They are closer to memoir fiction in that occurrences are truthful but draw on hindsight and reflection. They do however fit with socio-narratology. Frank used his experiences as a parent offering story telling performances in his children’s school as evidence in developing his theory, ‘Although the occasions were not research, ten years of coordinating story telling festivals as a volunteer complemented and enhanced my academic work’ (Frank 2010: 162). Similarly, the episodes described in the vignettes were not research but have informed my thoughts about the relevance of socio-narratology to the selected

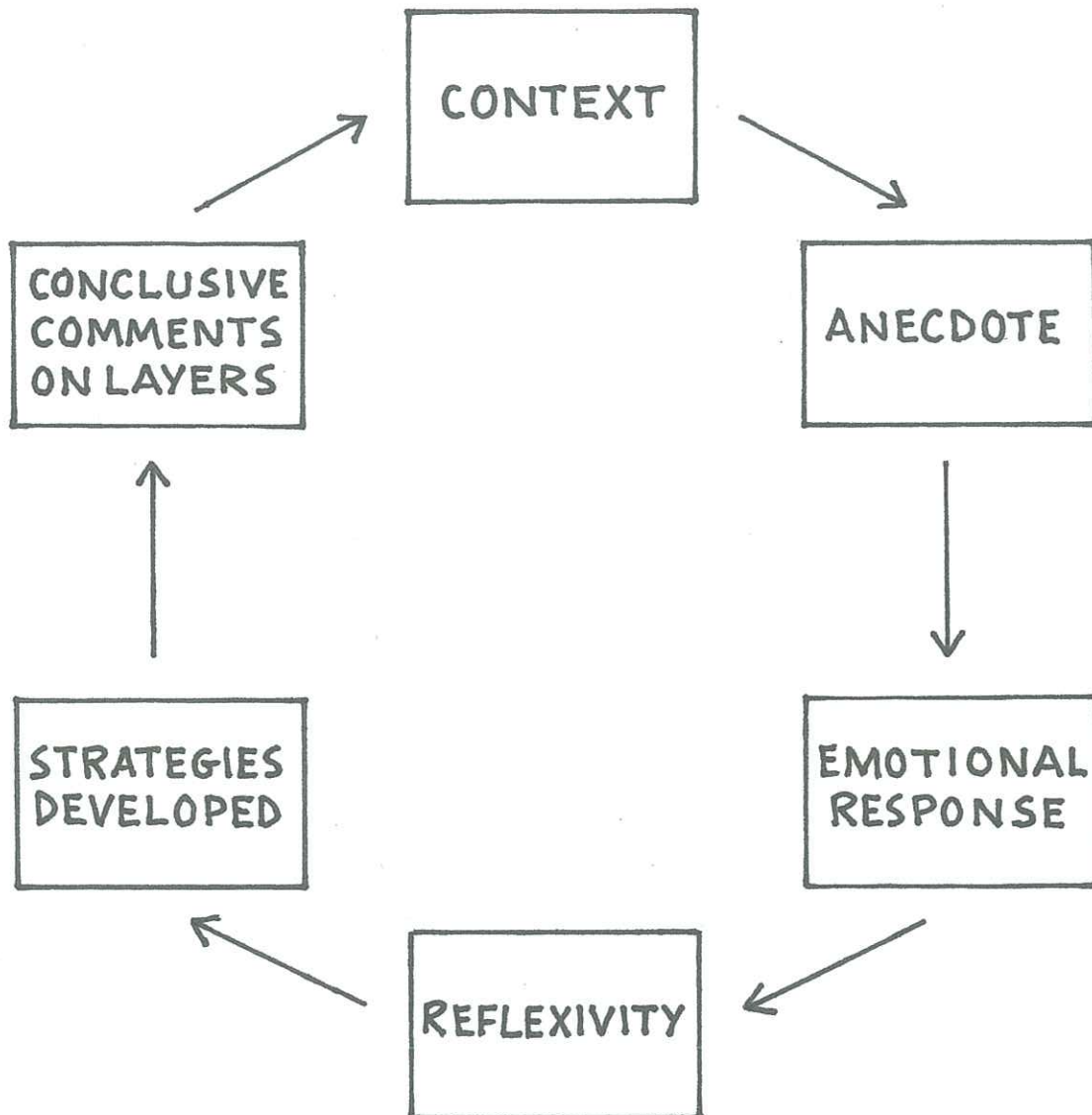
fiction and reveal insights and synchronicities to practice which were not available at the time.

The autoethnographic vignettes describe how I have used fiction during my professional career. The context of all the vignettes is my career in NHS practice as a Chartered Clinical Psychologist with older people. They are drawn from a range of services and reflect different degrees of clinical and managerial responsibility. They describe fiction as therapy, as carnivalesque and as a master class choice. They raise issues about the role and relevance of reading fiction for individuals within institutional systems and anxieties about the potential commodification of an activity which may be important, as it is for me, as a bastion of self-worth and identity. They reflect my longstanding belief that reading not only offers access to limitless worlds, alternative and diverse realities which would never be otherwise encountered and understood but can have an impact on the individual. Arthur Frank (2010) and Mary Talbot (1995) reframe this as fiction at work and active in the social world. The vignettes describe how I had put fiction to work, the research interventions are testing how fiction might work in the clinical space underpinned by theory and available in the future for empirical investigation. This becomes important when anticipating the use of fiction in the clinic as a resource for patients and supporters and in training of health professionals. Accepting the socio-narratological stance that stories are active in our understanding of the world it follows that reading dementia fiction could potentially enhance our understanding of the illness without necessarily having direct experience of it.

Jayne Pitard (2016) suggests that a structured vignette analysis (Diagram 4) in which each part adds a different perspective to reveal the layered account. Layered accounts 'juxtapose fragments of experience, memories, introspection, research,

theory and other texts' (Adams et al.: 85) which move the anecdote from reminiscence to the academic reflexive voice and I have aimed to use Pitard's broad structure in the commentaries.

DIAGRAM 2



Structured vignette analysis (Pitard 2016)

2.5. Autoethnographic vignettes: Fiction in clinical practice

a) Fiction as (unorthodox) therapy

Whilst working within an Older Person's Mental Health team I was asked to see a lady to offer some therapy for her 'depression and anxiety'. I visited her at home and still remember her with an extraordinary vividness. Remembering patients without the help of recognition of a face or one's own writing in the medical notes is never guaranteed but Mrs Y is memorable because what we did felt illicit and fun.

Mrs Y was in her mid-90s and had been widowed for more than twenty years. She was petite, almost bird-like in her frailty but still actively mobile within her house and still managed all her personal care. She could see, hear and her mind was still razor sharp. Her two children lived abroad but kept in regular 'phone contact and visited each year for a short stay. Her 'help' visited each week to clean and shop. She had outlived her old friends and colleagues and in my view, and hers, she was 'low' rather than 'depressed' and 'wary' rather than anxious. She knew that her independence was a fragile as her body and her greatest fear was falling.

Mrs Y was a graduate and had been a professional civil servant. Her house was filled with books. During our ten sessions what we did was talk about and exchange fiction. The most memorable book we discussed was John McGahern's *That They May Face the Rising Sun* (2002). I cannot recall the detail of our discussions, simply that we had both admired the deceptive simplicity of the prose. Our sessions ended because Mrs Y became physically unwell and was admitted to hospital.

Mrs Y was the sort of person I would wish to be if I reached ninety plus. I respected her and we enjoyed each other's company. I retain the copy of *That They May Face the Rising Sun* (McGahern 2002) which I lent to Mrs Y and note that I read it in February 2003. It has survived two house moves and two major book culls. While Mrs Y and I admired the luminous prose, the powerful sense of place and the sensitive characterisation of this isolated community in the west of Ireland these parameters could be matched by much other fiction. What *That They May Face the Rising Sun* makes narratable is the potential importance and completeness of lives with a restricted scope, such as the one Mrs Y was living, as having equal relevance to those people accessing a much broader canvas. It is a 'simple' novel with a clear linear structure as the reader follows the characters' response to the seasons and

rhythms of countryside tasks and activities. With the familiarity of weddings, deaths and inheritances the lives described are ordinary rather than extraordinary but within the novel there are profound truths about what it is to be human and in a community. In *Reading and Reader* (2013) Philip Davis draws on a phrase used by Orhan Pamuk in *The Naïve and Sentimental Novelist* (2010) that even novels with a horizontal and linear narrative ‘have hidden within their architecture a secret inner centre, a hiddenly [sic] connecting keyhole for which readers must seek’ (Davis 2013: 94). This connecting keyhole can be viewed as the answer to Frank’s DNA question: What does the story make narratable? In *That They May Face the Rising Sun* this secret centre is held in the phrase ‘she was beginning to understand that to be without anxiety was to be without love and that it could not be shared’ (McGahern 2002: 94). This description of anxiety resonated with Mrs Y and enabled us to reconstrue the ‘pathology’ for which she had been referred as an intrinsic part of being human, and an aged human, facing death. The power in this therapeutic episode was that in the novel Mrs Y could see that a part of herself, which others had decided was troublesome and needed to be resolved, was inherently ordinary and thus it offered succour as well as a great read.

In *Narrative Medicine* (2006: 196) Rita Charon describes herself as having a ‘screw loose’ for a particular patient, Mrs Nelson, for whom she stepped out of her usual practice and made home visits on ‘one Friday morning of each month. We all derive pleasure from being together, being with the heroine of the story, and doing our joint work in a more effective way’ (ibid: 196). Mrs Nelson was able to stand for ‘something transcendent for myself, something primal for my life as a doctor, and something resolutely spiritual in my life. It is as irrational as it is clinically salient’ (ibid: 196). She ascribes this transcendence to her practice of writing narratives or

‘thick descriptions’ (ibid: 192) about some of her patients rather than completing ‘charts’, ‘I do not write about many patients in my practice, but I find that writing about some of them intensifies the attention I am able to pay *all* of them’ (ibid: 197). It is evident from the vignette that I had a ‘screw loose’ for Mrs Y which was driven, not through writing, but through a shared love of reading. Like Charon’s home visits, what we did together was unorthodox practice.

b) A carnivalesque use of fiction

This vignette describes a serendipitous use of fiction and which I now recognise as being something different. It comes from a period when I was working as a clinician and managing a Memory Service which I had been asked to initiate and develop. I was enormously proud of the service we delivered which was innovative, and, importantly for me, was kind. For the NHS Trust it was the first service in the NHS region to achieve national accreditation.

In 2011 I applied, on behalf of the NHS Memory Service which I worked in and managed to be the receiver of books from the first World Book Night which I intended to distribute to some patients, carers, professional colleagues and local NHS management. It was an initiative driven by Jamie Byng of Canongate Press by which one million books, forty thousand copies of each of the twenty five selected titles (See Appendix 6) would be given away by each of the twenty thousand people selected to be ‘givers’. Each giver distributed forty eight copies. To be a giver one completed a written application describing to whom the books should go and why the book might be important. The list of titles is varied, as a receiver one can only pick one title for allocation. I chose Gabriel Garcia Marquez’ *Love in the Time of Cholera* (1989) because it was a book I had read and loved and put on reading lists for courses on which I taught. It was, I recalled, pragmatic about the compromises of a long and stable marriage and simultaneously romantic about love in senescence.

I only told management what I was doing after my receiver status had been confirmed. While I had applied with the intention of distributing the books as stated I felt that if it met with management disapproval I would distribute them through voluntary agencies such as the Alzheimer’s Society or Age Concern.

Unexpectedly I received a World Book Night copy of *Stuart: A Life Backwards* (Masters 2005) from a GP colleague in the Mental Health Outreach services.

World Book Night is now supported by The Reading Agency with some funding from Arts Council England. The Reading Agency is a charity with the tag line 'Because everything changes when we read' and a mission statement to increase life chances for everyone by helping people to become confident and enthusiastic readers. I would have liked to have given every patient/supporter under the care of the Memory Service a book but the size of the service, one with many hundreds of people known to us, made this impossible so I distributed the books to those who I thought would be pleased to receive a copy. Immediate professional colleagues received the books as part of my obsession with reading and the senior NHS managers received theirs with a degree of bafflement and some amusement. The Trust's Communications Team, always on the look-out for a good news story used it to generate some local press coverage.

In allocating the books to patients and carers I was able to use the clinical histories I had taken as the basis of my choice. Through these I knew the background, interests and likelihood of pleasure in the receiving and for at least two couples the World Book Night was successful. One book had been given to a recently retired academic who was fighting hard against his diagnosis to the despair of his wife. She contacted me to say that the book had come as a surprise and her husband now used it as evidence that "somebody thinks I'm not finished yet." Another had been given to the wife of a patient who I knew was a reader. She had talked about receiving the book at her book group and then talked about her husband's condition more openly. This is limited feedback, but I was glad that it had come from people within the service rather than management, and with hindsight I

wish I had restricted the distribution to patients and carers where it might have been more creatively useful.

The choice of the book fulfils Frank's remit of the dangers of fiction. Having distributed it and **then** re-read it I was slightly aghast at the sexual explicitness. While Florentino Ariza's various sexual liaisons are there to demonstrate the range of potential sexual and loving relationships which remain respectful and mutual, the relationship between Florentino Ariza and América Vicuña can only be read now, as being at the very least, distasteful to current sensibilities. My recollection of the book was that of the pre-divorce romantic and had been that it was about the elegance of courtship in old age and the retention of optimism that good things can still happen and that devotion pays off.

What I had not recalled, and did not mention in my application was the sensitive portrayal of failing memory, made all the more poignant now we know that Garcia Marquez developed Alzheimer's Disease. In the novel Ariza describes his mother's memory as 'being erased long before she died' (Marquez 1989: 188) and describes the tribulations Ariza faces in caring for his mother compassionately and sensitively with such accuracy that is hard to imagine that there is not some familial knowledge:

There was also the final crisis of Tránsito Ariza, whose mind had been left almost without memories, almost a blank, to the point where she would turn to him at times, see him reading in the armchair he always sat in, and asked him in surprise: "And whose son are you?"

(Love in the Time of Cholera, 213)

It is suggestive of John's observations of his mother in *Grace and Mary* (Bragg 2013). Florentino Ariza finds a less than satisfactory carer for his mother who was:

always more asleep than awake, and at times she gave the impression that she, too, forgot who she was. So that [sic] Florentino Ariza would stay home from the time he left the office until he managed to put his mother to sleep.

(Love in the Time of Cholera, 214)

Such a change of lifestyle would have a familiarity for many supporters and carers within the Memory Service who radically change their lives to support the person with a dementia. That Ariza's mother when left alone while the carer was delayed at the market by a downpour distributes the family fortune of gold and jewels to the neighbourhood children as sweets would match the fears of many supporters and carers without the apparent comfort of a Lasting Power of Attorney.

For me World Book Night was a democratic act for a quirky and innovative service. Only with hindsight am I able to recognise World Book Night as a carnivalesque event. Carnival is one of Bakhtin's concepts and implies the temporary overturning of an accepted hierarchy or order. The World Book Night was carnivalesque for the Memory service because it equalised receiving. The same book went to patients and senior NHS managers.

Although the intention was innocent, the involvement of World Book Night 2011 by an NHS service can be readily construed as part of an increasing commodification of reading, the use of books for an alternative goal other than highly individualised activity. (Walking is suffering a similar fate). NHS surgeries now have leaflets suggesting 'bibliotherapy' for the milder forms of distress such as anxiety or low mood. NHS bibliotherapy involves self-help manuals and is instructive rather than comforting. It forms part of Step 1 and Step 2 'low intensity' intervention for Cognitive Behaviour Therapy (CBT). NHS therapists have used

guided reading of Jeanette Winterson's memoir (2011)⁴⁷ with clients who shared similar childhood experiences and William Styron's *Darkness Visible* (1990) has been recommended to some patients to validate their experience of the abject awfulness and physicality of severe depression.⁴⁸ The potential use of fiction to support patients and supporters in a memory clinic is about validation rather than instruction.

c) Fiction in teaching and supervision

The following vignette describes how I had used fiction in training health professionals and in clinical supervision.

The teaching of other health professionals is part of the clinical psychologist's role. As a part-time university lecturer and as a clinical supervisor I have used fiction on course reading lists and in supervision. In the 1970s and 1980s I would encourage medical and nursing students and clinical psychology trainees to read texts such as *All Passion Spent* (Sackville-West 1931), *At the Jerusalem* (Bailey 1967) and *Ending Up* (Amis 1974) which I would try and sell as – 'how to work when you don't really want to'. It was through fiction that I wanted to give students and trainees a fix on the experience of ageing and somewhere to hang the 'gerontological' issues taught on the syllabus. At that time it was viewed as innovative and radical and elicited a mixed response on course feedback. The readers amongst the students loved it and the non-readers ignored the texts. I was not deterred and continued to promote fiction as a source of legitimate clinical knowledge, particularly about mental health issues. As a clinical supervisor I always suggested fiction texts and at the end of placement gave trainees *The Good Apprentice* (Murdoch 1985) because it had the best description of what was labelled 'agitated depression' in psychiatric textbooks.

Dementia began to play a more prominent role in health professional training and syllabuses changed to reflect its increasing prominence as a health and social care concern. Texts such as *Have the Men had Enough* (Forster 1985) were accessible and grounded in identifiable situations. *Scar Tissue* (Ignatieff 1993) in comparison was never such a successful teaching text for health and care practitioners. It was too abstract, too solipsistic and too focussed on the experience of the son, rather than the mother with dementia.

⁴⁷ Janet B. Personal communication

⁴⁸ Annabelle G. Personal communication

Although I felt that I was a radical and innovative voice in the way I was using fiction in clinical teaching and supervision to extend the experiences of trainee health professionals I was promoting fiction as a supervisor/teacher who read rather than placing either the text or the process in any formal pedagogy. By the late 1980s literature was starting to be used in the US for teaching gerontology leading Jon Hendricks (1987) to argue that it was a significant resource for theory building and interpreting the meaning of ageing but per se could not offer a unitary model. Anne-Wyatt Brown (1990) extended the remit of literature and ageing and documented the areas in which it might be used which include attitudes towards ageing, psychoanalytic explorations of works and their authors and the application of theories of ageing towards autobiography. She anticipated a legitimate field of ‘literary gerontology’ in the future and has been vindicated with the development of European Network of Ageing Studies (ENAS) which has a section on Aging and Gender in Contemporary Literary Creativity in English on their website.⁴⁹

d) Fiction as a master class text

This vignette is from a time when I was an established member of ‘Old Age Psychiatry’ and ‘Elderly care’ services and had reputation as being iconoclastic⁵⁰ but enthusiastic about developing exemplary care across the services and was involved in teaching junior medical staff. Do Not Resuscitate (DNR) orders had been identified as being problematic and worrisome so I competed for, and received, a small grant to develop an in-house training video to help them with the decision making and interpersonal issues involved. It would never have won a BAFTA but it was innovative and was a bid for equivalent excellence in health care for the older

⁴⁹ <www.agingstudies.eu/>[accessed 30 September 2015]

⁵⁰ I was given dispensation in ward rounds and team meetings to ‘not hear’ details of surgical procedures as I was a fainter.

person. The vignette predates the publication of Narrative Medicine (Charon 2006). I had not heard of any departments of Clinical Humanities and had not read anything by Arthur Frank, but I had read *The Corrections* (Franzen 2001) as a UK paperback.

Lewy-Body Dementia (LBD) was 'invented' or labelled as a different dementia in the late eighties/early nineties and gained its Diagnostic and Statistical Manual of Mental Disorders (DSM) designation and definition in 2000. I recognised that patients we had never understood and had failed to help in the seventies had the disease. It remained a poorly understood diagnosis and one which had important sequelae for patients because of their sensitivity to neuroleptic medications which are often used to treat hallucinations in psychosis. The hallucinations of LBD have a different character and intensity to those experienced in severe mental illness. In LBD the hallucinations are usually more benign and often have a source within the current environment, for instance, the pattern on curtains, moving shadows, the corner of a cushion. Like Alfred Lambert in *The Corrections* (Franzen 2001) the patient is aware that they are not real but cannot help but respond to them as being so. Whilst writing an information leaflet from the memory clinic for trainee doctors and General Practitioners describing LBD ('It's a bit like Alzheimer's and a bit like Parkinson's Disease but it isn't either' with a helpful diagram) I discussed *The Corrections* (Franzen 2001) with the Consultant Physician/Medical School Dean. He read it and subsequently made it the only set reading for Senior Registrar Physicians, (StR6) level trainees, attending his master class on Parkinson's Disease which he ran prior to their final membership examinations. The trainee consultant physicians were asked to read the text, identify and diagnose the clinical problem and then suggest a treatment regime or 'correction'. This might include medication to ameliorate hallucinations or tremor, or the involvement of other health professionals such as Occupational Therapists to offer suggestions about eating and seating.

Medical training has always depended on first hand observations of patients and the clinical practice of colleagues. In the 1890s Jean-Martin Charcot, Professor of Neuropathology at Sâlpêtrière, Paris demonstrated 'hysteria' for students and the public on Fridays and Consultant 'Grand Rounds', also often weekly, are the current equivalent. Medical master classes extend this model explicitly for senior and experienced clinicians teaching colleagues who are about to complete their specialist training. They work as an exact equivalent to those held in the arts: an expert in the field teaches practitioners who are already highly competent. In music the focus is on a performance or an analysis of a particular piece with the aim of adding finesse to a

piece or performance. So it is with the medical master class where the focus is a specific disease or technique. In this vignette the Lead Consultant placed in front of the senior trainees a fictional text rather than a patient. They were asked to draw relevant information from the text in the same manner in which they might a patient and family member. Unlike the demonstrations by Charcot in medical master classes significant attention is paid to the informed consent and agreement of any patient in training events. However, even with consent and full agreement of the patient, the variability of LBD makes patient involvement problematical for any master class. LBD has unpredictable levels of consciousness which vary from day to day and on some days from minute to minute, which makes involvement with a master class difficult to plan and potentially distressing for the patient. In *The Corrections* (Franzen 2001) the description of mental and physical LBD symptoms, and the range of responses to them by family members, is so vivid and accurate the text can act as a substitute for a patient and their supporters. It makes narratable a neurological condition. Initially this is of unknown aetiology but which is presumed to be Parkinson's Disease (PD). That it is not solely PD is confirmed after Alfred's admission to hospital for a 'drug holiday' after which he is transferred to the Deepmire Home with 'parkinsonism, dementia, depression and neuropathy of the legs and urinary tract' (ibid: 651). What makes *The Corrections* (Franzen 2001) such a useful clinical text is because it is not solely about Alfred's illness but about the impact it has on a long and stable, but essentially distorted marriage. The varied lives of the other family members and the protagonists in *The Corrections* (Franzen 2001) acted as the patient and family in the consultation. Trainee consultants would need to take these into account when devising a treatment regime based on the rich clinical information in the text.

Alfred's tremor dominates the narrative as it would in real life as the most obvious symptom of Parkinson's Disease and Franzen's descriptions of the Alfred's experience of his symptoms are both visceral and rooted in the practical. However such symptoms happen to a person with their own take on their condition which trainee consultants would be expected to acknowledge in the development of a treatment regime. Whereas the NHS position is that patients should be informed and have access to information about their illness *The Corrections* (Franzen 2001) offers health professionals a reminder that although information might be offered, it may not be read or accepted.⁵¹ Alfred's approach to the information leaflet given to him by his physician, Dr Hegpeth was that:

There were chapters in Hedgpeth's booklets that even Alfred, fatalist and man of discipline couldn't bring himself to read. Chapters devoted to the problems of swallowing; to the late torments of the tongue; to the final breakdown of the signal system

(The Corrections, 78)

This can be compared with the information gained and promoted by Enid, "The important thing is to keep doing things," Enid said, "to keep active, to always just go." to which Alfred can only reply "I don't give a damn what your magazine article said. I am not well and Hedgpeth admitted as much" (ibid: 115).

Enid first notices Alfred's tremor as different the moment after they have received the telephone call from Denise to tell them she had got married, 'the tremor was at once looser and more intense than the one he had sometimes got from drinking coffee' (Franzen 2001: 140). For Enid, and the reader, this call marks a change in the family dynamics. A second pivotal moment in the book is a lunch in

⁵¹ This position is understood in the development of the patient information leaflets discussed as a research outcome in Chapter 5.

New York prior to Alfred and Enid's embarkation on an autumn cruise.⁵² Chip has already fled from the family get-together to chase his film script across the city and the Lamberts are left to the attentions of their daughter Denise. The descriptions of Alfred's symptoms during the lunch are hyper-vivid and, because the clinician/reader knows more about Alfred's experience than either Enid or Denise it demands of trainee consultants reading the text for the master class the question: Would you recommend a cruise for Alfred at this stage of his presentation? The clinician/reader and the trainee consultants can only suggest no. While Alfred can try to tell both Enid and Denise, 'I am increasingly bothered by my affliction' (ibid: 115) they both remain self-deceiving about his condition. Enid continues to think that what Alfred has 'is very mild' (ibid: 115) and Denise fails to respond because she recognises how important the cruise is for her mother.

The lunch is one of the most poignant episodes in the novel. Alfred tries to eat Denise's up market dainty nibbles:

And his moment came, the lull he'd been waiting for. Leaning forward and steadying his taking hand with his supporting hand, he grasped the butter-sailed schooner and got it off the plate, bore it aloft without capsizing it and then as it floated and bobbed, he opened his mouth and chased it down and got it. Got it. Got it.

(The Corrections, 78)

Franzen then adds the layer of pragmatism by telling the reader about the process of eating. Alfred 'had bent low over his plate to ensure that any salmon or haricots verts that fell from his fork would land on china' (ibid: 114) whilst in the next room Enid is describing to Denise the 'elegant elegant' (ibid: 113) party she and Alfred recently attended. This juxtaposition allows the reader to imagine the purgatory of the lunch for Alfred. Trainee consultants need to acknowledge the

⁵² That this is termed a 'fall cruise' in the text adds a degree of comedy to subsequent events.

impact the illness has on the lived everyday experience of their patients who like Alfred wait ‘for a lull in his tremor so that he could reach out and safely eat what she’d brought him’ (ibid: 77).

Not only is Alfred having difficulties with the mechanics of eating successfully he is fighting the fluctuating hallucinations of LBD. He ‘couldn’t absolutely rule out the possibility, for example, that his wife Enid was handing him a plate of feces in the parlor of a brothel’ (ibid: 76). This image diminishes slightly and Alfred is able to ‘gaze with gratitude at the snacks which were holding about ninety per cent as food’ (ibid: 76). The pleasure of even the loveliest snacks is removed by the horror of the remaining 10% of the perception.

Alfred struggles through to dessert, ‘sitting on the edge of the chaise in a somehow penal posture’ (ibid: 86), dropping more of the hors d’oeuvres on the floor and down himself. He is suddenly besieged by a different hallucination, ‘There are children, he said, sitting up straighter. “Do you see them?” He raised a trembling index finger.’ “There.” His finger moved laterally, following the motion of the children he saw. “And there. And there.” (ibid: 146).⁵³ Enid identifies the ‘children’ as the reflections of sunflowers in a vase. Knowing the extent of Alfred’s hallucinations the reader knows that this mistake in an ordinary environment is likely to impact on ‘the very elegant fall color cruise on which it would be extremely important that Alfred not make mistakes like this’ (ibid: 146).

During the cruise the mundane activities of getting dressed and using the bathroom develop increasing prominence. None of the other selected fiction texts

⁵³ This could be almost verbatim from clinical conversations I have had. Patients have been concerned that I should not sit on the “Chinaman in a coolie-hat” on the sofa (it was a cushion) or be frightened of the snakes on the wall (patterned curtains).

pay such attention to these parts of life that preserve independence and self-esteem. From the start of the novel there are hints that Alfred is developing problems with maintaining continence. This is likely given the presumed condition of PD and its impact on initiating action and speedy movement. He has been solving this problem at home by urinating in an old coffee can in his workshop but on the cruise so fears incontinence that he takes an old black raincoat with him everywhere so that he can cover any ‘accidents’.

The problem was that his nervous system could no longer be relied on for an accurate assessment of his need to go. At night his solution was to visit the bathroom hourly and always to carry his old black raincoat in case he had an accident to hide.

(The Corrections, 382)

Even though the raincoat offends Enid’s ‘romantic sensibilities’ (ibid: 382) this is Alfred as problem solving inventor and engineer. A more aware wife might have suggested a newer coat.

The impact of Alfred’s physical decline is compared with his previous strong moral strength and is demonstrated through an episode of incontinence. After the fall, when he is back at home and Denise, at Enid’s insistence is ‘helping’ Alfred with his exercises, he loses bladder control and ‘a tropical humidity was rising off him, a tangy almost-smell of letting go. The pajama fabric on his thigh was hot and wet in her hand, and his entire body was trembling’ (ibid: 599). In the following conversation, as Denise tries to find a towel and help, Alfred reveals that he was aware of Denise’s youthful entanglement with his colleague at Pacific Midland, Don Armour. Through this, Alfred’s position as an unconditionally loving parent is revealed to Denise who is able to acknowledge:

She'd never really known her father. Probably nobody had. With his shyness and his formality and his tyrannical rages he protected his interior so ferociously that if you loved him, as she did, you learned that you could do him no greater kindness than to respect his privacy.

(The Corrections, 605)

In doing so the 'odd truth about Alfred was that love, for him, was a matter not of approaching but of keeping away' (ibid: 605) is confirmed. It is Denise who finds Alfred in the midst of an ill-timed self-administered enema. 'She found him in much the same position, with an old beach towel wadded up between his legs. Kneeling among the shit smells and piss smells, she rested a hand on his quaking shoulder, "I'm sorry," she said' (ibid: 612).

None of the other selected texts address bodily functions but they feature heavily in the lives of patients and supporters. A trainee consultant needs to know how these are managed to avoid the solutions taken by Alfred. The text reinforces for the trainees the need to ask patients and families about toilet habits and bowel function rather than waiting to be told.

Franzen is not afraid to address pragmatic aspects of failing function. Correct seating is an issue between Alfred and Enid. Alfred prefers his comfortable broad-armed chair whereas Enid would prefer that he sit in a high backed straight chair as suggested by Dr Hedgpeth. This, like Alfred's refusal to wear his hearing aid after he had compromised in having one fitted, could have come straight from clinic conversations and reflects the hyper-realism of the text. Trainees would be expected to acknowledge this and identify who else in the medical team might be able to offer help or treatment. Alfred's multiple pathologies accrue leaving him angry and belligerent towards his blankets (ibid: 634), the Physiotherapist (ibid: 637) and Dr Schulman (ibid: 641) which are described with the same power and veracity Franzen

brings to the earlier hallucinations. The battle grounds of dementia and chronic illness in the home are much less existential and more prosaic than *Scar Tissue* (Ignatieff 1993), *The Wilderness* (Harvey 2009) and *The Garden of Evening Mists* (Eng 2012) might suggest.

The second part of *The Corrections* (Franzen 2001) performs a different function. The focus is on the three children as they try to navigate the future for their parents. Each child has a novella length chapter which narrates their development and relationships within the family and leaves the reader sympathetic to each of their positions. However, reading the full text, the reader's sympathy remains firmly with Alfred, not only because he is ill and misunderstood, but each character loves him in changing and unorthodox ways. All the family, including Alfred, are deeply flawed, and while Enid and the children make various 'corrections' in that they amend their familial stance Alfred's debilitation ensures that he remains uncorrected and unavailable for correction. The family adjust around the new circumstances because Alfred cannot. Most, but not all families make a similar accommodation. That illness changes the dynamics of partnerships and families need to be acknowledged, even in a medical clinic.

'When had it happened that his parents had become the children who went to bed early and called down for help from the top of the stairs? When had this happened?' (ibid: 634) is a question most adult children supporting frail and failing parents ask. Asking it drives 'the correction' each character undergoes. Enid eventually recognises that Alfred is ill and is not going to get better (ibid: 608); there will be no experimental drug and no extended visit to Philadelphia. Chip, apparently the most hapless and least successful sibling, is eventually recognised by Gary and Denise as being the most cherished child, 'Chip seemed *beloved* to the old man.'

(ibid: 629) and Alfred ‘looked at Chipper and you knew he’d never lie to you. There was a sweetness to Chipper that nobody else could counterfeit’ (ibid: 638). It is Chip to whom Alfred calls in the night, ‘Chip, Alfred called. I don’t understand this blanket. CAN YOU HELP ME?’ (ibid: 634) and to whom he pleads in extremis for his release from what he feels is incarceration of the hospital and his own body:

“I’m saying put an end to it!” He banged on the arms of his captivating chair. “You have to help me put an end to it!”

He looked at the window through which he was ready, at last, to throw himself. Or give him a gun, give him an ax, give him anything, but get him out of here. He had to make Chip understand this.

(The Corrections, 643)

Having just been incontinent and unable to identify how many fingers the attending doctor was holding up this seems to be almost impossibly lucid and a fictional sleight of hand and yet these windows of lucidity do occur in reality and leave families reeling with the level of insight they reveal. The insight is unpredictable and often only momentary, but shocking in its poignancy and depth. Alfred has a further window of lucidity when he leaves the Deepmire Nursing Home for a Thanksgiving Dinner saying “Better not to leave than to have to come back” (ibid: 652).

Alfred remains at Deepmire for two years. He does not succumb to his illness with grace but rails against his lot, trying to hang himself with bed sheets, hurling himself against a window and slashing his wrists with a dinner fork. In reading the text as a proxy patient the trainees need to consider the psychiatric aspects of the disease and treatment and where a patient might most suitably be placed in care. In *The Corrections* (Franzen 2001) the reader has access to Alfred’s humiliation and despair⁵⁴ through his anger and the knowledge that a nursing home was the last place

⁵⁴ I have always wanted a further psychiatric evaluation of Alfred. He is admitted to Deepmire with depression as part of his constellation of symptoms. Depression is under treated in dementia and may

he wanted to be. With the knowingness of the adult child Gary reminds him that he may have no choice — as indeed he turns out to have not.

‘He was a lion to the end’ (Franzen 2001: 653) until the final week of his life when:

He lay curled up on the bed and barely breathed. He moved for nothing and responded to nothing except to shake his head emphatically, once, if Enid tried to put an ice chip in his mouth. The one thing he never forgot was how to refuse. All of her corrections had been for naught. He was a stubborn as the day she’d met him.

(The Corrections, 653)

Questions inevitably arise about why *The Corrections* (Franzen 2001) was selected for the master class and not the other texts categorised as ‘didactic fiction’. The authors of *Remember Remember, Forgotten* (Lewis 2010) and *Still Alice* (Genova 2009) have researched, developed and written the novels with the express purpose of teaching and educating readers about dementia and in doing so to offer support and clarification to people experiencing similar situations. They are all well-meant, sympathetic to dementia sufferers and respectful of them. They are sad, but they are not dark. Franzen, in comparison has a much broader spectrum ‘to connect with that which is unchanging and unchangeable, the tragic dimensions of life’ (*Paris Review* 2007). The strength of the text lies in the multiple intersections. In a Venn diagram of the novel the portion of the story which belongs solely to a single character is small. *The Corrections* (Franzen 2001) is well-suited to a master class. Each of the selected texts knows something of dementia but *The Corrections* (Franzen 2001) exposes something more than dementia and about the flux of old age, debilitation, families, marriage, being a parent and being a child. Franzen describes

have had a part to play in Alfred’s anger at his lot. His depression is understandable but this does not mean it should not be treated and an antidepressant might increase his ability to tolerate his predicament with more equanimity.

the structure of *The Corrections* (Franzen 2001) as ‘a horizontal line, representing the present action, was interrupted by chunks of backstory which would rise at various slopes like something surfacing. Like a missile rising up out of the past to intersect with a plane flying horizontally in the present’ (*Paris Review* 207).

The vignettes describe the informal use of fiction in clinical practice. With hindsight I recognise that in an NHS primed for, and promoting evidence-based practice, I should have explored how fictional texts could be used in health professional training but I didn’t. I could have made exploring the evidence for using fiction a Continuing Professional Development (CPD) or annual appraisal priority but there was something satisfying to me about my relaxed but enthusiastic use which was deemed singular and idiosyncratic. It was a position I secretly enjoyed. The experiences described provide the background for the research interventions which look at fiction in clinical practice underpinned by a theory of narrative. This position would have been unthinkable from my position as a full-time clinician. It has needed the space of formal study and the distance from practice to think heretically about fiction in the clinical space explored in the following chapter. It maintains autoethnographic practice as a ‘layered account’ but the writing shifts from memory and introspection in the vignettes to a more formal theorizing of the clinic as a story telling venue and a playful use of texts before the Triple Analysis of the memoir texts.

Chapter 3

Research interventions: interrogating the texts or: *Treatment interventions*

This chapter describes the research interventions which comprise this thesis. They are driven by the socio-narratological understanding of stories and autoethnographic methodology to provide sequential but separate analyses of storytelling in the clinic and the memoir fiction texts.

The first research intervention uses my experience as a clinician to explore how stories are created in the clinic by analysing the consultation through Frank's socio-narratological understanding of narrative as one of relationships. Each of Frank's story telling dyads is examined as it relates to the clinical consultation after examining the clinic as a storytelling venue.

The second intervention builds on the fiction-creating aspects of the clinic and uses literary reverse engineering to interrogate the clinical veracity of the memoir fiction texts by using the information in the texts to create a set of faux medical notes for the three characters Mary, Alfred Lambert and Mother who are at the core of the memoir fiction texts. This is an innovative and experimental means of testing the clinical accuracy of the texts. A clinical history is completed for each character with a dementia. This identifies the clinical gaps in the information contained in the memoir texts.

The third intervention developed out of the clinical information gaps identified in the faux notes. Each of the novels contained rich information about dementia which was not captured in the clinical history. This led to the development of focussed reading templates for what I have called a Triple Analysis of the memoir fiction texts. The reading templates use Frank's Dialogical Narrative Analysis

(DNA), Charon's version of Close Reading and the clinical history to examine the texts and reveal the strengths and limitations of each.

Having described how fiction in the clinical space had been used in the previous chapter, this chapter develops methods of analysis of texts and spaces to advance the argument for an imaginative use of fiction in the clinic and in health professional training. Frank asserts that fiction is at work in the community and this chapter develops how this might become explicit in a health community of professionals and patients. Frank also states that 'what people know as experience hitches a ride on stories those people know; the stories shape what becomes the experience' (Frank 2010: 22). This statement has at least two sequelae: that patients and supporters attending a clinic will do so with their own set of stories about dementia gained from its cultural visibility and penetration, and that if stories shape experience, then the stories told about dementia should have a degree of clinical authenticity if they seek to be active, educative, and supportive, as the authors of the didactic fiction express.

3.1. Socio-narratology and the clinic: *Treatment intervention 1*

The first research intervention is by necessity an exploration of the clinic because it is the source of clinical stories. A visit to the clinic features in both the didactic fiction texts and the memoir fiction texts. In comparison the key protagonists in the literary fiction are already diagnosed and the work of those narratives is about how the protagonists manage their diagnosis and their future.

3.1a. The clinic as a story telling venue

Frank's three elements of a story: story, listener and teller, ignores a fourth element, the story telling venue. In socio-narratological terms Frank's venue for stories is society and culture but at a more immediate level the place where a story is told

determines what story is to be told, how it will be told and to whom. Frank asserts that 'stories act' (Frank 2010: 17), they are at work wherever they are heard, read or used and the story does its work in a context rich with meaning. When the context has not been set the story fails, it has not been able to act to its full potential and the listener or reader is left bemused and disappointed. The physical venue of the clinic sets the context for the story to be told, the permission to tell it and the expectation that the story teller will want to do so.

Frank labels this narrative habitus, as the 'disposition to hear some stories as those that one ought to listen to' (2010: 53). He pays attention to the societal environment of storytelling but pays less attention to the micro environment, how the immediate situation of the venue might impact on the story told. In the waiting area of the clinic a patient was overheard remarking to her daughter, "It isn't much like *Holby City* is it?" in a tone of disappointment which suggested that she had anticipated the encounter in a particular way informed by the television drama. As Polletta points out 'Storytelling is shaped by its institutional context' (2012: 229 in Holstein and Gubrium) which affects where you begin the story, what of the story is allowed, the response to it and how it will be evaluated. Fiction has the capacity to act in a similar manner to the portrayal of hospitals in television drama. In the clinic the patient as story teller tells their story in a very particular environment which sanctions asking intrusive questions. The story teller is not allowed free form.

The relevance of the micro-environment to the story told is most evident when patients are seen at home and any medical power is curtailed via the common courtesies of visiting rather than consulting. There the story telling and listening, which uses the same clinical template, generates a different dynamic worthy of its own investigation.

The clinic was an interview room and waiting area between two wards, one in active use and one used for storing hospital beds. The second consulting room was an ex day room, often used for other purposes. Any clinician using this room had to actively try to create a clinical intimacy for the story to be told by arranging the chairs and table and explaining that, despite appearances, the consultation was confidential, the windows were mirrored, and although we could see out no one passing could see in. The clinic had been developed as part of a government dementia strategy to promote early and increasing rates of diagnosis in each NHS region and primary care practice. It was designated a 'flagship clinic' meaning that it was not used for training and no junior medical staff or health professionals were involved other than as observers with permission from patients.

Although the physical environment of this clinic resembled a converted police station, the tone of the clinic was set by the practices of the staff and the clinicians. The dress code of the clinicians was more formal than when home-visiting. No white coats or uniforms were worn but everybody dressed to signify expertise and professionalism. This was not solely Foucauldian medical power but demonstrated a respect for the impact of the potential diagnosis. The dress code was an acknowledgement that patients and families had often waited close to the government target for an appointment and the consultation was an event which was both anticipated and feared by people attending the clinic. It demanded a degree of gravitas, of which dress was a part, in the creation of a space where the patient's story could be told and listened to with respect and courtesy. Whether the clinician comes out of the clinic room to greet the next patient and thus allows the people waiting to glimpse the person they are due to see; whether they apologise for any queue or waiting time; whether laughter is heard from the clinic room and how

people exit the consultation, all inform how the patient's story is told in the consultation.

The storyteller waited in an environment laden with information. Noticeboards displayed photographs and names of clinic staff. Posters about infection control, hand washing and confidentiality were displayed alongside ones advertising specific voluntary sector support, such as Alzheimer's Society contact information and activities such as Singing for the Brain. There was self-help information and posters promoting attendance at groups such as 'Making the Most of Your Memory'. The noticeboards signified that the patient and supporter was not attending solely for treatment but should be actively engaged with their illness and commit to self-help. They reflected the developing rhetoric of Department of Health regarding

responsibility for one's own health. The displays on the noticeboards would have fuelled Enid Lambert's vindication that Alfred was being remiss in not trying to overcome his symptoms.

In the clinic the patient and supporter have intimate knowledge of how they have reached the position of attending. The clinician has a professional knowledge about the likely diagnosis and its sequelae. These are inhabited positions demanded of them by the clinical situation which come together to create a text in which the narrative authority passes to the clinician and the omniscient narration, which the patient often expects to hold, also passes to the clinician. Satisfying fiction texts have a narrative tension which usually arises from conflict. The narrative tension in the clinic is generated by two interdependent sets of knowledge held by those present: the patient's knowledge of the development of their illness and the clinician's

knowledge about the implications of their symptoms. The story collected is not neutral, as Gabriel Weston (2013) a practising surgeon and novelist points out:

the competent clinical inquisitor is all the while asserting their own semantic frame, encouraging the patient to dwell on key symptoms, ignoring the noise of emotion, veering away from anything that has no pathological meaning, doing what is necessary to help a diagnosis to emerge. The doctor is rewriting the patient's story while seeming only to bear witness to it.

(Dirty Work, 5)

The clinician may need to rewrite the story but the patient/supporter needs to feel that they have authored it. What is in the notes is an edited version of the story as the third research intervention demonstrates. The questions asked of the patient determine the story one is told. Sometimes the responses to questions are written verbatim. Mr Lambert's clinical history contains direct quotes, most notably 'I am increasingly bothered by my affliction' (Franzen 2001: 115) whereas in *Scar Tissue* (Ignatieff 1993) none of Mother's viewpoint is available for documenting. It is the narrator son whose point of view predominates and fills the history.

Once written in the notes the clinical history becomes a working text no longer available to the patient except under very specific circumstances. It is amended and edited by an increasing range of professionals but the clinical history, which is held on a specific template becomes reified and monologic, unavailable for change.

3.1b. Memory clinics in the selected fiction

Two of the didactic fiction texts, *Still Alice* (Genova 2009) and *Forgotten* (Lewis 2010) describe in detail a psychometric assessment of memory functioning in a clinic. In *Remember Remember* (McHaffie 2010) the third didactic fiction text, Mrs Mannering is visited at home for an assessment by her community nurse and this episode will not be the focus here.

Still Alice (Genova 2009) and *Forgotten* (Lewis 2010) are novels which have been written by authors who have observed memory clinics. Susan Lewis thanks two psychiatrists for guiding her through the diagnostic procedures of early dementia and in her novel David attends the BRACE centre in Bristol. In her 'A Conversation with Lisa Genova' in *Still Alice* (299) she acknowledges the help of the Memory Disorders Unit at Massachusetts General Hospital where she was enrolled in a neurosciences PhD programme and was able to observe neuropsychological assessments of patients.

The neuropsychological assessment of Dr Howland in *Still Alice* (Genova 2009) is clinically accurate. Dr Howland is encouraged to bring someone to the next appointment because 'you may not be the most reliable source of what is going on' (Genova 2009: 55). This is blunt but understandable although Dr Howland 'felt embarrassed, like a child' (ibid: 55). The consultation is thorough and includes a neuropsychological assessment. Despite having completed many of the assessments before as a control for her research students, Dr Howland is unable to recall the address she has been asked to remember and the assessment moves to test her recognition. In dementia recognition memory is much more robust than recall and is the aspect of memory which allows many people to remain safely at home surrounded by that which is familiar. It is when this familiarity is disrupted that the intensity of problems with memory and self-care are often revealed. This is the position of Alfred Lambert in *The Corrections* (Franzen 2001) whose 'fall' from the ship changes the nature of the family's subsequent response to him. Such 'precipitating events' are often what prompts a person or family to seek a referral and is reflected in the 'Why now?' opening question of the template used in the clinic.

Having taken many of the ‘tests’ before Dr Howland knew what to expect at the clinic. She knew she would:

get prodded and assayed, scanned and tested, [but] she guessed that he didn’t need to investigate further. She’s told him her story, and she couldn’t remember John Black’s address. He already knew what was wrong with her.

(Still Alice, 59)

She also knows, as many people presenting with early onset memory problems do, that something is seriously awry because her experience is so out of kilter with her peers and the neuropsychological assessment confirms this for her. In contrast, a diagnosis of a dementia may be more of a shock to the older person and family who have attributed changes of functioning to age or minor illness.

In *Forgotten* (Lewis 2010), the neuropsychological assessment of David is described over six pages (p.356-362) which detail the questions asked and David’s responses until:

in the end, after providing basic descriptions of such words as ‘rhinoceros’, ‘escalator’, ‘stilts’, ‘compass’ and ‘abacus’, not all of which he managed accurately, then failing to name animals beginning with S, Fiona brought the ordeal to a close.

(Forgotten, 360)

Winding up the consultation the clinical psychologist warns David and Lisa that the results of the assessment might not be available for up to three months, ‘I’m afraid we’re short of doctors, but I’d hope, in your case, that it won’t be as long as that’ (Lewis 2010: 362). Given Lewis’ observation at the BRACE unit the author appears to be preparing readers for a potentially long wait for a follow-up appointment in the NHS.

Despite the stated intentions of the two authors to inform and support the reader such detailed descriptions in fiction of the various ‘tests’ are not always helpful. Assessment procedures and neuropsychological protocols vary widely between clinics and between patients. As a clinician/reader I compared my standard neuropsychological battery of tests for people with a possible early onset dementia with the clinical psychologists in the fiction. In the same way, readers of *Still Alice* (Genova 2009) and *Forgotten* (Lewis 2010) might assess the practices of the clinic they visit. This would fulfil Frank’s belief that fiction is at work in community and that ‘stories shape what becomes the experience’ (Frank 2010: 22) at both the individual and the cultural level.

3.1c. Storytelling dyads in the clinic

Arthur Frank argues, in *Letting Stories Breathe* (2010) that the narrative analysis in socio-narratology is dialogic because ‘it is always about the relationship between *at least two* and most often three elements: a story, a story teller and a listener. None of these could be what it is without the others’ (2010:16). The elements in relation to each other set up a series of storytelling dyads: storyteller and listener, story and storyteller, the listener and the story, which will be explored in turn.

Frank’s dyads are more obvious when considering straightforward storytelling. In the clinic the story telling elements work simultaneously and the demarcation between the elements is not always clear cut. In the clinic the patient, as storyteller, tells their story verbally as they describe the problem they are consulting about. The clinician acts as the listener to the story but this role is complicated by their need to be the editor of the story as they write the clinical history in the notes. Mrs Andgrace’s notes in Appendix 7 demonstrate how descriptions in the text are

recorded in the faux notes as clipped, terse statements such as ‘Local girl. Lived here all life’. In the consultation described in *Scar Tissue* (Ignatieff 1993), which is ostensibly about Mother’s story, she says only ‘We are fine today’ (Ignatieff 1993: 55) in response to the welcome by the neurologist before making her ‘laboured transit to the door’ (ibid: 56). The neurologist continues to act as the listener to the story and as a clinician wants to create a story of ‘memory function, with a stable name and clear prognosis’ whereas the narrator has a different story to tell, one of an ‘illness of selfhood, without a name or even clear cause’ (ibid: 60). In a memory clinic it is common practice for patients to be accompanied by a supporter or supporters who are asked to contribute to the clinical history.⁵⁵ Clinicians try and manage the range of potentially competing stories by asking one family member to be the main point of contact and spokesperson to avoid having to deal with multiple family members who, like the brothers in *Scar Tissue* (Ignatieff 1993) and the siblings in *the Corrections* (Franzen 2001) have different views about their parent’s illness and how it should be managed. Dr Hedgpeth has been fortunate in only having to deal with the Lamberts as a couple and not the extended family. After Alfred’s fall they become actively involved with and express their views about his care (Franzen 2001: 629-630).

3.1d. Dyad 1: Storyteller (and listener)

In the memory clinic from which this research story is told the story teller usually came with at least one supporter. The patient had consented to attend and was there because either they, or someone else, was concerned about memory functioning and whether this was normal for their age and circumstances. The patients and supporters were greeted by unregistered nursing colleagues who managed the ‘front of house’

⁵⁵ The largest number of supporters I ever tried to manage was seven: husband, sister and five children whose primary concern was diagnosis and possible heritability.

NHS bureaucracy and viewed their role as enabling people to have the best experience possible in the circumstances.⁵⁶ The waiting area, an open plan entrance and corridor, often acted as a rehearsal space for the patient's stories prior to the formality of the clinical consultations. Patients and supporters would ask staff what was likely to happen and what they might be asked. This meant that aspects and details of the story were encouraged by comments such as 'You must be sure to tell the doctor that'. This rehearsal primed the story teller's narrative and enriched the clinical story because it allowed clinicians to be alerted to pressing concerns and specific requests, such as supporters needing some individual time with the clinician without the patient present. Attendees and supporters were surprisingly candid in discussing their difficulties in this public space, often with each other. It became a 'focussed gathering' (Goffman 1961: 9) of people who shared a commonality by attendance and related to each other solely on that basis.

The clinic is a space of watching as well as telling and the patient, the clinician and supporter observe and interpret each other as part of the storytelling (Frank 2010: 86). For the clinician this is part of the history-taking routine but in the consultation the observation of the storyteller by the supporter becomes pronounced, as if the novelty of the venue enables them to observe the patient with a more dispassionate eye. The consultation is often a novel experience and supporters are usually equally engaged in the encounter, silently answering the questions posed to the story teller in readiness to step in and help if requested to do so by the patient or clinician. It would not be unusual for the consultation to reveal for the first time the

⁵⁶ We were extraordinarily proud of being the only clinic in the hospital providing tea and biscuits in the waiting area which we did without any formal management approval or budget. We 'borrowed' milk with permission from a neighbouring ward and between us quietly provided the rest. We served it on non NHS crockery. We hoped that it signified to the people attending the extra level of care that we aspired to deliver - i.e. not just acceptable.

full extent of the cognitive problems, for instance, forgetting how many children a person had and their names. This is portrayed in *Forgotten* (Lewis 2010) where David's appointment at the BRACE unit confirms all Lisa's anxieties as she watches her new husband struggle with the psychometric tasks. Asked to place the hands of a clock at 1.45:

Lisa could hardly believe her eyes. After seeming uncertain he ended up drawing the small hand pointing to the one, and the other between the four and the five.

She was so thrown that it took her a few minutes to catch up as Fiona launched into a whole series of questions about the time and clocks, some of which he got right and some he didn't.

(Forgotten, 360)

In the clinic the listener's prime task is to elicit the story of the presenting problem as the clinical history. Patients would often be equally determined to tell their significant stories of their life in response to my questions about family and employment.⁵⁷ Occasionally, as a listener, I would be willing to be engaged with them because I could use the narrative to assess the patient's use of language, social awareness and whether they could be distracted from the story once begun. The telling of a familiar, well-rehearsed story compared with how the patient dealt with the questions of the clinical history demonstrates both the depth of their difficulties and their ability to present to the world when on familiar territory. Identifying this has implications for how supporters might help the person with a dementia.⁵⁸

After fifty-five minutes in a privileged space, free from external interruption, where the patient and supporter are the sole focus of attention, the consultation

⁵⁷ Everything I know about the life of a Tiller Girl or Spitfire pilot I have learnt from a clinical history.

⁵⁸ After observing the assessment of her husband a wife elected to entertain at home where she could control the seating plan and ensure that her husband was always seated next to someone who would be receptive to his stories. He had many to tell and was an accomplished raconteur.

should provide a comprehensible narrative culminating in a working hypothesis or clear diagnosis to drive future care. The ‘agglomeration of complaints and symptoms which may be unclear, unconnected and mysterious’ (Balint 1957. Cited in Conrad 2007: 46) which the patient and supporter bring to the consultation is transformed into something which is understandable or, if further investigations are required, capable of becoming understandable. The disorganised story of anticipation, fear and expectation is given form and coherence by the clinician. How dialogic the consultation is depends on the individual clinician and token gestures towards the patient such as, ‘I’m sure you’ve had enough now,’ she said, ‘so tell me, how did you find this assessment?’ (Lewis 2010: 361) does not reflect a truly dialogic position but a continuation of a specific discourse, produced and interpreted through complex and unequal power relations.

The role of the listener as Editor-in-Chief in a consultation is most apparent when a patient says, ‘I’ve never told anyone this before’. This may be evidence of a successful consultation but it raises ethical dilemmas and a degree of panic for the clinician about what may be revealed. It is best managed by clarifying the myth of patient confidentiality. Medical notes are not the equivalent of the confessional and the patient’s request not to write something down cannot be met. The situation needs to be handled with tact and sensitivity but, however managed, it leads to decisions about what is said, may be written down, and what may be left unsaid. While the patient may decide not to disclose the information, the clinician must give some indication in the notes that this non-disclosure has taken place. Such situations make Michel Foucault’s ‘le regard’, the medical gaze ‘of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention’ (1973: 89) explicit.

Whereas Foucault views the relations in the clinic as unequal Frank does not and together the storyteller and listener create a story which, as the clinical history, written in the notes, becomes a text. Once in the notes the authority of authorship passes to the clinician. The dyad has enabled the telling of the perceived problem experienced by the patient and the text can be put to work in their best interests.

3.1e. Dyad 2: Story (and storyteller)

The storytelling in the clinic begins for the listener before any questions have been asked and utterances made. It begins with observations of the demeanour, posture, physical well-being and dress of the patient as they move from the waiting room to the consulting room.

Authors use similar observations to create their characters. James Wood describes the novelist Ford Madox Ford getting his characters ‘up and running — what he calls ‘getting a character *in*’ (Wood 2008: 77). How this happens aptly describes the observations at the start of the consultation:

A stranger enters a room. How do we immediately begin to take his measure? We look at his face, his clothing for sure. This man, let us say, is middle aged, still handsome but going bald— he has a smooth space on the top of his head, fringed with flattened hair which looks like a pale crop circle. Something about his carriage suggests a man who expects to be noticed; on the other hand, he smooths his hand over his head so often that in the first few minutes that one suspects him of being a little uneasy about having lost his hair.

This man, let us say, is curious because the top half of him is expensively turned out— a fine pressed shirt, a good jacket— while the bottom half is slovenly: stained, creased trousers, old unpolished shoes. Does he expect, then, that people will only notice the top of him? Might this suggest a certain faith in his own theatrical ability to hold people’s attention? (Keep them looking at your face.) Or perhaps his own life is similarly bifurcated? Perhaps he is ordered in some ways, disordered in others.

(How Fiction Works, 77)

This watchfulness of patients primes the clinician, and in the case of dementia, prompts the clinician to look for any evidence of movement disorder or overt signs of physical illness. They are looking for the unusual or unexpected such as Alfred Lambert's 'paddling at the air with loose-hinged hands' (Franzen 2001: 17) as one of his most obvious symptoms. His 'poorly controlled feet' (Franzen 2001: 17) would make a clinician wonder about a rare, and potentially treatable dementia, normal pressure hydrocephalus (NPH) for which a particular gait is a diagnostic indicator.

Having visually assessed the patient the clinician proceeds with the completion of the clinical history. The clinical history is a story which needs to be told coherently and quickly within the 'clinical hour'⁵⁹ and expected to cover key areas: the patient's view of the problem, personal history, family history, educational and professional background, previous medical history (PMH), Mental State Examination (MSE)⁶⁰ patient/family expectations from the consultation, provisional diagnosis if appropriate and plans for future care. In the memory clinic the template for the history taking evolved over time. It was used by all members of the memory service team in their initial contact with the patient to ensure that the stories told by patients and supporters had a consistent structure which would enable the signs and clues about possible dementia to emerge. It was developed with the aim of ensuring that the history taking should create as little anxiety as possible for the patient and place them as central by beginning with a direct question, 'Before we start what do you want to happen from the assessment?' Although I was not aware of it when creating the template it is a move towards a dialogic rather than monologic position and engages the patient immediately as someone with a view on the situation which

⁵⁹ Usually aimed to be 55 minutes to allow the clinician to process the consultation, write any extra notes and prepare for the next patient.

⁶⁰ This includes appearance, behaviour, cognition, speech, objective and subjective mood, thoughts, hallucinations, and insight.

has to be taken into account. This theme of questioning ‘Do you have...?’ and ‘Can you...?’ persists through the assessment. An even more dialogic position would be for the clinician to say ‘Tell me about...’ but the danger in pursuing such a questioning style is that the consultation extends beyond the allocated time.

All questions are addressed initially to the patient with the clinician seeking clarification or corroboration from supporters when questions appears to be distressing or difficult for the patient or when the supporter indicates, either by verbal disagreement or with the non-verbal commentary of a shake of the head that the information is inaccurate. How disagreements are handled can reveal family dynamics as Franzen demonstrates in *The Corrections* (2001: 20).

Despite the constraints of the history taking template presented here in Section 3.5⁶¹ it contains the common structures of fiction. The main theme of the consultation is the exploration of the presenting problem, how it started and now manifests itself in the life of the patient. Characters are revealed through questions about **Family view** and **Relationships** and setting in questions about **Why now?** **What life events?** Problems and conflicts are addressed throughout the history by ascertaining difficulties with **Activities of Daily Living** and queries such as **Is there someone with a particular carer/supporter role?** and **Do they struggle to help?** The course of the illness asked as **When problem with memory first noticed?** runs as a thread throughout the clinical storytelling. The clinical template is for an initial interview and the listener is asked to ascertain **Does the person want to be told if they have a diagnosis?** This forms the patient’s solution/resolution about how they want the problem to be solved. There are multiple points of view represented in the

⁶¹ The clinical histories for Mary, Alfred Lambert and Mother are presented in Appendix 7, 8 and 9. They are written in longhand as if in the medical notes. For ease of reading and analysis a typed, colour coded summary history for the three characters is in Section 3.3.2.

history template ranging from **What do you think is causing your memory problem?** and **Does the family have any concerns about the person's capacity to make sensible and logical decisions about important issues? These are:**

The sections in the template are the equivalent to chapters in a novel. They signal a pause in the narrative. My clinical practice was to indicate to the patient a change in the area to be explored to guide the patient and the supporter steadily through their story. The clinical history begins with questions about childhood and the past which a patient with possible dementia is most likely to be able to answer independently before it turns to the challenges of the present. The aim is to provide a coherent chronology of events and overview of the range of difficulties the person is experiencing. Taking a clinical history authorises a specific manner of storytelling which Frank describes as 'narrative induction' (Frank 2010: 61 citing Linde) by which means the person is recruited as a patient, a process Frank calls 'interpellation' (ibid: 197).

The clinical template was practical and useful in the clinic but its limitations become apparent when completing it from the fictional portrayal of Alfred Lambert in *The Corrections* (Franzen 2001). The reader of the text is aware that a main issue for Alfred Lambert is his hallucinations which are experiences he is unwilling to share or talk about, although he responds to them and describes them when his actions are queried (Franzen 2010: 146). To be acknowledged in the medical notes hallucinations would have to be reported by Alfred or by Enid as a response to the question in the Psychological Health section of the clinical template '**Seen things that others cannot see/hear or believes things others think odd?**' At the time of the assessment, Enid is reluctant to recognise them as a problem and Alfred is unwilling to talk about them. Instead his clinical history is dominated by movement

difficulties which are observable phenomena both to the clinician/reader and to Alfred, but minimised as a problem by Enid.

The focus of the story telling in a memory clinic is driven by the anticipation that it will lead to an understanding of their memory problems and a diagnosis. The diagnosis of a dementia depends on the history, the development of the problem, the clinician's experience of all the other people with a dementia they have encountered as well as the current presentation. It is therefore a clinic where clinicians pay particular attention to the accuracy and detail of the clinical history because there are no definitive biochemical and pathological markers to confirm the diagnosis.

Once told and set down in the medical notes this version of the patient's story becomes unavailable to them although they will be asked to retell it many times. Clinicians want to hear a patient's story directly, as new and original, because this first hand eliciting cements the patient in the clinician's memory. It allows all the behavioural cues of language, such as fluency and timbre of voice, in addition to their anecdotal stories, to contribute to the memory of that patient. The first hand telling of the story has a vividness and immediacy which never reaches the notes. Valuing the unique and memorable elements of the clinical history is helpful to clinicians in a memory clinic because patients are likely to present with similar narratives of progressive loss of function and the history is taken using a standard template. Memorable information locks that patient in the clinician's memory and makes them available more readily for clinical discussion as Nancy, a surgeon (Weston 2013) points out:

How good I have felt because I always had some detail to tell about my patient's domestic circumstances, if I did happen to get asked about them. I might have a hobby up my sleeve, a revelatory occupational hazard, a touching detail, the name of a pet, the shadow of a recent bereavement.

(Dirty Work, 155)

This stance cannot be readily shared with the patient who must feel that during the consultation they are the clinician's only patient even though both patient and clinician know that this is not the case.

As in fiction there are multiple readings available in the medical notes which lead to different discourses about dementia. These range from their use as a case presentation in medical teaching or in a clinical investigation or correspondence copied to the patient being discussed with a home carer or friendly neighbour. Any reading of the notes depends on the experience and knowledge of the reader and rather than being a 'frozen, observable substance, a concrete cultural object' (Talbot 1995: 25), medical notes are an 'unstable text' despite what patients/families may expect from the apparent empiricism of the medical model. Medical notes are interpreted by the reader; the meaning of the evidence in them is not set, as medical second opinions and medical evidence in court indicates. Even with a relatively straightforward case of dementia, the notes can only offer at best a contingent conclusion. The only items with critical certainty are computer generated blood results which are analysed without human intervention and then 'flagged' on a computer screen as abnormal when they fall outside certain parameters. Even here their meaning and relevance for the patient is interpreted by the clinician.

The clinical history becomes a record as a part of a larger document and a means of 'reassembling lives' (Frank 2010: 85). For a patient suffering with dementia whose access to their personal memories will diminish and disappear over the course of the illness the notes have the potential to become an archive. The details documented in the history are a unique and irreplaceable source of

information about the person and can become important for future clinicians who are then able to use phrases such as 'I see you were a ...' as a means of creating a rapport with a patient as well as indicating to patients and supporters that the notes have been read. Viewing the notes as a personal archive requires Derrida's *Archive Fever* (Derrida 1996) to be acknowledged as contributing to this understanding. Although he evaluates the notion of the archive as it relates to Freud it illuminates what is happening in medical notes. He identifies the fluid relationship between what is in the archive which is demonstrable and tangible such as biochemistry results, and what it archives, the meaning they signify for the person. Derrida identifies an archiving impulse as intrinsic to being human and is represented in memory clinic notes as the desire by patients to have their story correctly documented at the beginning of their patient career, to ensure the archive is correct. Suggestions for amending the history taking to account for this desire and develop the notes as a more personal archive are suggested in Chapter 4 as a practical research outcome.

For Derrida, there is a 'there' where documents are gathered together, ordered, sheltered and available. This works as a definition of medical notes. Medical consultants, who have prioritised access and use of the notes, act as 'archons', the guardians of documents, and in commandment bestow authority on the archive by this pre-eminence. They:

not only ensure the physical security of what is deposited and of the substrate. They are accorded the hermeneutic right of competence. They have the power to interpret the archives. Entrusted to such archons, these documents in effect speak the law: they recall the law and call on or impose the law.

(Archive Fever, 2)

Derrida's description of the 'archontic dimension of domiciliation' (ibid: 3) is helpful in understanding the medical notes as an archive with power and salience, and not objective.

The medical notes as an archive become a public extension of a person's memories and there is a strong argument for encouraging the creation of a format whereby a truly personal archive could be created for the person with a dementia for insertion in the medical notes. Currently the health profession most closely involved in personal archives is Occupational Therapy through their promotion of Life Books and Memory Boxes for use in care homes and institutions. Residents, with the help of family and supporters, are encouraged to have a shoe box filled with objects designed to promote memories which can then be used as a point of contact between care staff and resident. They are created as well-meant artefacts but a shoe box of trinkets for discussion creates a commodification of personal memory. Such memory boxes do not have a powerful 'archon' behind the archive and thus without the structure of a medical organisation are difficult to maintain. More meaningful as a personal archive is the acknowledgement in *Grace and Mary* (Bragg 2013) by John of his mother's repertoire of songs and poems which they use to maintain their strong mother-son relationship. They act as an archive because they are mutually meaningful and embedded in each of their lives and help John and his mother to understand who they are in relation to each other.

3.1f. Dyad 3: Listener (and story)

As a clinician I heard many hundreds of stories told by patients as the clinical history and transposed the dramatic episodes told to me by silently questioning how these might be presented as fiction. As a reader I would do the reverse, and think about how a novel I was reading would play out in the clinic. In the clinical interview, with

the agreement of all present, the history is sought by a form of direct questioning which should appear to the storyteller as a conversation with an engaged and interested listener. The patient and supporter have an important story to tell about how they have reached this position which might be told in myriad ways. To keep the story in check the clinician, as listener, drives the narrative by their questioning and begins the ownership of the clinical history. Only the clinician knows what needs to be covered in the time allotted and good clinicians make the patient and supporter aware that they may be interrupted to enable the listener to keep control of control of its narrative structure and pace.

In *Scar Tissue* (Ignatieff 1993) the narrator, his father and his brother attend a neurology appointment with Mother to receive the results of various investigations. The manner of medical consultation described in the novel remains familiar after two decades. The narrator views the neurologist ‘With guilty goodwill, I think here at last is someone who will understand’ (Ignatieff 1993: 55) but any goodwill is lost when the neurologist starts to refer to Mother in the third person. ‘Mother, she says, ‘is performing pretty well on some tests, not quite so well on others’ (ibid: 56). The narrator, correctly in my view, finds this inappropriate and indicates to his brother that Mother should leave the interview. The neurologist does not appear to the narrator to view Mother as anything other than an object of study and thus can never be truly understood. The neurologist is taking a monologic position in readiness for the diagnosis and only for a brief moment does the interview shift to a potentially more dialogic position when the neurologist says ‘Tell me about that’ when the narrator’s father links the ‘possible cerebral trauma’ (ibid: 56) on the scan results to a car crash.

The monological position is indicative of the medical power at play in the episode when the narrator finishes the sentence:

‘the gold standard for all diagnosis in these cases is...’

‘Autopsy’, I butt in.

A thought crosses her mind.

‘So you know about these things?’ she says, brightly.

I nod and I don’t know whether she is marking me down as one of those tedious neurological autodidacts or as a mature professional she can take into her confidence. Whatever she thinks, she knows I will be doing the talking.

(Scar Tissue, 57)

The neurologist has accurately assessed where the power in the consultation lies, which is not with the patient or her husband. This is something the clinician has to do very quickly and is part of the performance aspects of consulting. The ebb and flow of the consultation proceeds as the neurologist gives a surprisingly frank summary of the situation, ‘Your wife will be dead in three years’ (ibid: 57). As a counter to this, the narrator gives examples of what he sees as the intact areas of Mother’s communication as a challenge to the diagnosis. Although Mother is unable to maintain a conversation the way ‘she listens and laughs when you say something that amuses her, nods to let you know she’s following what you say’ (ibid: 58). The neurologist parries this observation with medical terminology and redefines this as her ‘prosodic variation is still intact’ (ibid: 58). The neurologist ‘remains good naturedly persistent’ (ibid.58) in her approach to the family and although the narrator takes issue with the term ‘still’ he does not pursue this. A further spat occurs over the term ‘disinhibition’ which the narrator views as ‘ugly’ (Ignatieff 1993: 60). ‘The neurologist looks at me evenly, as if debating whether to despatch this illusion as well. She must have heard it from relatives a thousand times before. She decides to

say nothing. It doesn't matter. I change tack once more' (ibid: 60). The narrator and the neurologist call a truce and the battle lines are clarified:

The doctor looks at Mother's PET scans and sees a disease of memory function, with a stable name and a clear prognosis. I see an illness of selfhood, without a name or even a clear cause.

(Scar Tissue, 60)

Many clinical consultations are similarly monologic rather than dialogic. Whereas follow up appointments may be more conversational and dialogic in their respect and acceptance of the position of the patient, the diagnostic consultation is almost inherently monologic: a single standpoint which utilises medical knowledge and expertise to inform the future. A gesture towards the patient might lead the clinician to ask, after delivering the diagnosis, 'How does that make you feel?' but this does little to reduce the monologism and pushes the patient/supporter into a corner of having to respond in an unprocessed and raw manner. A more dialogic stance would be to offer the position of complete distraught as an option and promise to return to the feelings about the diagnosis at a follow-up appointment. In discussing 'good doctoring' for carers as being equally important as that for patients Levine (2004) points out that:

Carers' expectations are remarkably modest. They remember the smallest manifestations of kindness, whether in words or action. What they want is courtesy, respect and acknowledgement of their fears and hopes. Translated into behaviour, the good doctor gives information in an understandable way, responds to questions, is available or provides a knowledgeable substitute, and remembers the key pieces of personal history that makes up patients' and carers' unique identity. The good doctor follows through and follows up.

(Clinical Medicine, 4.3.May/June 2004.p. 245)

She argues that such a model of 'good doctoring' must be modelled and reinforced in medical education and that the humanities can inform and enrich the task. One of the ways it can do this is to understand the clinic less as the repository of the

dominant medical culture of certainty, scientific evidence and hierarchy but as a story telling space.

Clinicians start and end their history taking with their own verbal tics which develop over time as phrases which seem to work. My clinical histories always ended with the following question to the patient and supporter ‘Is there anything that I don’t know that you want me to know and is there anything that you feel I haven’t covered?’ The aim of this was to ensure that the patient and family felt their story to be complete and that they had been involved in its accurate creation. In retrospect it was an attempt to create a more dialogical position.⁶²

By collecting patient narratives in the same format it allows the clinician to access all the previous narratives they have been told in the clinic as ‘historically prior texts’ (Talbot 1995: 25) which enable the clinician to tease out any anomalies in the story to help drive diagnostic accuracy. Terry Eagleton’s position on originality in fiction that ‘everything has been done before; but it can always be done again, and the act of doing it again is what constitutes the novelty’ (2013: 180) is equivalent to the taking of the clinical history. The recognition of sameness and individuality in the stories aids diagnostic accuracy but also made the memory clinic, for me, the most professionally stimulating environment. The narrative habitus of the clinic, the expectation of stories describing a decline in memory functioning, and fear of what this might mean, was ‘woven out of other phenomena, so that nothing is ever *quite* new or ever *quite* the same’ (ibid: 180 My italics). It was the suspense and excitement of the story unfolding which made the memory clinic a vibrant and exciting place to work and such a good personal fit for me as a clinician/reader.

⁶² It had been driven by my experience as a patient when my story of the presenting problem was submerged leaving me not confident in either the diagnosis or the treatment.

Every clinic offered new ‘stories’ which were often as compelling as any fiction.

Despite the constraints of time and the environment the clinical history could act as a form of life review or guided autobiography and lead to personal revelations which were profoundly moving or very funny and I have both wept and laughed with patients and supporters.

3.1g. The heresy: medical notes as fiction

As a clinician I used medical notes as professional tools. At the start of my career each profession kept their own notes which were never shared with other professionals, or with patients. By the end of my career practice had changed and each patient had a single set of physical health notes which (theoretically) moved with the patient between departments. A patient referred to a psychiatric department would have a set of mental health notes opened for them which were not routinely shared with physical health teams although psychiatric teams could access physical health notes. Patients were encouraged to have copies of correspondence written about them.

I enjoyed the succinct accuracy that writing in the notes required and I loved being the first person to open a set of notes. Reviewing old volumes of notes revealed historical medical practices and professions such as almoners and remedial gymnasts which have disappeared. Styles of report writing and entries in the notes have changed. Social work reports from the 1970s gave detailed descriptions of a patient’s life outside hospital and were often small literary masterpieces. I suspect that Hilary Mantel may well have developed her meticulous approach to writing during her time as a medical social worker, an experience which formed the basis of her early novels. Writing in notes is a skill and is taught during the training process of health professionals. A clinical supervisor has to counter sign entries and remains professionally responsible for what is written.

Writing in the notes has to become a natural professional task but it should never become routine. As an NHS manager and clinician who audited notes the style, range and accuracy of entries started to make me wonder about notes as class of fiction. As a reader I began to wonder whether it would be possible to develop a genre of fiction which took a topic from the list of known stressors such as bereavement, divorce, unemployment, incarceration, or moving house (Holmes and Rahe 1967)⁶³ and fictionalise these as medical notes.

As this research developed I used this longstanding thought to reverse engineer the process and create a set of faux notes from the memoir fiction.

The creation of the faux notes lays bare the similarities in the selection of information for the narrative in both the memoir fiction texts and the medical notes.

⁶³ Holmes, T.H. and Rahe, R.H. ‘The Social Readjustment Rating Scale,’ *Journal of Psychosomatic Research*, 11. (2) 1967, 213-218.

It tests ‘the heresy’ of the clinical history *as* fiction to create a clinical history *from* fiction. They become a genre hybrid ‘eliding boundaries between fiction and nonfiction, fable and report’ (Frank 2010: 92).

3.2. Creating the faux notes: *Treatment option 2*

This thesis has promoted the memoir fiction as offering the most clinically accurate and veracious portrayals of dementia. This research intervention is a means of testing this presumption through the creation of sets of medical notes which are accurate in style and documentation for the three characters with a dementia in the memoir fiction texts and was made possible through a direct link from practice. On my retirement, colleagues presented me with a complete set of my medical notes which documented my foibles, passions, and quirks as a manager and clinician as comically pathological. It was a warm-hearted and idiosyncratic *Festschrift*. As expected, it contained truths and exaggeration but it was rooted in the life and experiences of the clinical team. Events cited had happened but there were multiple ways of remembering and documenting them. In this manner ‘my’ notes share similarities with the memoir fiction: the circumstances are real but what is written about them may not be verifiable or universally agreed, as one would expect from memoir. What is written in ‘my’ notes was not to document my career but to offer a range of ‘truths’ about me and what had happened. Having ‘my’ notes meant that the familiar templates and documentation, some of which I had created, were available for me to use with the fictional characters.

The process began with creating notes⁶⁴ for Mary from *Grace and Mary* (Bragg 2013) whom I have called Mrs Andgrace. Her faux medical notes are in Appendix 7. The faux notes for Albert Lambert from *The Corrections* (Franzen

⁶⁴ As a courtesy I informed the author of my intentions.

2001) are in Appendix 8 and for Mother from *Scar Tissue* (Ignatieff 1993) in Appendix 9. Presented in the appendices as reduced photocopies they do not have the texture and tangibility of genuine notes. Each text was read again specifically to complete the clinical history. My practice of recording evidence changed after completing Mrs Andgrace's notes. The evidence from that text is in the superscripts in the correspondence section of her notes. The evidence from the text for the handwritten notes is in parentheses in the clinical history. As with many medical notes deciphering medical handwriting can be time consuming and wearisome so the hand written clinical history records have been combined onto a single history template in Section 3.3.2 using colours to indicate the text to which it refers. This method enables comparisons between the texts to be made more easily.

Medical notes have to be created by the administrative support team for the service who talk of 'making up' the notes. This 'making up' involves the preparation and labelling of the cover to enable efficient filing of information. In the fray of clinical practice, the irony of this phrase was not apparent. Frank would argue that stories told anywhere, including the clinical history and the 'made up' stories that constitute fiction, share structures which allow them to be compared. Information in medical notes is not (usually) fabricated yet it shares many attributes of 'made up' stories. They have a narrative structure, contain various voices, some of which are more dominant than others, and raise issues of authorship. Whilst working as a clinician I had used the medical notes as unconsidered, unchallenged artefacts. My thoughts about the content of the notes developed through the creation of the faux notes and the dual meaning of the phrase 'made up' has led to me to consider the medical notes as a fictional text. With hindsight I think this explains why I felt such a strong professional fit with the memory service because it fulfilled the position of

stories described by Frank (2010: 3) a ‘sense of self that those stories impart, the relationships constructed round shared stories and the sense of purpose that stories both propose and foreclose’. Stories enhance our lives. Such a thought would have been heretical in the environment of practice.

The creation of the faux notes fulfils the criteria of an inventive research method which ‘addresses a specific problem, and is adapted in use in relation to that specificity’ (Lury and Wakeford 2012:11). Re-reading *Grace and Mary* (Bragg 2013) and creating the notes for Mary as Mrs Andgrace I returned to being a **clinician**/reader as the use of the familiar clinical templates and documentation brought the experience of practice flooding back. The text became ‘real’ and the need to provide evidence using superscript page numbers in the correspondence provided a focus for reading. It was not possible to create a complete set of notes which included correspondence for either Alfred Lambert from *The Corrections* (Franzen 2001) or Mother in *Scar Tissue* (Ignatieff 1993) because the texts give few details about any on-going medical support after Mr Lambert and Mother have been admitted to full time nursing care. *Scar Tissue* (Ignatieff 1993) predates the availability of ACI medication and reflects a likely reality of medical intervention in long term care institutions at that time. Similarly in *The Corrections* (Franzen 2001) Alfred’s last reported intervention with a doctor is with Dr Schulman (Franzen 2001: 642) whilst he is still in hospital and before his discharge to the Deepmire nursing facility where he lives for a further two years. The clinical history template for Alfred Lambert in *The Corrections* (Franzen 2001) and Mother in *Scar Tissue* (Ignatieff 1993) was completed and is presented in Section 3.3.2.

The process of trying to make complete medical notes for the characters revealed aspects of the texts which were incomplete and left me as a clinician/reader

frustrated. I would have liked to have interviewed Mother from *Scar Tissue* (Ignatieff 1993) in a less charged setting than a diagnostic appointment with a consultant and without her familial male hegemony to see if this allowed her to be more responsive and accessible. Mother's (ex) daughter in law does visit her in the care home (Ignatieff 1993: 147) which suggests female warmth and solidarity in a family of male high-achievers. The process left me with clinical questions about practical issues of care, for instance, the role of Occupational Therapy and input from Social Care is under-reported for the clinician/reader. This suggested that the reverse engineering of medical notes might be an innovative way to test their clinical veracity. In addition it could provide some empirical evidence of the clinical worth of the texts and for using fiction texts as a teaching tool for health professionals. Using the clinical history template gave a focus for reading which subsequently led to the development of templates for DNA, Charon's Close Reading and ultimately to the creation of Augmented Narrative Analysis (ANA) which is discussed as a research outcome in the following chapter.

The creation of 'faux notes' from the selected memoir fiction texts allows an alternative means of unpicking the narratives of dementia contained in them. They demonstrate the partiality of the 'truth' of the story and are a form of deconstruction by which the original texts can be read differently as clinical case histories and thus an adjunct to practice. Their creation demonstrates Frank's primary claim and operating premise for socio-narratology that it 'attends to stories as *actors*, studying what the story does, rather than understanding the story as a portal into the mind of the story teller' (Frank 2010: 13). When a key aspect of a narrative is illness the reverse engineering shows how the illness performs in the text to reveal its degree of clinical veracity. Using the text to complete the clinical assessment engages the

reader actively in the text and provides a mirror image of the transfer of real events into memoir fiction. It highlights the conflicting relationships, ambivalences and potential inconsistencies between the declared level of the text which may be recorded in the clinic, and what the text describes. In *The Corrections* (Franzen 2001) almost all Alfred Lambert's real and distressing hallucinatory experiences are missing because he is unwilling to, or cannot, articulate them. John is a good and caring son in *Grace and Mary* (Bragg 2013) but the experiences of Mary are interpreted by him. Whilst the narrator advocates for Mother in *Scar Tissue* (Ignatieff 1993: 106) this is done through the eyes of an egocentric and possibly pathologically narcissistic son who 'had to be with my mother, had to see her every day, had to attend to every single thing she needed, as if this was the proof that my wife had never grasped who I really was' (ibid: 115) and was prepared to sacrifice his marriage for his relationship with his mother.

Information from the memoir fiction is transformed into the writing styles of the clinical notes such as the clinical history template, the daily record and correspondence. The author of the memoir fiction takes events from their experience of illness and transposes them into fictional narrative. The narrative is fiction; it does not have to be accurate and yet the memoir fiction is accurate enough to be able to create from it sufficient evidence to complete clinical templates. In creating the faux notes a clinician transforms the experiences of the authors who have watched the dementia of a parent and subsequently turned into fiction, into a different entity.

Although there is a move in the NHS towards electronic records these will still be created by a clinician interacting with a patient: the difference is when, where and how it is recorded. This thesis considers paper records used in a memory clinic. The creation of the medical notes, on paper or electronically, sets the context for the

stories contained in them, but also the limitations. Once the medical notes are opened they contain at least two stories running concurrently; the patient's story and the story of the care or treatment given to the patient. Neither stands alone, the patient's story as the clinical history is collected and collated by the clinician and the narrative of treatment is told by an increasing array of individuals working with the patient. In addition the notes as a text contain multiple sub plots which are interwoven through them. Such sub-plots might include the Driver and Vehicle Licensing Agency (DVLA) and driving, or lawyers needing clarification about the patient's capacity to make certain decisions.

The medical notes have similar paratextual elements to those in books. The notes have front covers, back covers, titles, and typography set by the institution which all influence how the text will be used and viewed. The most obvious paratextual elements of the medical notes are on the cover which is made of a robust card designed to last the course of a patient's life. The three boldest elements on it relate to institutional ownership. Most predominant is the name of the institution not the name of the patient. The patient's name, date of birth or hospital number is there, three times, to ensure that whichever way up the notes are, they can be filed accurately in alphabetical order. Between the Patient number and the NHS number in the top right hand corner of the cover is the Mental Health number indicating that these are psychiatric notes. Whereas physical health specialities share a single set of notes psychiatric notes are held separately. For some patients and supporters attending the Memory Clinic being diagnosed with a dementia and finding themselves also labelled a psychiatric patient was a double stigma. What the Mental Health number does is set up a different narrative expectation of what might be contained in the notes, how they might and by whom they might be read.

On the cover the largest lettering is **CONFIDENTIAL** which means confidential to health professionals. The conflict between **FILING IS EVERYONE'S RESPONSIBILITY** and **CONFIDENTIAL** was a post-career revelation. Whilst the NHS mantra is that the notes are the patient's notes, the cover of the notes suggests the reality; they belong to the institution and access to them by the patient is only through request, payment, and in specific circumstances. It is the cover of the medical notes which makes them into visible artefacts and props in the drama of the clinic, part of the professional performance of consultation. When piled face down (to maintain confidentiality) on a desk, they signify the busy-ness of the clinic to the patient and supporter and the presence of others who have been or may be waiting to be seen and thus help to contain the timescale of the consultation.

Once opened the narrative begins, albeit with a false start. I have never seen any of the boxes on either the inside of the front and back covers completed in any set of notes but their presence implies arcane medical practices. The internal filing system provides the grammar, the structural rules which should be followed when making up the notes. All eventualities should be covered but there remains a miscellaneous file which holds everything which does not fit readily into a designated section and is akin to Appendices.

The notes should contain everything relating to that patient. Each incidental item becomes part of the story and has potential relevance should the notes be required for legal or audit purposes and should have the patients name and number on it. The story in the notes is viewed as complete and definitive. Nothing about the patient should be held outwith them.

The NHS asserts with grand rhetoric that for good care the most important story in the notes is the patient's story with the ambition that 'by 2018 every citizen will be able to access their full GP health records at the click of a button.'⁶⁵ Information about health records seeks to involve the patient by using terms such as 'you may' or 'you need.'⁶⁶ However, to see one's own hospital notes a formal request must be made although there is nothing to prevent a clinician reading to a patient what they have written. Medical notes become increasingly complex documents which are put to multiple uses by a wide range of people but are used as routine tools in clinical care. The notes provide data 'for hospital service activity reporting, monitoring the performance of the hospital for audit and research' (Academy of Medical Royal Colleges 2008: 4), for local NHS planning in addition to recording and communicating information about patients and their care. They hold the history of the person, the presentation of their condition and promote continuity and coherence of care. In addition, the notes (should) tell the story of the day to day work of the clinician with the patient and provide a clear narrative and rationale for everything which happens to the patient. Like realist fiction, notes must allow the reader to plot the story, and, like realist fiction, need to be believable. Unlike fiction, which can be immersed in subjectivity, medical notes should be objective, limited to the tangible and measurable and conversations with patients recorded close to verbatim. Such objectivity works well for blood pressure and cardiac tracings but less well for health care with patients with a dementia such as Mary, Alfred Lambert and Mother. Clinicians navigate this need to record reliably, but without judgment, by the frequent use of words such as 'appear' and 'apparent' and 'staff report.' In *Grace and Mary* (Bragg 2013) Dr Tait notes in April 2009 in the Daily Record 'No

⁶⁵ <NHS Choices.Accessing records.www.nhs.uk >[accessed 2 December 2015]

⁶⁶<NHS Summary Care Record.Health and Social Care Information Centre 2015>[accessed 2 December 2015]

apparent distress.’ The Memory Nurse (A.M. Nurse) records that Mrs Andgrace ‘Appears happy and settled’ in May 2009 and in July 2010, by which time Mrs Andgrace is physically very frail, Dr Tait notes ‘Staff report more time in bed’. The entries are restricted to observations rather than investigations of the person’s experience.

Within the notes there are sub genres of writing which have their own rhythm and cadence. The entries in the Daily Record are succinct, sometimes terse as in Mrs Andgrace’s Daily Record for January 2012 and with authoritative, monologic tones in the correspondence. Each sub-genre has to maintain narrative coherence but the notes also need a clinical coherence to demonstrate safe practice.

The Daily Record acts as the clinical diary recording who did what, when, and where. Its purpose is to document an event in the life of a patient. Mrs Andgrace’s daily record in the medical notes is completed in long hand by A.M. Nurse and the consultant psychiatrist, Dr Tait. There will be another daily record completed by care home staff documenting Mrs Andgrace’s care. This tells a different story about Mrs Andgrace and as coroner’s courts reveal, multiple stories may be told about the same event. It is in the daily record that legibility, spelling and neatness of presentation are most pronounced and the quality of daily record keeping is widely variable between teams and individuals (Carpenter et al. 2007). Written entries should be in black ink, with the date and time of what happened in the left hand margin, and the date and time of the written entry in the right hand margin. They should be completed as contemporaneously as possible and be signed with the clinician’s signature and name and designation in capitals. A clinical encounter is reduced to a few prosaic lines such as the ones in the Daily Record for Mrs Andgrace in November 2009, ‘Maintains social graces.’ They are lines which can provide professional protection if

care goes wrong and the daily record should be written 'as if' the coroner is overseeing the entry but must also provide sufficient information for a clinician involved to understand what has occurred and to provide logical subsequent care. The clinician must accept, that, like fiction, the notes are 'addressed' and written for an audience. They cannot, and never will, contain all the information although they are used in the treatment of the person as if they do. As dementia fiction is partial so is the daily record. It is an edited version of what happened but, unlike fiction, it is required to stand up to scrutiny of peers at audit, or the legal profession if care is challenged.

The daily record, where 'if it isn't written down it didn't happen' is the rule, curtails the remit of the notes and denies access to any transcendental moments in a clinical encounter. It reduces such episodes to records such as that of Mrs Andgrace in June 2009, 'Found MMSE difficult-abandoned for gentle conversation. Knows where she is broadly.' or the more usual banality in notes of 'Patient seen'. Although the writer of the notes is fulfilling corporate requirements and safe professional practice they bring to the notes their 'habitus' of personal knowledge, emotions and experiences. Reading the daily record and correspondence about a patient written by a familiar colleague is not the same as reading notes sent from a different hospital. It is most apparent when considering referral letters as clinicians begin to know what is meant by the language used by those who refer regularly to the service. In Mrs Andgrace's referral letter from the Consultant Physician to Dr Tait, Consultant Psychiatrist the phrase 'I am sure her son Mr John Andgrace will wish to discuss her care with you' is medical code for 'ignore him at your peril'. Dr Tait accepts the advice and involves John in his mother's care.

In terms of fiction the daily record acts as the author's first draft in a notebook as the storyline develops. The difference is that any entry, once made cannot easily be changed. It can be amended by a single black line signed with the writer's initials and the date and time of amendment but no entry should be erased or redacted. In comparison the correspondence may involve multiple drafts. The correspondence holds the considered information and demonstrates the thinking and of the author. Medical letters use a measured prose style and have been edited. They are dictated, typed, checked by the writer and amended if necessary. Only when letters are signed are they placed in the notes as the final proof copy, ready for distribution. The correspondence is the most active element in the notes because it contains the summary and trajectory of care. In fictive terms it initiates action and creates the narrative drive as the story of treatment unfolds. However the practice of filing the letters with most recent on the top, means that in the clinic, what has gone before can easily become lost to consideration.

It is now considered good clinical practice to ask patients whether they would like a copy of any correspondence about them and Mrs Andgrace's son, on her behalf, is copied into all the letters from Dr Tait to the GP which means that the correspondence is no longer strictly confidential. The practice of sharing correspondence with patients has been encouraged as the discourse about the patient as a consumer, rather than a simple receiver of care, has developed and is viewed as shifting some of the power of Foucault's 'le regard' back to the patient. However, in the clinical setting any equalisation in power relationships that the 'cc' at the end of a letter was meant to bring about, has meant that what may once have been said in a letter, such as potential prognosis, predicament or uncertainty, may be tempered and the real information shared in a telephone call. The rule for medical correspondence

copied to patients is that there should be nothing in the letter which should come as a surprise. This is complicated by the estimate that patients forget between 40-80% of what is discussed during a consultation (Ley 1979). A copy of the correspondence acts as a document confirming the discussions in the consultation. What letters copied to patients, particularly in a memory clinic, do best is act as an aide-memoire for the patient and provide a succinct account of what has taken place in the consultation for family members who may not have been present.

In Mrs Andgrace's notes Dr Tait will have read her referral letter (See Correspondence section of her notes). The referral letter is another sub-genre of medical writing which acts as the equivalent of a literary review in outlining and clarifying expectations for the reader. Referrers are as varied as reviewers in the amount of information they share with the reader. The letter from the GP to Dr Tait holds no surprises; the expectations are clear. Dr Tait is being asked to prescribe anticholinesterase inhibitor (ACI) medication. It would be a 'routine referral' to a memory service. In comparison the referral letters for Mr Lambert and Mother are likely to be much more complex and nuanced because of Mother's age and Alfred Lambert's complex presentation and multiple pathologies.

As other clinicians add their activities and opinions the notes fill with many different kinds of information: letters, daily records, computerised blood results, images of scans and their interpretation, X-ray results and formal NHS bureaucracy such as Mental Health Act section papers. Secondary narratives: those told doctor to doctor, family to clinicians, doctors and lawyers and in a memory clinic, between doctors and the DVLA begin to proliferate. These secondary stories become what Frank (2010) terms actors in the creation of an archive about the progression of the

dementia and how the disease affects all areas of functioning. The notes tell the story because the patient is increasingly less able to.

At follow-up appointments the patient or supporter will retell much of their story but never again as part of the medical history, which stands discrete and obvious in the notes owing to its particular template. It is the one place in the notes where the patient's story rather than the activities of health professionals dominates. At follow-up the clinician summarises all the secondary narratives to provide a meta-narrative of the story of the illness for the patient and supporter.

By themselves medical notes are meaningless. Any meaning in them is created by the reader, usually a clinician who 'holds together in a single field all the traces by which the written text is constituted' (Barthes 1977:148). That the meaning in medical notes, the apparent epitome of empiricism and evidence based medicine, is transient is apparent when reviewing a patient's old notes⁶⁷ which provide not only a personal but a social history. They provide created truths and diagnoses which fit, *for that time*. Such 'truths' may be shocking in terminology and viewpoint when read decades later.

3.3. Developing the reading templates: *Treatment option 3*

The completion of the clinical history template for the characters Mrs Andgrace, Mr Lambert and Mother using the clinical details in the texts gave a specific focus to the reading. It demanded that evidence from the texts was accumulated and used in answering the questions. Transposing DNA and Charon's Close Reading into templates offers a visible structure for reading. This development suggested how texts might be used in training health professionals to hone assessment skills.

⁶⁷ When requesting old notes to review care, the label vol. 2 of 8 on the cover fills the clinician with foreboding.

Completing the templates from the same text demonstrates the partiality of methods of assessment. Using texts as proxy patients in health professional training the templates demonstrate what is omitted in any one template but revealed in others and illustrates much more readily the different emphases of symptomatology in each text. The clinical history template as the Memory Service Assessment (MSA) demonstrates it is possible to chart the course of the illness and the views of family members. However, the standard clinical questions are limited in their ability to access the experiences of Alfred who says very little about his condition prior to the 'fall'. The reader is aware that he is experiencing strange hallucinatory thoughts but he does not share these with family members.⁶⁸ What is clear from viewing the text through the lens of the clinical history template is that the tremor is Alfred's predominant symptom and his main concern. What this template does not offer, nor does it do so in the clinical setting, is any understanding of the meaning of the symptoms to Alfred or to the rest of the family. It remains superficial.

The structure of the clinical template determines the story the patient tells, so the structure of the template determines what is revealed. Working in tandem the templates confirm the range of stories which are available from the text or patient and that the patient's story in the notes is not the only story, although it is often treated as such, which 'finalises' the patient. Using reading templates has the potential to develop dialogical practice and led to the development of Augmented Narrative Analysis (ANA).

The reading templates were created as ways of examining texts which used narrative analysis whereas the clinical template was drawn direct from practice. It

⁶⁸ This is not unusual. One patient of mine with LBD who saw small pixie-like creatures on the top of road signs told me that she no longer mentioned these to her husband as it distressed **him**.

had been developed by me in my capacity as manager of the service.⁶⁹ The creation of the clinical history template was pragmatic, designed for a particular service and not to any formal model of assessment. It had to be fit for purpose and designed to ensure that it could be used by all members and disciplines within the team and collected in a time-efficient, succinct and systematic manner which was easy to navigate by colleagues. The information had to be available for managerial and clinical audit and research. Most importantly the assessment had to be helpful to the patient enabling them to feel successful rather than challenged in the clinic. After a short preamble, it begins with enquiries about family history, something which a patient with a potential dementia would usually feel confident about answering. The direct interrogation of memory functioning using a psychometric assessment is at the end of the assessment. This is in contrast to the fictional portrayals of neuropsychological assessment in *Forgotten* (Lewis 2010) *Remember Remember* (Mc Haffie 2010) and *Still Alice* (Genova 2009) which place it as central to the clinical encounter. That the diagnosis of dementia rests on the diagnostic triangle of three equal elements: history, presentation and psychometric scores would not be apparent from these dementia fiction texts. In the clinical history template, the formal assessment of memory and cognition is reduced to part of a story and physical health and everyday functioning are recognised as equally important.

The clinical template records, as well as the patient's information, the clinical routine and legitimizes processes and procedures. It was used for auditing performance of the service and individual practitioners. Harold Garfinkel's ethnomethodological study ' "Good" organizational reasons for "bad" clinical records' (1967) is equally apposite now. In addressing the 'normal, natural troubles'

⁶⁹ Lakeside Community Trust is fictional.

of collecting information from notes as a researcher and outsider to the local record keeping mores he acknowledges the manner in which records of activities with a patient are recorded ‘intricately and sensitively’ and are ‘tied to other routinized and valued practices of the clinic’ (ibid: 192).⁷⁰ In developing the template I fell into the risk identified by Garfinkel of ‘imposing upon the actual events for study a structure that is derived from the features of the reporting rather than from the actual events themselves’ (ibid: 195). It became a template which increasingly evolved to meet the system of audit and NHS bureaucracy rather than capturing the experiences of the patient and their story. As a response to the growth of the numbers of colleagues using it and the demands that it meet data collection criteria for a number of internal and external agencies it became increasingly monological and less reflexive.

The clinical history template systematizes information into a standardized artefact, developed for use in a medical context, and open for evaluation. It meets the following criteria for using documents as a source of data (Scott 1990: 6. Quoted in Bryman 2012: 544).

- *Authenticity*. The template was developed by me whilst in practice. As is evident in the version number (KA version 10)⁷¹ it was an iterative process over a decade from the start of the service. The template had to adapt to be able to collect data available for internal and national audit and changing bureaucratic agendas yet provide the primary source of a patient/supporter’s account of the development of a dementia. However, it is rarely if ever, validated with them and as such, has the potential to contain the clinician’s

⁷⁰ This is evident in Alfred Lambert’s faux notes (Appendix 8) Pages 2 and 4 of his daily record do not have his name at the top. In practice I should have checked that each page was correctly labelled before returning the record to the records cabinet.

⁷¹ I practised using a different surname from my current one.

version of events, rather than the patient's. Information gained was written in long hand and the utility of the information in the free text boxes could be compromised by legibility and idiosyncrasies in recording as well as constraints of space.

- *Credibility.* The template is used here as it was used when in practice apart from the substitution of Lakeside Community Trust.
- *Representativeness.* The collection of the clinical history is standard psychiatric practice (Waite 2009) and medical practitioners use their own internal, ingrained history taking pattern. The clinical history template represents my pattern, made overt and imposed on the service. It reflects personal priorities and values in developing a service which I recognise now as an attempt to be dialogic. Its creation and the freedom to impose it on the service was one of the few benefits of being an NHS manager.
- *Meaning.* The evidence collected in the template will be used for as long as the medical notes are in use. It was developed through practice and designed to fulfil the multiple demands imposed on NHS documentation. Patients might query why a question such as 'Can you cut your own toe nails?'⁷² might be asked but there is no question on the template which does not have some relevance for current and future care. Designed as a bespoke document for a specific service, for it to be fit for placing directly in the medical notes and not simply as an aide-memoire, it had to remain acceptable to corporate and Department of Health standards required for medical notes. It required regular updating and amendment to make it compatible with NHS

⁷² There is evidence that the inability to bend to cut ones toe nails suggests potential difficulties getting in and out of a bath. The question allows a verification of the responses to other questions relating to self-care and Activities of Daily Living (ADL) activities.

procedures. The questions asked are a mixture of the prosaic, 'Do you have a downstairs toilet?' to the deeply personal and at the time, ground breaking, query about any experience of domestic violence. This question was asked to elicit whether domestic violence had ever been part of the person's behavioural repertoire. If so, there is the possibility that it may occur again if disinhibition becomes a prominent BPSD symptom. Domestic violence is akin to problems with continence, if questions are not asked about it, it will rarely be revealed. My practice was to seek permission from patients to ask what would normally be highly intrusive questions and reassure them that while not every question might be relevant for them, every question was relevant for someone, and reiterate that memory problems and dementia was no respecter of class or education. Such a preamble served to prepare the patient and their supporter that they were being taken seriously.

Scott further distinguishes documents, as opposed to records, with regard to authorship and accessibility. Authorship of the template is clear. It was created by me and offers an increased degree of authority and legitimacy over the analysis of the document.

The DNA reading template uses the structures outlined by Arthur Frank in *Letting Stories Breathe* (2010). It places the text in context, asks what capacities are at play in the novel and then asks the reader to respond to the questions posed by a Dialogical Narrative Analysis. The use of boxes to answer questions from the texts helps to make the task a more clinical than literary one. Further questions and a query have been added by me to the DNA template: How useful might the novel be in the clinical world? Which passages might be useful as photocopies within the clinic? and Health warnings.

Rita Charon ‘developed a drill of sorts for reading texts’ (Charon 2006: 114) and this template formalises her categories of frame, form, plot and desire into text boxes. Much of what Charon describes as ‘frame’, the location of the text in the world, who is narrating has been answered by the text boxes at the start of the DNA template: Classification of the novel, Summary of the plot and Why has the novel been selected? and has not been repeated. The attention for this text box in this template is about ‘the forces holding this particular writer and reader together’ (Charon 2006: 115) and what has been left out of the text. She argues that readers and clinicians who are attuned to what is left out of a text become more able to decode its meaning and become more curious about it. This interest in the text transfers into clinical practice and better enables the clinician to elicit medically salient facts from patients.

3.3.1. The Triple Analysis of the memoir fiction texts.

The Triple Analysis of the texts mimics a patient attending a clinic who is seen by a variety of professionals all of whom complete their own assessment and, in my experience, are likely to feel that ‘their’ assessment is the most crucial to understanding the patient and their care.

The Triple Analysis uses three reading templates for texts rather than patients. The clinical history is used in exactly the same form as it was with patients when the expectation was that no box should be left unfilled. The templates created from socio-narratology and Charons’ Close Reading Drill are developed from their exposition in the *Letting Stories Breathe* (Frank 2010) and *Narrative Medicine* (Charon 2006) to mimic the style of the clinic assessment. Each offers an alternative focus for reading the texts. The clinical assessment asks questions expected in any medical specialty and to meet the requirements of the annual audit of medical notes.

Extra attention is paid to the practical impact of the presenting problem in everyday life and, anticipating a diagnosis of a progressive illness, to documenting the legal and financial position of the patient and supporter in terms of Lasting Power of Attorney and benefits claimed. These will form part of the discussions about future care once the diagnosis has been confirmed. Understandably this assessment is not focussed on narrative analysis but the aggregated clinical assessment in the following section does illustrate the authorial interest, notably the amount of information available in the texts about Activities of Daily Living and Psychological Health. This reflects the concerns most frequently raised in the clinic by patients and supporters and adds veracity to the clinical authenticity of the texts.

The DNA template asks questions of the narrative in the texts. The initial sections: characters present, summary of the plot and reason for selection act as the sections in the clinical template Family History and Relationships. The capacities used are what Frank describes as the ‘equipment’ (Frank 2010: 27) of the story which is in play when answering the DNA questions. Unlike the clinical history the capacities and DNA questions reveal the themes and felt experiences of the protagonists in a way that the clinical history does not. It offers a more humane understanding of the presenting situation and is developed as a research outcome, Augmented Narrative Analysis (ANA) in section 4.4.a., which takes the DNA template and adapts it for clinical use.

In contrast Charon’s Close Reading template takes a more concrete and documentary approach to the texts in terms of their form and structure. This is not surprising given that the Close Reading drill was developed by a practising clinician to hone history and assessment skills in anticipation of direct patient contact. Charon’s category of Frame is the equivalent of asking about the person’s

background, Form the development of the problem and Plot their current presentation. Desire is Charon's most elusive category but is the only section in all of the templates to acknowledge that that reader, (or clinician), is in a relationship with the text (or patient). Despite Frank's assertion of the tripartite nature of stories: listener, teller and story working as one his DNA questions do not address the role of the listener directly. The DNA question 'What is the effect of people caught up in their own stories, whilst living with people caught up in other stories?' is the closest but is an oblique approach.

As in clinical practice the assessments used by different health professionals are geared to their specific expertise and knowledge base. Similarly the reading templates reflect different theoretical and practical concerns. Now that there are single, rather than multiple patient notes the assessments of all the different health professionals are available and can be shared. This should offer a more comprehensive understanding of the patient and thus lead to care which is more responsive to the complexity of the patient's experience. The Triple Analysis is the equivalent for texts.

To complete the clinical history template Mrs Andgrace from *Grace and Mary* (Bragg 2010), Mr Lambert from *The Corrections* (Franzen 2001), and Mother from *Scar Tissue* (Ignatieff 1993) were assessed using the evidence in the memoir fiction text. Each character is at a different stage in the progression of the disease; Mr Lambert from *The Corrections* (Franzen 2001) is assessed during a crucial weekend in New York prior to Enid's much anticipated 'fall cruise'. At the assessment he is accompanied by his children and Enid as supporters. Mary is assessed at a point before starting her ACI medication having already seen the consultant, Dr Tait. In *Scar Tissue* (Ignatieff 1993) the clinical history template is completed at the point

Mother attends a neurology appointment with her sons and husband. How the characters present for assessment is as varied as any memory clinic list.

Returning to the clinical history after completing it some months before is reminiscent of clinical experience in a Follow up appointment. There are some clinically unhelpful phrases such as 'Non significant' referring to sight problems. Does this mean not significant for Mary Andgrace, for the assessor or in that particular environment? Nor is it always clear from the assessment what is reported information and from whom, and what is observed at assessment. The lack of superscript in the clinical history shares similarities with memoir fiction in that the reader has to trust the integrity of the author.

3.3.2. Clinical history template completed for the characters in the memoir fiction texts

This template is a collated summary of the three handwritten clinical assessments from the faux notes in Appendices 7, 8 and 9. The written record from *Mother from Scar Tissue* (Ignatieff 1993) is in blue, Alfred Lambert's record derived from *The Corrections* (Franzen 2001) is in red, and Mrs Andgrace's record from *Grace and Mary* (Bragg 2013) is in green. They are recorded in order of date of publication.

| | | |
|-----------------------------------|----------------|---------|
| Name :Ignatieff Franzen, Bragg | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

MEMORY SERVICE ASSESSMENT

*Lakeside
Community
Trust*

| | |
|--|-------------------------------------|
| GP | Surname:IGNATIEFF..... |
| When last seen: | First Name:Mother..... |
| Present at assessment: Clinician/reader/text/author..... | Hospital No: NHS No: |
| Date of assessment: ...Feb 2015..... | Date of Birth: Age 60(47)..... |

Introduction:

Who we are
 Who referred you
 Happy with who is present
 How long we will be there

With permission
 What we will do and consent to assessment
 Consent to refer on if necessary

(if possible, something in every box) *Based on information available in Scar Tissue (Ignatieff 1993) up to neurology appt. on p.55*

Based on information available up to the fall from the ship (390) on Luxury Fall Cruise (??Irony)

Based on information gained from the complete text.

Before we start do you know what you want to happen from the assessment?

Hb. Prompted appt. with neurologist (10). 'Scientifically, it is not clear.'(34)

Not able to state. Says happy to chat

Current Concerns

Client view

Doesn't say, narrator feels mother had 'just the old foreboding' (7) about family history.

Predominant view; 'There are things in life that simply have to be endured'(201)

Motor problems-spills (10) ,10 yrs or so (11)

Can be variable –'sudden vigour' (25)

'These shaking hands belonged to nobody but him, and yet they refused to obey him'(77)

Says has no concerns.

What do you think is causing your memory problem?

Mrs Lambert dates problems from call about Denise's divorce.'Dad needs to work a little on his attitude.'

Doesn't feel memory a big problem. Down to age.

Family view

Enid: 'what he has is very mild and almost completely controlled with medication' (20)

Denise: 'Dad is sick' (36) and wants him signed up for Corektall (240)

Gary: 'wants us to sign up to assisted living' (72) , this train should not be on these tracks'(199)

Has been seen by Dr Tait. Phone call. Son aware diagnosed with AD/VD by Dr Tait. Son gave details of history.

Why now? Any new life events?

When problem with memory first noticed?

5+ years ago

Has the problem been gradual or stepwise?

Always had a problem getting words out. (20)

Gradual steps

Family History

Born & brought up:

Mother had probable dementia. Institutionalised (5). Got lost (4).Not able to identify family members. (5)

Local girl. Lived here all life.

Family Structure:

Married. Hb. Immigrant. Russia. Doctorate in soil chemistry.

2 sons. Doctor/medical researcher (25). Narrator is a philosophy lecturer.

Widowed .1 son.

| | | |
|--|-----------------------|----------------|
| Name: Ignatieff Franzen, Bragg | Date of Birth: | NHS No: |
|--|-----------------------|----------------|

Views of childhood (nil untoward, happy, unhappy):

Lived all life within 15 mls Alton (17)

Says good childhood.

Parents (+ causes of death):

See earlier comment

Not able to give details.

Employment History

Education:

Teacher training college.

Says enjoyed school.

Age of leaving and qualifications:

Says enjoyed school. No details.

Main area of employment:

Ran engineering dept. Midland Pacific railroad last 10 yrs. (78) Amateur metallurgist

Home- maker- no 'career' (17)

Amateur painter. Suddenly stopped ? reason

Only able to say war work.

Relationships

Marriage (how many times):1,1,1.

Any history of Domestic Violence?

No , but a 'shouter and a punisher' (25)

No BUT she has struck hb. 'My father has been struck several times.' (490)

Children (g children & g g children) names and contact (visits, phone calls, skype)?

Gary, Denise, Chip

Narrator-regular ++++ visitor? Over zealous/concerned

Doctor- more rational than br.??less concerned

1 son John. Knows has grandchildren. Not able to name.

Is there someone with a particular carer/supporter role? Who? Name & relationship:

Hb.has taken over household and care. Become' father and nurse' (42)

Cousins visit+++

Do they struggle to help? (any ill health, live away, work full time)

Wife now does on the QT (6). No longer able to do reliably (8). Gary concerned house 'only large asset'. (199)

? Is son depressed

Son London,visits regularly. Phones +++

Do they help with finances?

Property transferred to sons.(39)

Son administers.

Do they have a Lasting Power of Attorney?

Son has.

Do you have Attendance Allowance?

??

Is there a Advance Directive? If so who has it? Where is it?

Carer

If appropriate – how many hours per week to you spend in your role as carer/do you receive any help?

Could the person be left for a weekend?

No- son visits rather than leave alone (43)

No= reason for admittance to NH.

How long could you leave them for? Was needing 24hr care prior to # NoF

What would be the concerns?

Cooking.

Wandering

Would you like a carer's assessment?

No

If the person feels that they are a carer complete Carer Checklist.

| | | |
|-----------------------------------|----------------|---------|
| Name: Ignatieff Franzen, Bragg | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

Do you drive?

No longer- misidentified window crack for door handle (23)

NA

Is the family happy to travel with you?

Any accidents or near misses? If Y details?

DRIVING-(if yes alert them to implications of assessment and diagnosis)

Activities of Daily Living (*think initiation, planning and organising, effective performance*)

Housing – Do you have any problems with your accommodation? Is it your own home, rented, sheltered etc?

Own home transferred to sons (38)

Own home. Gary feels couple need 'to sell this fucker now, we can't lose another day' (199)

In NH

Do you have any problems with personal hygiene (bathing/showering)? What are they?

'I lower her into the bath' (47)

'Al, you're lying in the shower' she said, 'This is not the place to sleep.' (??)

Has full nursing support with all ADLs but accepts.

Do you have any problems with dressing? What are they?

Can dress self (75)

Will assist when prompted. Full support given.

Do you have any problems with continence? What are they? (*constipation, getting caught short etc*)

'had a final pre-dinner session in the bathroom, his third session inside an hour' (336), 'application of a second diaper' (363), 'workshop smells of urine' (6) uses the Yuba can there.

She says NO. Staff report faecal and urine. Managed with pads and toileting.

Do you have a downstairs toilet?

Do you have any problems with shopping? What are they?

Needs prompting to continue. Still eats with knife and fork. Uses cup. Needs prompting to drink

Do you have any problems with eating (*any weight loss*)? What are they?

Do you have any problems with meal preparation (*do you cook like you used to*)? What are they?

Yes: pots left boiling on stove. 'After that, a roast left to carbonise itself in the oven' (32)

NA

What level of ability

Cooks unsupervised

Reduced skills

Can no longer cook complex meals

Can make sandwich, cereal, toast

Meals on wheels

Can you use the telephone or does this cause difficulties? What are they?

Yes speaks to son when he calls. Not able to initiate.

Can you make appointments?

Can you take messages reliably?

| | | |
|-----------------------------------|----------------|---------|
| Name: Ignatieff Franzen, Bragg | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

Can you do your housework or does this cause difficulties? What are they?

Takes ages to paint seat (5). Blames the equipment.

NA

Do you go out regularly? (inc. church, clubs, outings, friends, neighbours, family) Where?

Son takes out. Mixes in home. Joins in with the singing and music.

Have you stopped going out or doing hobbies you used to enjoy? If Y why? Memory or other reasons?

Suddenly stopped painting. 'She realized instantly that she does not know how to go on.' (33)

'when he came inside for lunch he found that his father had done no more than remove the old switch plate' (203)

Yes

Would you like to take up any of these activities again? Which ones?

No.

Do you need help accessing activities? What help?

How far can you walk?

Unable to transfer/walk independently. Will help. Not walk unaided.

Do you need a stick/frame etc?

Doesn't use

'shuffled forward with the jerking momentum of a man who knew there would be trouble if he had to stop and start again' (??)

Uses chair for more than few assisted steps.

Have you had any falls recently? Explain:

'Dad fell down the basement stairs again (71)

None recent.# NoF→GH admission.Slow rehab because ?memory loss

Who looks after your feet?

Home organises

Can you cut your own nails?

NH

Can you get in a car? Use a bus?

Just – but problems with seating-rising from an ‘act of sitting down was a loss of control, a blind backwards freefall’ (73)

Son can still manage → car unaided.

Do you have any problems taking your medication? What are they?

Staff administer.

Can you tell me what medication you take and why? (*concordance, understanding, memory, correct*)

***State list given by patient, state seen latest script and date.**

Dr H has him on a new medication (19)

‘canary yellow spansule for incontinence, the small Tums-like thing for the shakes, the white oblong to discourage nausea, the wan blue tablet to squelch hallucinations from the small pink Tums-like thing’ (381)

Galantamine P₂ given by Dr Tait.

Side effects or allergies?

None reported in notes/son. Staff will report if ↓ response to Galantamine.

Self managing?

‘I took my pill, I took my pill. I took my pill.’ (??)

Blister pack?

Compliant with medication?

Do you take any over the counter medication? If so what?

| | | |
|-----------------------------------|----------------|---------|
| Name: Ignatieff Franzen, Bragg | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

Physical health

Current physical Problems

Narrator thinks 'punched, drawn, even slightly stooped.' (28)

Patient view

How is your physical health?

Hard of hearing (5). Motor problems, 'padding at the air with loose hinged hands.(17) Dr H. diagnosed PD (140)

She thinks fine for age

Have you had any hospital admissions?

Unable to recall (See ref.letter)

For what & when?

In GH prior to admission to NH. Fall #NoF→rehab.↓mobility. OT felt not able to manage at home because of memory.

Do you see your GP very often?

NH call.

When was the last time?

On admission.

Do you feel fit and well today? If not please tell me why.

'I am increasingly bothered by my affliction' (115)

'Good days and bad days' (381)

"Yes dear I do'

Do you have any pain?

Says not.

Do you smoke? How many? (consider safety issues and health advice)

Non

Do you drink alcohol? How much?

Do you use any other substances?

NO!

Do you have any giddy turns or 'funny dos'? (Are they related to epilepsy, heart, diabetes?)

Episode in church reported ?TIA

NO but weirdly ambidextrous!(21) 'features would glaze over' and 'snap back' (27)

| | | | |
|---------|-------------|----------|--|
| Bowels | Incontinent | Heart | Cardiac medsBP/statin GP P _x |
| Bladder | Incontinent | Lungs | NR |
| Asthma | NR | Diabetes | NR |
| Thyroid | NR | Epilepsy | NR* breast lump. See ref.letter |

Did you have rheumatic fever as a child?

Son thinks not

Have you had any trauma to the head? Any boxing? Any KO? Details?

RTA- hit head. Concussed. 'My mother's head is flat against the chrome radio, as if she is listening with her ear pinned to the sound.' (36)

Have you had any illnesses abroad? (*malaria*)

Do you have any problems with your sight? Details?

| | | |
|-----------------------------------|----------------|---------|
| Name: Ignatieff Franzen, Bragg | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

Do you have any problems with your hearing? Details?
 "he couldn't hear her shouting back' (5)
 Still able to hear conversation at ordinary volume.

Have your eating preference changed? (*preference for sweet things, eats anything*) Details?
 None reported

Do you feel your taste has changed?

Do you feel the cold more?
 Yes

How do you sleep?
 Sleeps more, 'naps deepened' (10)
 Sleeps well (staff) & she says she does

Bed time?

Getting up?
 Staff let her lie in=b'fast in bed then get her up.

Do you feel rested?
 Snoozes a lot.

Any recent changes?
 Hb wakes to the 'sound of mother tip toeing about in their bedroom' (42) Can't be persuaded to come upstairs-
 'convinced she has to stay waiting for someone' (42)

| | |
|---------------------|------------------------------|
| Problems with skin? | None reported by staff. |
| Bruises easily? | None reported. None visible. |
| Cuts? | Ditto |
| Rashes? | Ditto |

| | |
|---|----------------------------------|
| Altered Sensation(<i>numbness/tingling</i>) | Says not. |
| Pressure Areas(<i>If appropriate</i>) | Staff report intact |
| Smell (gas) | Poor / none / good / not as good |
| Smoke Alarm? | NA |
| Carbon monoxide? | |

Have you had your blood pressure and pulse taken recently?

On admission. Staff monitor per GP request.

If not within 6 weeks take new BP and pulse.

BP:

Pulse: ✓

Psychological Health

Previous contact with MH services? (pt or family)

None reported

Nil reported

None

Any recent changes to mood?

'all the time now she looks frightened.' (45)

She says no

| | | |
|-----------------------------------|----------------|---------|
| Name: Ignatieff Franzen, Bragg | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

Low mood/depressive episodes?

'I've suffered from depression all my life' (23), same, 'flat voice' (98)

Denies

Thoughts about self harm? (or harm to others – verbal or physical)

None reported

'Absolutely not –why should I?'

GDS/STORM needed?

No

Can you relax?

Oh yes

History of anxiety or worries?

Less willing to settle at night. See earlier comments.

Agitated at prospect of travel (12)

'My husband gets strange at night, sometimes' she said, averting her eyes, 'very agitated and difficult' (367)

None reported

HAD needed?

No

Seen things that others cannot see/hear or believe things others think odd? Details.

Nighttime- waiting for someone 'she can't say whom.' (42)

Dr Hedgpeth worried about hallucinations (20)

'I thought I saw children. No sunflowers' Enid said, 'You saw sunflowers' (146)

'whispering conspiratorially that he's seen a t**d run between the beds' (363)

No –denied, non reported by staff

OCD symptoms?

'checking his watch incessantly' (199)

Nil

Memory

Changes in language? (*quality of conversation, sentencing*)

'where's that thing...you...flip...things...with?' (33)

Loses thread 'I am-' (12)

Can be v chatty at times.' Surface' -cocktail party.

Changes in personality? (*check with others present*)

No longer conversational in company 'little beyond Yes and No.' (45)

Always been stubborn 'I have made my decision' (176). Since retired 'couldn't get interested in life.'(5)

Staff report she is as ever.

Repetitive questions?

Repeats spatula question 'And then a third time.'(33) 'I lost track at sixty three' (44) 'We ring the bells over and over in the same sequence.' (46)

How does your memory affect everyday life?

'First the glasses, then the purse. Then the shoes.' (32) Old memories still well preserved (40). 'She remembers captions of New Yorker cartoons.' (40)

Gets disorientated (13), a 'little confused sometimes' (243) 'He's pretty sharp' (Denise:243)

+++ but easily reassured

If there's a crisis what would you do?

- Main meal yesterday
- Family news and network (*remember who's who and what they're up to?*)
Not able to recognize Jack as grandson 'who does he belong to?' (45)
- TV remote controllers
- ATM
- Own appointments
- Misplacing items
SPECS! 'Have you seen my glasses?' (31)
- Central heating
- Household appliances (e.g. kettle, washing machine, cooker, microwave)

VVV supportive environment so few demands.

Any memory disasters?

No longer able to set table (44)

Had wandered from home.

| | | |
|-----------------------------------|----------------|---------|
| Name: Ignatieff Franzen, Bragg | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

Does the family have any concerns about the person's capacity to make sensible and logical decisions about important issues? (*moving house, finances*) Yes/No YES Enid/Gary/Denise disagree about Alfred's approach to his patents and buy out ?? rationality

'Are you saying this is an issue of competency? No this is fully in character' (??)

Yes

These are :Not able to understand finances/risk any more

Do you have any concerns about the person's capacity?

These are: *understanding* ✓
 retaining ✓
 weighing ✓
 communicating in detail

NOW DO ADDENBROOKE'S (ACE-R) OR MMSE TEST

Able to read 'does so in a childlike singsong, without inflection, unaware that the words are forming into meanings' (47)

Action

Does the person want to be told if they have a diagnosis?

Not addressed at asst. Son aware of diagnosis.

Do they give permission for their memory difficulties to be discussed with anyone else? Who?

Yes with son

Onward referrals:

Consultant Y/N

What are the key issues for clinic? *Has been seen*

Social services Y/N

| | |
|--|-----|
| OT | Y/N |
| Carer assessment | Y/N |
| Other? | Y/N |
| Assessment summary or outcome: | |
| Liaise with NH staff to commence Galantamine. Monitor regularly. Phone. Visit. | |
| Who else can we talk to about your memory? | |
| My son | |

| |
|---|
| Could you come to clinic at short notice? |
| Dr Tait will review in 6mths in situ. |

Print Name: ...KATE LATHAM ...Clinician/reader.....

Date: 2014-2015

Signed:

NHS No:

G:\MemoryService\Initial assessment\CMS Assessment 12 06 12.doc KA Version 10

The clinical template was not designed for texts but for patients who would normally be asked to tell their own story using the guided questions on the template. Patients are usually able to elaborate and expand their answers and talk about their experiences in a way that static texts cannot. The clinical information for both Mother and Mrs Andgrace is gained through other informants such as the Narrator and John.

Using this template reinforces the awareness that the reader only knows what the author chooses to tell us and is relevant to the narrative. This is in comparison to the clinician who needs to know what is important for diagnosis and the impact of their problems on everyday life so that the appropriate support can be considered. The clinical template reveals the most concentrated information from the texts as is

available to complete the section Psychological Health and in particular memory and language and the impact changes in these functions have on those around them.

3.4. Dialogical Narrative Analysis for the memoir fiction texts

The following template is derived from Frank's practice of Dialogical Narrative Analysis. It has been designed to mimic the clinical template and provide a similar systematic focus for questioning the text as the clinician using the clinical history template questions a patient. It begins with the equivalent of a patient's demographic data: author, publisher, number of pages and a subjective classification of the novel which place the text in a literary context, the equivalent of the socio-demographic data collected in the clinic. The reader is asked for information about the main characters in the novel, a summary of the plot and a rationale of why this text was selected for Dialogical Narrative Analysis. In the clinical template equivalent information would be contained in the referral letter. The DNA template then asks the reader to respond to which of Frank's capacities are at play in the novel before asking the key question of DNA. Numbers in parentheses refer to the page with the supporting evidence in the text. The DNA template moves beyond socio-narratological practice and focusses on the potential clinical relevance and appropriateness of the text for various groups. These questions provide the evidence for the patient information leaflets discussed as a research outcome in the following chapter.

Name: *Grace and Mary*

Lakeside

Author: Melvyn Bragg

Literary

Publisher: Hodder & Stoughton

Trust

Date: 2013

Pages: 249

Referred for:

Dialogical Narrative Analysis

Classification of novel: Serious fiction. Memoir fiction

Characters present: Mary, Grace, Mary's mother, John, Mary's son, Dr Tait, Consultant Psychiatrist.

Summary of the plot:

The story is told from the point of view of rather bookish intellectual John, whose mother Mary is in a nursing home in Cumbria. Mary is the daughter of Grace of whose life John is ignorant other than as someone who left a 10/- note in an envelope on her infrequent visits. John reconstructs Grace's story and Mary's illegitimacy to further understand his mother's plaintive plea for Grace as her memory progressively fails and she sinks into physical frailty and dementia.

Why has the novel been selected?

Bragg is an only son and has spoken in press interviews and at a literature festival about the experience of watching his much loved mother's decline with Alzheimer's disease. It

is a novel which portrays the most common form of dementia: Alzheimer's Disease in the context of very old age. Mary does not only have memory loss but eventually has the multiple pathologies of great age. She cannot walk, feed herself or dress and needs incontinence pads. Such honest difficulties are not laboured but accepted. Of the memoir fiction selected it is the most clinically veracious and the source of the most complete set of faux notes.

What capacities are at play in the novel?

- Trouble

The cognitive and physical decline of Mary.

- Character

The close observation of his mother's decline tests John's character and forces him to think about issues of heritability, ageing and familial duty. He asks these in a series of rhetorical questions throughout the novel.

- Point of view

A single deeply sympathetic point of view.

- Suspense

This capacity is not in play. The end of the novel is assured.

- Interpretive openness

The limited cast of this novel and the single point of view restricts the interpretive openness but increases accessibility to the reader. John makes clear whose story is being told and why from the outset.

- Out of control

Nobody and nothing is out of control. The novel demonstrates a steady and inevitable decline towards death without histrionics or angst. Both Mary and her son John accept that she is at the end of her life and that what is happening is sad, but natural. It describes decline through non mawkish descriptions of physical frailty. What Bragg describes in the text tallies with what he has talked about openly in the press.

- Inherent morality

The response to Mary's diminishing memory allows John to demonstrate the depths of his familial love whilst agitating about whether he is doing his best for her by placing her in a nursing home. Would his mother be better with him in London? (21) The novel is inherently decent and demonstrates the best sort of nursing home care where zero-hours contract would be unlikely.

- Resonance

The text is a straightforward double narrative structure.

- Symbiotic

Frank states that stories work 'first with people, but also with objects and places' (Frank 2010: 37). In *Grace and Mary* place is important because it holds Mary's past and gives her access to her memories which would be unavailable elsewhere (47-48). The trip from the nursing home to provide fun and pleasure (181-187) can be compared with the 'fall color cruise' and Alfred Lambert's trip home for Thanksgiving in *The Corrections* (Franzen 2001). John's trip is not wholly successful because 'he had hoped for a revelation and staved off disappointment' (186) but, unlike the cruise, is offered to Mary when it is still, just, within her physical capabilities.

- Shape shifting

Not in play.

- Performative

The most significant performative property is in the generation of a realistic sympathy for all the characters.

- Truth telling

The novel tells essential truths about trying to care from a long distance, being a regular visitor and decision maker about care and the white lies of confabulation. Mary repeatedly asks when she will be going home (22) and John never tells her that the house has been sold and that she will never return home (46). Text books on dementia care might promote truth telling but in the moment we are probably likely to err on the side of the kind white lie.

- Imagination

The novel lyrically demonstrates how the past is a continuum that informs our responses to the present until the end of life. Whilst more benign, realistic and kinder than the other memoir fiction texts it is what all the memoir fiction does, it fulfils.

What particular work does the story have the capacity to do?

What does the story make narratable?

Grace and Mary tells about the realities of very old age. Bragg makes an elderly lady in a nursing home 'claimsworthy' not only to John but the reader. Mary is not portrayed as angelic but rather doughty. Behaviour that has been resolute when fit and healthy now in dementia shows itself as apparent meanness when she plaintively asserts that John never comes to see her or forgets that he has already spent the day with her. John makes narratable the dilemmas many children face over the care of loved parents and the tedium of some visits (162).

Who is holding their own in story, but also, is the story making it more difficult for other people to hold their own?

The half of the narrative devoted to Grace's mother, not considered in detail here, makes the comparison between the bond between Grace and Mary and Mary and John. The bond between Grace and Mary, which is still present at the end of Mary's life as John tells his mother he is writing about Grace (246) could never be articulated or demonstrated because of Mary's illegitimacy. The bond between Mary and John has a natural warmth and intimacy quite unlike the creepy intimacy between the narrator and Mother in *Scar Tissue* (Ignatieff 1993).

Grace creates a meaningful and successful life as a teacher, but at a cost. Mary holds her own with determination and confidence in the community as a mother and widow which has fostered success, bookishness and intellectual endeavour in her son. John is currently working on a biography of John Wycliffe.

Like the narrator in *Scar Tissue* (Ignatieff 1993) John questions big issues, the nature of existence (200) the meaning of memory (199) and the possibility of inheriting a dementia. Unlike Ignatieff's narrator these do not lead to a tail spin of anxiety and depression. John holds his own by being grounded, the reader suspects, by the happy but ordinary childhood provided by Mary and rooted in place.

What is the effect of people being caught up in their own stories, whilst living with people caught up in other stories?

Whilst this is the most straightforward narrative of the three memoir texts there are three interwoven stories. Grace's is told in alternating chapters with that of Mary, a structure which intensifies the interrelatedness. Grace's story is told as a partly imagined, partly researched past whilst Mary's is told through prompting, reminding and recognition of place through the photographs in the book about old Wigton (97), the sight of daffodils and the day out.

John has to imagine much of Grace's story to make sense of Mary and I doing so 'reaffirms the value of the story teller' (Salley Vickers review of *Grace and Mary* *Independent* 14 June 2013).

What is the force of fear in the story, and what animates desire?

How we age, who will care for us and how we will be cared for are questions the culture asks us to consider. The media story is one of inadequacy of current services and help with the prospect of fewer and more stringent access criteria for what might be available in the future. *Grace and Mary* offers a model of positivity. Despite dementia and frailty Mary is cared for and cared about. Grandchildren breeze into see her and offer her an excitement that John in his regular visits is unable to do (162). The positivity is not mawkish or sentimental but indicative of the model of sewing what you will eventually reap. All the memoir fiction analysed portrays this through the use of the story of the family background to explain the responses to the present.

John's desire to be a more than adequate is presented through rhetorical questions which he answers with a realistic pragmatism.

How useful might the novel be at work in the clinical world:

- With patients

Can be read as an accessible and straightforward account of dementia in very old age written with sensitivity and compassion.

- With family/supporters

Reassuring about long distance care. Good about visiting and potential activities.

- With health professionals

Narrative provides a model of good care: how to give medication if the patient is unwilling to take it, following the needs of the patient.

From the evidence above which passages might be useful as photocopies in the clinic.

P 81. Honesty about old age.

P. 23, 97, 123, 168 Visiting- ideas for what to do and gives permission to have a short nap when doing so.

P. 144. The joys of singing when much else is lost. Contact through poems learned at school (169).

For Health professionals:

The text acts as a case study. The dementia portrayed is not dramatic or unusual and would be encountered by all health care professionals working in the NHS and social care. The text could be shortened by removing the chapters which relate to Grace which

maintains the focus on Mary' slow physical and mental decline.

Health warnings

No health warnings attached.

Signature of reader: Kate Latham

Date: February, 2015

Designation: Clinician/reader

Lakeside

Name: *Scar Tissue*

Literary

Author: Michael Ignatieff

Trust

Publisher: Chatto & Windus

Date: 1993

Pages: 199

Referred for: Dialogical Narrative Analysis

Classification of novel: Literary Fiction

Short listed for the Booker Prize 1993

Characters present:

Main characters.

Narrator, a philosophy lecturer. Narrator's mother, 'Mother', ex teacher and non-exhibiting amateur artist. Narrator's brother, neuropathologist. Narrator's father, soil scientist.

Secondary characters.

Neurologist. Narrator's wife and children. Moe, a patient with ALD, a form of Motor Neurone Disease who is a patient of the narrator's brother, Miranda, narrator's lover.

Summary of the plot:

Mother's slow decline into early onset Alzheimer's Disease is narrated through the eyes of her philosopher son. The author uses flashbacks and retrospective reasoning to reconstruct his parent's marriage and portrays a loving idyllic childhood. His older brother, with whom he is rivalrous, becomes a physician. The narrator describes himself

as 'tall, thin and of a gloomy disposition' (9) from whom words pour out in an 'anxious, self-justifying stream' (6). He teaches philosophy. Prone to intense introspection to the nth. degree he becomes increasingly absorbed in the nature of his mother's decline and probably over attached and enmeshed, with a surprising degree of intimacy, 'I put on my pajamas and get into bed with her' (46). After his father's sudden death Mother is placed in nursing care. The narrator is increasingly depressed, hypochondriacal and guilt ridden, although it is never clear why his mother's illness should have such a profound effect on him. The narrator spends increasing amounts of time with Mother and in doing so forgoes his marriage and loses his teaching position. After Mother's death the narrator manages a détente with his wife and a rapprochement with his brother. The two siblings demonstrate different emphases to illness. The physician brother understands the disease through science whereas the narrator understands his mother's illness as an examination of the self. The *Scar Tissue* of the title unites the two themes in that it indicates brain pathology and the illness as experienced by the patient which is built out of the accumulated experiences of the past.

Why has the novel been selected?

Ignatieff was the first novelist to transform his experiences of observing the decline of a parent with a dementia into fiction. Ignatieff had earlier written a piece, 'Deficits' for the Granta edition 'Death' (Summer 1989) which he reprised in the novel. It was the first 'dementia fiction' to describe the end stages of a dementia.

What capacities are at play in the novel?

- Trouble

The trouble that provides the narrative drive in the novel is Mother's early onset dementia which intensifies the tensions in the relationship between the two brothers.

- Character

The narrator's character is tested and found wanting. The portrayal of the Narrator's existential fear and guilt is solipsistic to the point of self-destruction rather than being sympathetic. Moe is cast as the counterpoint to the Narrator with his stoic stance, a position which he is able to articulate to the Narrator.

- Point of view

The Narrator provides the predominant point of view in the novel. The brother and the neurologist offer an alternative take on the nature of disease. The story is driven by the narrator but forces the reader to contemplate the legitimacy of his responses to the situation

- Suspense

Not at play. The novel begins with the death of Mother.

- Interpretive openness

The reader has to imagine why the narrator might be so enmeshed with Mother. The reader is forced to consider the Narrator as essentially over- attached and unable to make the bridge to mature adult hood where responsibilities shift from the parent to being a parent and partner. The reader has to question the appeal of Miranda as a nurturing mother figure who does have the maturity to bow out as superfluous to the Narrator's needs

- Out of control

Ignatieff's entry into Canadian politics in 2006 created a new interest in his writing. Questions about *Scar Tissue* went on to dog Ignatieff in his political campaigning. A primary criticism was that having lived outside Canada for over thirty years he had a lack

of attachment to the country and his commitment to politics was untrustworthy. *Scar Tissue* was read as a narrator, very similar to Ignatieff who was narcissistic and detached, which represented his political position and to 'accusations of self-involvement and disengagement' (de Falco 2012). She argued that 'the public persona constructed and criticized by Ignatieff's political opponents does indeed bear an uncanny resemblance to the narrative persona he creates in *Scar Tissue* and that this contributed to his short lived political career. She reports that his brother was unhappy with the portrayal of the family.

- Inherent morality

Scar Tissue raises issues about the nature of 'good' care by family and professionals. The neurologist is portrayed as seeing only the disease, not the person and Miranda as offering an intuitive response to the nursing needs of Mother. Ignatieff describes the difficulties in practising dialogically, 'The obstacles to trust, however remain enormous. The problem is how to build a relation between doctor and patient in which real individuals can exchange understandings, rather than re-enact the symbolic roles of parent and child. Crucial to this relation is a shared appreciation of the limited purchase of medicine upon fate' (67).

- Resonance

Scar Tissue is an important and powerful novel because it is unlike anything before in its portrayal of the viscerality and inevitability of the end of Mother's life.

- Symbiotic

The story works with the disease as a condition waiting to be told. The inevitability of dementia creates a narrative drive not of 'what happens' but 'how' it happens. Because there is no cure for dementia it inevitably demands accommodation from all those involved.

- Shape shifting

Decline is implicit in dementia so shape -shifting is not a capacity at play.

- Performative

As the first novel to tell of dementia from the early symptoms to death it enabled dementia to be named and described in subsequent fiction. Of the many performative functions of stories Frank describes *Scar Tissue* reports a dementia but, because the narrative is so concerned with the responses of the Narrator, the position of Mother as sufferer, is less sympathetic.

- Truth telling

Frank makes the distinction between technical accounts, for instance, the portrayal of

dementia in *Remember Remember* (McHaffie 2010) and stories which '*become* true as they are told' (Frank 2010: 41 Original italics). This story becomes true as it is told by the Narrator, even though the reader would like to shake the Narrator out of his self-indulgent introspection.

- Imagination

In the telling of Mother's deterioration Ignatieff makes visible, for the first time, the passage of a named dementia.

Scar Tissue (Ignatieff 1993)

What particular work does the story have the capacity to do?

What does the story make narratable?

The story makes narratable the disintegration of the self in two ways; through the cognitive decline of Mother and the maelstrom of emotional upheaval in observing it at close quarters. The Narrator navigates his responses to the changing relationship he must have with Mother as the dementia becomes more pronounced and she is less available to him. He loses his sense of coherence as a person and is aware of what is happening but is unable to help himself.

It narrates dying.

The Literature, Arts, and Medicine Database lists the keywords of the novel as: Adolescence, Aging, Art of Medicine, Caregivers, Children, Chronic Illness/ Chronic Disease, Communication, Death and Dying, Dementia, Depression, Disability, Disease and Health, Doctor-Patient Relationship, Empathy, Family Relationship, Grief, Hospitalization, Human Worth, Illness and the Family, Individuality, Loneliness, Love, Marital Discord, Medical research, Memory, Mental Illness, Mother-Son Relationship, Mourning, Narrative as Method, Nursing, Obsession, Parenthood, Religion, Suffering, Survival , Technology, Time, Women's Health <<http://litmed.med.nyu.edu> >[accessed 6 February 2015]

The novel provides a focus for all the aspects listed but the focus for this DNA is dementia. Just as patients arrive at a memory clinic with other conditions, for instance, arthritis or cardiac arrhythmia, the clinician acknowledges them but does not formally address them.

Who is holding their own in story, but also, is the story making it more difficult for other people to hold their own?

The Narrator barely holds his own.

Mother does not hold her own but her decline is driven by the heritability of faulty

neurones which the Narrator feels sure that he has inherited. The certainty is despite his physician telling him that it is too early to detect any evidence. The potential of detection of detection decades earlier than symptoms present has re-emerged as being prescient. The Narrator's brother holds his own by accepting any heritability whereas the Narrator rails against this as an insult to selfhood. Moe, holds his own through a thought through stoicism.

What is the effect of people being caught up in their own stories, whilst living with people caught up in other stories?

This is a fiction text but was read by the author's political opponents as autobiography. The bulk of the Mrs Ignatieff's care was provided by her husband and other son and Ignatieff's job as author was to 'get it down somehow' and to 'get a grip in the experience' (Personal communication). Although the narrator of the text is caught up in his story of observing Mother's decline that he is unable to consider or respond to other stories running concurrently, notably that of his wife and children, nor indeed of any story relating to Miranda, his lover and one of his mother's nurses. de Falco (2012) reports that Ignatieff's brother was unhappy with the voyeuristic tone of the novel.

The Narrator sets himself up as the only person who is responding to Mother as a whole person rather than the sum of symptoms. This is not a dominant narrative in relation to dementia with the result that he is presented as unsympathetic. The brother, as rational and scientific, is viewed as not acknowledging the minutiae of Mother's responses which the Narrator feels are still present and available to him as frequent, almost permanent visitor. The reader sees these responses as over involvement rather than indicative of heartfelt care.

The *Scar Tissue* of the title is an indication of marks that signify an event in the past which have left a wound or mark and is indicative in this text of the family dissension, rift and hurt that is the result of dementia. Scar tissue creates a change which the physical body works around and absorbs. It leaves the organ permanently changed but still functioning. A lesion, detectable only with a brain scan reminds the family that they were all involved in a car crash when Mother hit her head on the dashboard. A child writes a sentence on a blackboard, rubs it out and repeats, the tyre tracks of the ambulance after the sudden death of the father and most poignantly the father's unfinished sentence in the typewriter become lost objects which signify both the impossibility of trying to hold everything as important and its converse, a cultural amnesia where everything is forgotten in relation to the importance of the present.

What is the force of fear in the story, and what animates desire?

Heritability of the dementia is the overriding force of fear in the novel. The Narrator creates and diagnoses himself as inheriting the dementia which has affected his mother, grandmother and great grandmother. He confuses heritability with fate and rather than turning to the 'adventure before dementia' motif the reader foresees for the Narrator a lifetime of misconstruing every slip of action, the everyday errors made multiple times per day, as the start of the disease.

Heritability of a dementia is an issue for offspring and he is realistic in his concerns given the increased risk of inheritance in an early onset development of the disease.

How useful might the novel be at work in the clinical world:

- With patients
Not a recommended read for patients.
- With family/supporters
Likely to be an acquired taste for this group. Narrator is too annoyingly egocentric to be sympathetic. Does not behave in a manner a clinician could be seen to condone.
- With health professionals
Interview with neurologist provides a good teaching vignette (J. Gen Intern Med.2011 Apr; 26(4): 435-455. Published on line 2010 Nov. 20 [Accessed 5-5-15]

From the evidence above which passages might be useful as photocopies in the clinic.

Not for clinic use.

For Health Professionals: Consultation with neurologist p 55-61.

Health warnings

The novel begins with a depiction of a gruesome death, 'she fought for life and lost, her mouth stretched open, gasping for breath, her eyes staring sightlessly up into the lights' and 'that frail body wracked with spasms, those lips wry with blood' (Ignatieff 1993: 1)

Signature of reader: Kate Latham

Date: February 2015

Designation: Clinician /reader

Lakeside

Name: *The Corrections*

Literary

Author: Jonathan Franzen

Trust

Publisher: Fourth Estate

Date: 2002

Pages: 653

Referred for: Dialogical Narrative Analysis

Classification of novel: Literary fiction. Memoir fiction.

National Book Award

James Tait Black Memorial Prize

Characters present: Alfred and Enid Lambert, Gary, Chip and Denise Lambert.

Summary of the plot: A saga of a mid-western disjointed family. Alfred, a domineering patriarch develops an increasingly complex neurological disorder. Enid, his frustrated and angry wife tries to maintain normality whilst machinating to have a last family Christmas together after their cruise to see the autumn colours of New England. The narrative drive of the novel is provided through the interlocking novellas which give the backstory to each of the main protagonists which reveal to the reader how they have reached their respective positions á propos the illness. Each novella has a slightly different structure and could be itself subjected to a DNA. This DNA is restricted to the sections of the novel directly related to Alfred and Enid and to each of the characters as they relate to their parents.

The narrative follows Alfred from the early symptoms to his death.

The Corrections is a big, social novel which engages with mainstream American culture.

Why has the novel been selected?

In his selection of essays '*How to be Alone*' which celebrates being a writer and a reader, Franzen writes about his father, Earl Franzen's illness. In the essay 'My Father's Brain' he describes the demise of his father in the 'slow motion way of Alzheimer's' (Franzen 2002: 38) in which 'Even as the surviving parts of his self grew ever smaller and fragmented, I persisted in seeing a whole. I still loved, specifically and individually, the man who was yawning in that bed. And how could I not fashion stories out of that love' (ibid: 36).

The Corrections is the story fashioned out of that experience of observing and being involved in the terminal decline of a parent and in doing so Franzen fulfils his desire to write books that 'ordinary people, non-professionals, could connect with' (Paris Review no 207).

The Corrections (Franzen 2001)

What capacities are at play in the novel?

- Trouble

The key trouble in *The Corrections* is loss of control. It is most obvious in Alfred's dementia and tremor and hallucinations. Other characters also display a loss of control in their relationships. Enid however gains an increasing sense of control and never ceases to try and correct Alfred, 'She had to tell him , while she still had the time, how wrong he'd been and how right she' been'(653).

- Character

Alfred's gradual deterioration tests the character of all the protagonists.

- Point of view

The internal novella structure allows the reader to be sympathetic to each characters point of view. As each back story is told the point of view of each character becomes compelling and increasingly plausible.

- Suspense

One of the narrative threads in the novel relates to whether Enid will get her family Christmas but the strongest suspense lies with the reader. Only the reader knows the intensity of Alfred's problems and the prospect of a cruise seems increasingly bonkers and ill intentioned.

- Interpretive openness

Alfred's 'fall' from the ship is left open to the reader's interpretation. That the reader, like the characters, is unsure exactly what happened creates the ambivalence about Alfred's position at the end of the novel and his plea to be relinquished from his misery.

- Out of control

Frank states that 'Stories have the capacity to act in ways their tellers did not anticipate' (Frank 2010: 35) *The Corrections* was chosen for Oprah Winfrey's televisual 'book club'. Franzen describes his unease with what this entailed in his essay 'Meet me in St Louis' (Franzen 2002) after which dramatic rescinding of the invitation appears both inevitable and a relief. He had already had his book described by one of the producers of the show as 'a difficult book for us' (ibid: 289) and his responsibilities as an Oprah author outlined

to him. As a 'grumpy Manhattanite' (ibid: 287) with 'uneasy relations with authority' (ibid: 289) and after his fatigue-driven conflation of "high modern" and "art fiction" to "high art" he is disinvented because he seems "conflicted" about the calibre of books normally chosen for the show. Franzen was subsequently pilloried for his apparent ingratitude and although 'I'll repent and explain and qualify, to little avail' (ibid: 300) he 'had committed perhaps the worst American sin, elitism; and the second worse American sin, a lack of proper respect for the forces of commerce' (Wood, *The Guardian* 9 November 2001).

- Inherent morality

This novel takes the stance that actions are rooted in the experiences of the past and that the position taken is relative. There is not a correct response to a parent's dementia only the response that one is allowed. Franzen has been open about how he responded to the demise of his parents.

- Resonance

Wood (*The Guardian* 9 November 2001) describes *The Corrections* as a 'Bleak house of the digital age' and 'the slightly damaged child of Don DeLillo's peculiar relationship with American culture and a 'kind of glass-bottomed boat through which one can glimpse most of the various currents of contemporary American fiction: domestic realism; postmodern cultural riffing; campus farce; "smart young man's irony" of the kind familiar in Rick Moody and David Foster Wallace; and, rather too often, an easy journalism of style.' Franzen acknowledges 'the visual influence of the dinner table scene in *The Corrections* that I wrote immediately after reading *Underworld*.' (Paris Review 207) and *Infinite Jest* (Foster Wallace 1996) on the 'gerontocracy of St. Jude, based on some mid-western houses that I happened to know well'.

- Symbiotic

'The most evident symbiosis is between stories and the people who tell them' (Frank 2010: 37). In his essay writing and Paris Review interview Franzen has been open about the links between the experiences of his family and those portrayed in the novel, 'it became all the more true in *The Corrections*: Precisely then, when I needed to focus all my attention on writing a novel, my parents were falling apart.'

- Shape shifting

Alfred's hallucinations fulfil this capacity. On the cruise he is 'straining to hear past the boundaries of his self' (325) as he responds to someone else in the bedroom who proceeds to torture him over the following pages. He is eventually able to acknowledge the unreality and absurdity of the situation 'an American executive sitting in diapers on the floor of a floating bathroom under siege by a squadron of feces. A person got the strangest notions late at night' (331) and that 'he had been dreaming and that the source of his anxiety was simply a drainage problem' (332). This is clinically accurate for the

hallucinations of LBD which are intense, often fleeting and hover between the real and unreal but remain a compellingly believable experience.

- Performative

The Corrections reports the development of a complex dementia, convinces about family relationships and amuses with comedic interludes of haplessness. For a supporter of someone in the throes of LBD and PD it could provide insight into the lived experience of hallucinations and the impact of tremor on every-day activities and instruction for health professionals about them.

- Truth telling

The text tells an essential truth which is not an exact copy of Franzen's experience. Rather it tells a truth which has been enacted elsewhere, in the Franzen family home. In telling the truth as a story, a fiction, the full significance of the truth of the story is revealed through the many capacities at play in the novel.

- Imagination

The Corrections makes 'the unseen not only visible but compelling' (Frank 2010: 41) by ensuring that the reader understands the horrors of the hallucinations that Alfred is unable to articulate.

What particular work does the story have the capacity to do?

What does the story make narratable?

The length of the novel and its structure allows the development of a neurological condition of unknown aetiology to be told in detail until death. Symptoms unfold throughout the novel mirroring the reality of the lived experience of such illnesses. Only with hindsight might it be apparent when symptoms first developed. Similarly, the novel's structure allows the dementia to be placed in a matrix of overlapping lives. Dementias do not happen to only one person but impact on a whole family or support network and the novel makes narratable the permission to respond to the illness in a manner which is less than perfect and driven by circumstances rooted in the past of family life. That all the characters are flawed and not necessarily likeable allows the novel to reflect the realities of family life and creates the humanity of the novel.

For the clinician the structure of the novel, its extended time frame and novella length chapters allow the clinician/reader the equivalent seeing a patient for follow-up appointments with different family members over the course of the illness. It is in these interviews when the various stories within the family become most apparent.

Who is holding their own in story, but also, is the story making it more difficult for other people to hold their own?

Alfred's gradual decline makes it progressively more difficult for each of the characters to maintain their usual modus vivendi and forces them into compromise and cooperation. Frank explains that 'one person's work of holding their own often becomes the threat against which someone else must hold his or her own.' (Frank 2010: 77). *The Corrections* can be read as Alfred's lifelong determination to hold his own position in both professional and family life. He is as recalcitrant about pursuing an increased financial payment for his patents as he is about refuting Enid's need for a demonstration of affection. A centre of Enid's story about Alfred is that he left for a business trip without kissing her goodbye. Through Alfred's illness the novel charts his progressive inability to hold his own as the power and control in the household and the marriage moves to Enid. Increasingly overwhelmed by his symptoms Alfred acknowledges that 'holding his own'

has diminished to managing his continence and that 'hourly stops [had] the added virtue of lending structure to his life. Simply holding things together— simply keeping the ocean of night terrors from breaching the last bulkhead— was his ambition now' (382). The skirmishes en route to the shift in marital and family power provide the dark comedy of the novel. It is Chip, who although first portrayed as the most hapless of the children, is eventually identified by his siblings as the '*beloved*' child who 'brightened the old man's face' (629.) As Alfred is less able to hold his own Chip *comes into his own*. Similarly Enid sees the potential to hold her own. Although loving Alfred, she has felt constantly let down by him. She is still trying to correct Alfred at the very end of his life and he remaining staunchly unaccepting of such corrections 'All of her correction had been for naught. He was a stubborn as the day she met him.' (653) Enid finds in his death that 'nothing could kill her hope now, nothing. She was seventy-five and she was going to make some changes in her life' (653).

What is the effect of people being caught up in their own stories, whilst living with people caught up in other stories?

The Corrections is a family saga. Long chapters, the length of a novella, are allocated to each of the main protagonists through which the reader sees the impact of living with Alfred on their childhood and current position. Chip's backstory is told in *The Failure*, Gary's in *The More He Thought About It, The Angrier He Got*, and Denise's in *The Generator*. This internal structure of the novel allows a different reading of the same events to emerge enabling each member of the family to become 'claimsworthy' (Frank 2010: 75) creating conditions of 'enrichment or diminishment' (ibid: 75) and maintains the value of each characters subjectivity. Such framing allows the reader to maintain a dialogic position towards each of them. Each character has story of events which is largely incomprehensible, and irrational, to the others. Enid does not believe Alfred is as ill as he makes out. Denise thinks her mother is not sympathetic or understanding. Gary thinks that Enid is in denial about how they are managing in St. Jude and wants them to move to smaller accommodation. Denise supports Chip with cash when required but Gary thinks Chip is a waster. Denise and Gary explore the possibilities of accessing an experimental medication for Alfred. Each child has a different take on the prospect of a family Christmas. Like many families each element is tied up with their own life until there is a drama which propels everyone, in the second half of the novel to compromise and rapprochement even as Alfred loses his abilities.

The episode in the childhood of Gary and Chip over the meal and the dislike of liver and rutabaga (298) is the clearest example of each character fulfilling what they need to do with their own stories. Enid claims that she 'could live on nothing but vegetables' (298) whereas Alfred loathes rutabaga but puts 'bite after bite of vile Revenge in his mouth, chewing quickly and swallowing mechanically, telling himself he had endured worse than this' (298). Chip cannot finish his meal because the rutabaga made his 'guts convulse in a spine-bending gag reflex' (298) whereas Gary claims to love rutabaga. Alfred helps Chip out with a 'single action of fork removed all but one bite of the rutabaga. He loved this boy, and he put the cold poisonous mash into his own mouth with a shudder' (299). Enid does what she thinks Alfred wants her to do, which is make Chip sit in front of what remains on his plate for the following five hours and twenty pages of the novel. Alfred unable to move from his position feels guilty about what has occurred but does not know how to resolve the impasse. The meal highlights the emotional responses of each character and signals events and the individual responses to them which run through the narrative: Gary 'never forgot anything' (316), for Enid 'what you discovered about

yourself in raising children wasn't always agreeable or attractive' (302) and there was something 'almost tasty and almost sexy in letting the annoying boy be punished by her husband' (302). Chip has seen Gary deal with the food he didn't like and knows he could do the same but 'refusal had a flavour for which a taste could be acquired' (305). Alfred's sense of isolation within the family that 'maybe every "real" thing in the world was a shabbily protean' (315) suggests a precursor to the hallucinations which are to torture him later in life.

Alfred's story, which has been the battle of his adulthood, of maintaining his probity, and after retirement and his health starts to fail, his privacy. He asks Gary 'again not to meddle' (200) when he challenges his father about the future in St. Jude. The centre of the story is not merely about coping with illness, it is about standing within the family hierarchy and the unspoken rivalries as each vie for Alfred's unconditional approval.

What is the force of fear in the story, and what animates desire?

Franzen claims in his Paris Review interview 'the fear out of which the book was written was that the new materialism of the brain, which has given us drugs to change our personalities, and the materialism of consumer culture, which provides endless distractions and encourages the endless pursuit of more goods, were both antithetical to the project of literature, which is to connect with that which is unchanging and unchangeable, the tragic dimension of life.'

The fear which unites Gary and Chip is the fear of being anything like their father. Gary vows to create a better work/family balance than his father and Chip becomes a good supportive son. What Denise fears is being placed in a position in which she will have to relinquish her east coast cooking life and retreat to the mid-west to look after ailing parents.

The awfulness of LBD is not understood or acknowledged by others. This is partly because Alfred does not tell people what is happening to him. However this is not a family in which a dialogical position is valued or understood. Each family member is entrenched in a monological position. As the illness of their father becomes more apparent the siblings are able to 'correct' to more dialogic positions. For Enid no correction is possible because Alfred is unavailable to change because of his illness and although she tries both remain 'uncorrected'.

The Corrections (Franzen 2001)

How useful might the novel be at work in the clinical world:

- With patients

In demonstrating that others have experienced hallucinations and struggled with tremors. Novel solutions to fears e.g. carrying a Macintosh.

- With family/supporters

To explain why issues such as seating, having tremor friendly food and fear of incontinence makes people do weird things.

- With health professionals

As a teaching resource using Augmented Narrative Analysis.

From the evidence above which passages might be useful as photocopies in the clinic.

pp 74-75. The importance of good seating and the difficulties in getting the person to use what is suggested when they prefer comfort.

pp. 76-86 What not to serve for a person with a tremor.

pp-77. What tremors might feel like to the person experiencing them.

pp. 145-146. Hallucinations happen at unhelpful times.

Health warnings

Pp. 627-653

The end of Alfred's life is tempestuous and harrowing. He asks Chip to help to hasten his end. This may well raise ethical issues if recommended by a clinician.

The descriptions of the hallucinatory turd might be offensive to some readers, but may be reassuring to patients who are experiencing hallucinations of a similarly coprophilic

nature.

Signature of reader: Kate Latham Date: February 2015

Designation: Clinician/reader

In comparison to the clinical template the DNA template, understandably, reveals Frank's **work** of the text. It is a template using categories and constructs designed for stories, not patients, and can be fully completed for each of the texts. Using the template highlights the relevance of the capacities for understanding the work of the text and as a precursor for answering the more abstract questions of DNA.

What the DNA does more fully than the clinical or Close Reading template is demonstrate that dementia is a social illness because it happens to a person who is in relationships with others.

3.5. Close Reading of the Memoir Fiction texts

Charon describes her Close Reading as the equivalent of 'reading' an x-ray by which the reader moves sequentially through specific aspects of the text. The template has been developed using the headings of Charon's Close Reading drill. It begins with Frame which locates the text in the culture, then considers elements of the form of the text. This is followed by an analysis of how time is handled in the text, then a synopsis of the plot before ending with a section Desire. It is deeply rooted in the systematic clinical examination taught in medical schools. The Close Reading template emphasises the structure of the narrative and how the story is told. This is facilitated by the use of literary constructs rather than the open sweep of the DNA questions which reveal the key elements of the narrative.

| | | |
|--|--------------------------------|-------------------------------------|
| Title: <i>Grace and Mary</i> | Author: Melvyn Bragg | Date of Publication: 2013 |
|--|--------------------------------|-------------------------------------|

**Narrative
Medicine
Charon's Close
Reading**

Frame:

Glimpses of Mary's emotional wellbeing are offered but the story is told through the eyes of her son John. Half the novel refers to Mary's illegitimacy and early life which are not addressed in this assessment. This background explains the importance of social standing in the community and being 'posh'. It explains why Mary had opted for never used fish knives as a gift rather than a prodded rug when she had left the factory. John pursues the topic with his mother who eventually admits it was, 'Swank! Just Swank!' (80). John finds succour because his mother is looked after by people from her own community in a building which she knew and was once 'posh'. Rather than exposing deficits in institutional care this novel describes it as being exemplary.

Form:

- Genre

This is Bragg's twenty first novel. His writing is solid 'mainstream' fiction which is given literary reviews. He has won the John Llewellyn Rhys Prize and has had two Booker Prize longlist nominations.

- Visible Structure

The novel consists of 26 chapters. Grace's story is 'nested' within the text as a story that John is writing and reads to his mother as a means of offering succour to Mary when she yearns for her 'real' mother Grace. John tells his mother a story about what her long dead husband would be doing that day to comfort her at the very end of her life. John uses stories to tell Mary 'what she knew and had forgotten.' (103)

- Narrator

John relates the story of his mother's life and decline into dementia. He asks rhetorical questions about the nature of memory, the self, imagination and identity. He imagines what he cannot know. John is exemplary but not saintly. He briefly contemplates whether he should hasten the end of her life and 'turn off the switch' (200).

- Metaphor

Dementia is portrayed as the opposite to sensible articles which have 'a brisk beginning, a clear argument, and a firm conclusion confidently ordering wholly comprehensible worlds' (163). Bragg uses description++ to root the situation in the particular 'her hands were a quilt of dark stains on silken, thin skin' (144).

John constructs the story of Grace as an edifice against the depredation of Mary's dementia.

- Allusion

To Bragg's own genre of well written, accessible novels, 'If you didn't believe in a character how could you possibly go on?' (220)

- Diction

Displays his knowledge of the Cumbrian dialect (37). Uses colloquial language e.g. 'banty hens' (58), 'up to speed' (161).

Time:

- Tense

The novel is related in the past tense.

- Order

The chapters interweave the stories of Grace and Mary.

- Story time
- Discourse time

The novel addresses the use of history through photographic record e.g. *Wigton Revisited* and John's biography of John Wycliffe.

- Velocity

The decline of Mary paces the novel's structure. As she becomes frailer and John's visits are more about watching rather than entertaining Mary he is contemplative about the nature of time and personal history and the relevance it has for the person 'her past appeared to be an ocean of unknowing' (199).

Plot

This is a story about place and the stories they hold for people across time and the generations. John tells the interwoven story of two resolute and stoic women, Mary, his mother, and Grace, his grandmother and in doing so offers a social history of rural and market town social and cultural mores in the twentieth century.

It addresses how a son, previously reticent and respectful about aspects of his mother's past, uses stories he knows she knows, to maintain her accessibility to him. Bragg draws on tropes of family life and objects to elicit and rehearse stories familiar to them both such as John and Mary hiding in Mrs Johnston's 'forage cupboard'.

Desire:

What was satisfied in you by reading the text?

This is a non-mawkish story about a profound filial love of an only son for a mother. The stigma of illegitimacy and the harsh position of family members and the community towards Grace contrasts with the affection and care Mary is shown within the care home where she is cared for by local people from the same community. The novel is moving because the dislocation of Mary and her mother is not repeated by John and Mary.

What seems to be satisfied by the writing of it?

John (or Melvyn Bragg) documents the life of a much loved parent.

Signed: Kate Latham

Date: July 2015

| | | |
|----------------------------------|----------------------------------|---------------------------------|
| Title: <i>Scar Tissue</i> | Author: Michael Ignatieff | Date of Publication:1993 |
|----------------------------------|----------------------------------|---------------------------------|

Narrative Medicine

Charon's Close Reading

Frame:

This novel predates any treatment for dementia and is brutally honest about the emotional the increasing absence of his mother's selfhood had on the narrator. Mother has no meaningful voice in the novel which is solely that of the narrator son. The novel raises issues about the nature of care: where we care, who cares and how we care by presenting polar opposites .The lot of Mother plays out against that of Moe, the empiricist brother versus the philosopher brother, the all competent and compassionate Miranda versus the wife who (quite reasonably) tries to break the obsessive nature of the narrator's involvement with his mother, the neurologist versus the philosopher.

Form:

- Genre

Novel. Beginning sets tone-'How do I tell her story?'(1) 'How to live with what we know' (5). Offers a 'time capsule' (9).

An account of how a person and a family cope with an early onset dementia. It is dated by the scanning techniques described, the self-help books described (62) and the citation of Susan Sontag.

- Visible Structure

Short untitled sections which contain amidst the linear narrative: the script of a lecture 'Illness and Stoicism' (64), start of a paper on de Kooning(149), book draft manuscript (174) and newspaper clippings (185) which relate to dementia and the narrator's state of mind.

- Narrator

Omniscient narration. The dementia is seen only from his point of view. Uses the methods above to offer alternative positions on dementia. Sounds depressed 'thin and

of a gloomy disposition' (6) and eccentric (stands on head to ward off dementia) 'I still do' (7). Egocentric and introverted 'my longing to have some kind of expressive or examined life' (25) Narrator is not likeable and self-obsessed. Abandons his own family to care (? too intimately) for his mother. Attachment issues.

- Metaphor

Scarring of the brain and the psyche. How events imprint indelibly on the self as 'scars' or paint on a canvas(171). The painting over the pictures (168) reflects the blurred existence and fog of a dementia Inheritance, fate and fear of them both. 'The one thing we cannot do is duck' (6). 'Accepting death would mean giving up on the metaphor as life as narrative.' (68) Describes life as a 'gravity wall' (!?) which 'I had pulled down with my own hands' (115). Broken necklace beads (75) =dementia (later picked up and taken home- fits with the inheritance theme).

- Allusion

Time capsules (v memory boxes?) Lost souls in purgatory (22) Sontag's Illness as Metaphor quoted in his lecture (67)

- Diction

Portentious (? overblown) 'We are programmed to betray' (4).

Deeply melancholic. Meditative. Not readily accessible reading.

Time:

- Tense

Use of intermittent present tense heightens the retrospective elements. Death of hb/father is dealt with in the past tense.

- Order

Begins with the death of the mother. Time frames shift as the narrator recollects aspects and events of family life.

- Duration

The narrative covers an indeterminate amount of time in the narrator's.

- Story time

For the mother time with accelerated ageing 'ageing has an infinity of gradients', she was 'slipping down a step ramp' (28). For the narrator, in contrast, 'So it went, the tear in the fabric of my life was getting larger year by year' (43).

- Discourse time

Dislocated within the novel, however, the text covers the complete progress of dementia and its aftermath for the family.

- Velocity
Slow and reverential.

Plot:

Begins with death of a parent, with early onset dementia (1).

Details the response of the narrator, his brother, his father and the narrator's wife's to the dementia and death.

Describes the symptoms of the early stages of the disease and decline, 'sometimes it is as if she has decided to take a vacation from me' (48).

Narrator contemplates (but does not) suffocating his mother (51).

Narrator uses mother's condition to explore issues of selfhood and memory through various genres of writing and self-reflection.

Husband's death precipitates narrator's mother into full time care.

Describes the selection of a home and the placing in care of a parent.

Narrator starts to uncouple himself from job and ultimately his own family.

Truth is told about death and its aftermath.

Miranda triangulates the position of caring with that of brother and narrator (126).

Narrator remains adamant that in the end stages of dementia personhood is retained.

Desire:

What was satisfied in you by reading the text?

That family can trump intellect and that intelligence is no guarantee of getting it right e.g. offering gun to son.

The clinician/reader wanted him to have some treatment for his undiagnosed depression.

Introspection is not always good for the soul.

What seemed to be satisfied by the writing of it?

'a vain exorcism of the spirits' (48).

Explores the saying of the unsayable and talking about death and the prosaic mechanics of the post death experience e.g. clearing the clothes (90).

Signed:

Kate Latham . July 2015.

appear throughout the text in each person's story which implicates them with this illness.

Following Charon's suggestion for close reading the chapters are:

St. Jude p. 1-13. This sets the scene as the mid-western 'gerontocratic suburbs of St. Jude' (1) and a typical day in the household which 'Unfortunately, Enid lacked the temperament to manage such a house, and Alfred lacked the neurological wherewithal' (7).

The Failure p.17-155. Chip's story of academic success and downfall. That he is portrayed as so hapless makes his redemptive decency in chapter six the more telling.

The More He Thought About It The Angrier He Got p.159- 253. Documents the married life of the eldest son Gary, who works in banking and is ostensibly the most successful of the Lambert siblings.

At Sea p. 277-390. Tells of the events of Enid's long awaited cruise leading up to Alfred's 'fall' and the immediate aftermath.

The Generator p. 393-528. The story of Denise's adolescence, marriage and career as a restaurateur. She is the most sympathetic towards Alfred.

One Last Christmas p. 531-644. Alfred's physical decline is described in visceral detail. Alfred's hallucinations take increasing possession of him which his flashes of lucidity make almost unbearably poignant.

The Corrections p. 647-653. 'All her corrections had been for naught. He was as stubborn as the day she'd met him' (653).

- **Narrator**
The novel, and each internal novella, is narrated by a third person omniscient narrator. This allows the reader to have shifting sympathy with each character in turn. Through these stories the reader knows more than each of the individual characters do about each other, an omniscient view which makes each character, while flawed and self-deceiving, deeply sympathetic. That the reader knows more about each character than the characters know about each other creates the truly dialogic position of the reader with the text and thus with Alfred.
- **Metaphor**
Various methods of correction from pharmacological, financial and emotional provide the drive of the novel. That they are resisted or futile reflects the underpinning existentiality of the novel.
- **Allusion**
In his *Guardian* review of *The Corrections* (9 November 2001) James Wood references Dickens *Bleak House*, Thomas Mann's *Buddenbrooks* and de Lillo's *Underworld*. It is Tolstoyan in scope and read as a sprawling family saga references the adage about happy and unhappy families.
- **Diction**

| | | |
|--------------------------------------|---------------------------------|----------------------------------|
| Title: <i>The Corrections</i> | Author: Jonathan Franzen | Date of Publication: 2002 |
|--------------------------------------|---------------------------------|----------------------------------|

Narrative Medicine

Charon's Close Reading

Frame:

This novel launched Franzen into literary stardom. Alfred Lambert's dementia and failing physical health is the pivot for emotional change in the family members. The length of the novel and the internal novella structure combined with an illness of relentless deterioration and long duration allow the 'corrections' each sibling experiences to appear legitimate and valid to the reader who develops an intimate knowledge of this dysfunctional family. That neither Alfred nor Enid are 'corrected' but remain locked in silent marital impasse created over many decades of marriage allows the portrayal of the Lambert's marriage to be compared with the relationships the siblings have with their various partners. It roots the novel as contemporary and not simply realist.

Form:

- **Genre**

This is a serious literary 'Big American Novel' of 653 pages. It documents how the various members of the Lambert family deal with the Alfred, the patriarch's complex illness, and why each member of the family responds in the way they do. It is Franzen's third novel, an international bestseller, and his most acclaimed to date. His previous novels had been well received by critics but remained within a category of serious literary fiction.

- **Visible Structure**

The text is divided into seven chapters and falls into two sections divided by the precipitating event, Alfred's survival following a 'fall'— or was it— from the deck of a cruise ship. In the first section there are four novella length chapters giving the back story of how Enid and the three children have arrived at their current position on that particular weekend in New York. The second half narrates the diagnosis and progression of Alfred's illness and the family reactions to it. Alfred does not have his own chapter. His symptoms

The registers of the novel shift with each novella and combines self-conscious high art, notably the themes of university teaching (41, 55), academic book collections (106) and literary theory (96) with the imagined accuracy of the clinical interview of the attending doctor which Alfred cannot understand, 'He was failing and he knew it' and resolves by being incontinent 'With a smile he let his bladder empty' (641).

Time:

The temporal scaffolding of *The Corrections* is structurally complex because the time arc is disrupted as each novella begins at a different stage of the family story but it is narratively straightforward because it can be read as a family saga. The story of the Lambert's marriage and the Lambert children's childhood is told which enables the reader to sympathise and understand the responses to Alfred's illness. Charon makes the point that clinicians are keen to identify the chronology and duration of symptoms but 'doctor's regimented diachrony may be at odds with the patient's expressive synchrony (121). The reader/clinician acknowledges that Enid dates the start of symptoms to Denise's telephone call about her marriage (140) but the clinician/reader, using the diachronic model seeking the historical development of symptoms is aware that the coffee being spilled is the likely start of the movement disorder which is the core of all Alfred's difficulties, including his dementia. Enid could not tell the doctor and Alfred would not tell the doctor which reminds clinicians that the history must remain open and dialogic. It is never finalised.

- Tense

This big novel uses the past tense in the novella length chapters to inform the current predicament of Alfred and Enid.

- Order

Alfred and Enid's life is intersected with the story of each of their children. Each sibling story throws light on the predicament of their parents and why each sibling has responded to their childhood environment the way they have. The novel begins with an example of the Pathetic fallacy: 'The madness of an autumn prairie cold front coming through. You could feel it: something terrible was going to happen' (3) and it does.

- Duration

With narrative economy a lifetime in the Lambert household is portrayed although the focus is on the events since Alfred's retirement. Such disruptions are useful when taking a clinical history enabling questions such as 'How have things been since..?'

- Story time

The scope of the story is the length of Alfred's illness but the narrative

- Discourse time

The length of the novel daunted some of the trainee/student readers to whom I recommended this. For me (see desire) any time spent with this novel was time well spent as it repays+++.

- Velocity

Not a longueur in the text.

Plot:

The plot of *The Corrections* pivots round the neurological disorder of Alfred Lambert who lives with his wife Enid in the mid-West and follows the course of his illness from the early symptoms to his death. Alfred has been a particularly internal, undemonstrative family patriarch of rectitude in his business dealings and with his family. This constrained approach to life is construed by the family, and in particular by Enid, as one of stubborn obtuseness. Alfred's personality skews all the relationships within the family which are played out through childhood and into adulthood as they each find their own way to manage his dominance. Now retired, aged, and ill with their three children spread across America Alfred is left to the care of Enid who continues to find him wanting as a husband and in great need of correction. Enid machinates to have her greatest wish granted, a last Christmas in St. Jude with all the family gathered around, as a show of solidarity, and as a visible demonstration of familial commitment and success in her community. The events in the novel take place as Alfred and Enid travel to New York to meet their son and daughter for lunch before embarking on an autumn cruise.

While the family could be described as dysfunctional the tensions and rivalries between the people in the family matrix are identifiable to any-one who is part of one. The family members care about each other and it is this which maintains the humanity of the novel amidst the satire. There is no chapter devoted primarily to Alfred. His back story and the developments of his symptoms are largely revealed through the narratives which focus on his wife and children. This reflects how illness often presents in the clinic, particularly in a dementia, when the 'patient', like Alfred, may be reluctant or unable to grasp the impact of symptoms on everyday living. That Alfred is construed by the family as having been chronically depressed complicates their view and fuels Enid's frustration with Alfred.

Whilst doing this it satirises aspects of American culture. Big Pharma, literary theory, higher education, banking and high end cooking are cunningly dissected and derided. It is expansive in its cultural commentary but its core remains the family saga.

Desire:

What was satisfied in you by reading the text?

Everything. For me as a clinician/reader and reader/clinician this is one of the great novels of the 21st century. Intelligent and layered, the control and integrity of the novels bears countless re-reading. There is something for everyone in this novel because the Lamberts are an 'Everyfamily'. The writing allows the reader to live within them and have ones sympathy shaped by each member in a virtuous narrative circle. Alfred, who is portrayed as monstrous over rutabaga is the epitome of paternal decency over Denise's liaison. Beyond what the novel can offer the reader in terms of access to family dynamics, views on illness and trying to manage a determined mother, that the buying of salmon steaks is, for me, always reminiscent of Chip and his leather trousers is evidence of Frank's stance that stories are active in one's life and not confined to 'reading'.

What seems to be satisfied by the writing of it?

Franzen has written about *The Corrections* and its relation to his own experiences with his father's illness in a number of essays which with deal the aftermath of his death and his writerly reflections on it. The range of American culture he depicts (and satirises) in the sibling novellas give Franzen, and the reader, a distance from the illness although it is still portrayed graphically. His essay references to the personal circumstances behind the novel are more intimate and candid. One might suggest that *The Corrections* is a raw telling of circumstances and the essays a response to the situation once it had been processed through writing it as fiction.

Signed: Kate Latham

Date: August 2015

The Triple Analysis of the three memoir texts offers confirmatory evidence for *The Corrections* (Franzen 2001) as being the most textually and clinically rich of all the memoir texts. More importantly it demonstrates how the choice of assessment elicits different information from the text. This is a relevant reminder for clinical practice. Each assessment reveals only one version of the clinical story and checks are not always made that this is the version acceptable to the patient.

Chapter 4

Implications of the research interventions: *Treatment review*

The research interventions drew on Arthur Frank's understanding of narrative and socio-narratological practice as it relates to fiction and the clinical history. This chapter extends the thinking to enable an exploration of how the interventions which have focussed on the memoir fiction might inform clinical practice as theoretical and practical research outcomes. Two innovative interview pro-formas, one for taking an alternative and more dialogic clinical assessment and the other a structured interview for a post diagnosis appointment have been created. Information leaflets for patients and supporters have been designed: one focusses on the memoir fiction and the other covers all the selected texts. The chapter ends showing how two of Bakhtin's concepts can inform dementia care.

4.1. The clinic as a story telling venue

Considering the clinic as a venue for narrative where the clinical history is elicited as a story with similarities to fiction reveal it as a place of relationships. This is in contrast to the more traditional view of the clinical interview as a singular, sacrosanct encounter between clinician and patient. The storytelling dyads at play in the clinic interact with the story telling space and open the stories told there to Dialogical Narrative Analysis (DNA) and reveal their similarities to fiction. Although the clinic and clinical history were designed to fulfil a medical function the manner in which they combine to answer the DNA suggests a degree of validity for the clinic as a place of stories.

What does the story make narratable?

Despite time constraints and NHS rituals the clinic is a venue which allows the concerns of the patient to be aired. It does this primarily through Dyad 1

(Storyteller and listener) whereby the story teller tells the story of the presenting problem; the listener listens to it, and records the story on a clinical history template. The template, in addition to incorporating the Mental State Examination (MSE), also contains the key narrative structures of set-up, conflict, and resolution which are drawn out by the guided questions of the listener. Together the story teller and listener create a narrative of the presenting problem and make it accessible for use and available for the work stories need to do as understood by socio-narratology. The patient has a story to tell, or they would not be attending the consultation, but they cannot tell this story alone. It is Dyad 1 which makes the patient's story of their problems work and fit for use as the clinical history.

Who is holding their own in the story, but also, is the story making it more difficult for other people to hold their own?

In the clinic this question is most effectively answered by Dyad 2 (Story and storyteller). Although the patient is asked in the clinical history about their concerns the concept of 'holding your own' could be used more creatively in the clinical template. It is a useful, well understood phrase which, if asked directly or paraphrased as 'What are you doing differently to manage your problem?' could explore how the person might be 'holding their own' and demonstrate the creativity patients bring to solving their problems. A similarly phrased question in the section 'Family View' might elicit any changes supporters have made, or anticipate making, to continue. These small changes in clinical questioning have the potential to shift the consultation from one which focuses on problems to one of acknowledging and validating the changes that the person is experiencing because of them. This becomes a more nuanced and subtle assessment and sets a tone for a diagnosis of dementia as change, rather than one solely of tragedy. It has

the potential to create a more dialogical understanding of the patient's position as more equal and successful in navigating the changes a dementia imposes.

What is the effect of people being caught up in their own stories while living with people caught up in other stories?

The clinical template pays insufficient attention to the patient's network of support and their concerns. A person with a dementia may not comprehend, or appreciate, the degree of support which is at work for them and the suggestions made in the previous section would address this more aptly. This DNA question reinforces the importance of wellbeing for supporters. It could announce attention to their wellbeing as being of importance which could be logged and addressed in future follow up appointments. If the clinician is caught up in her or his own story they are unlikely to be optimum listeners and this DNA question could be useful adjunct to clinical supervision and promoting reflective practice.

What is the force of fear in the story and what animates desire?

An attempt to answer this DNA question is present in the clinical template through questions such as: Before we start do you know what you want to happen from the assessment? and whether the person would like to be told their diagnosis. It is addressed through Dyad 3 (Listener and story) but could be reinforced more strongly by different clinical questions which address both fear and desire directly, for instance: 'What frightens you most about attending here today?' and 'What do you most need to get done?'

How does the story help people, individually and collectively, to remember who they are? How does a story do the work of memory?

This DNA question, which is the most elusive in terms of fiction, is particularly pertinent when considering the story in the clinic and the text in the notes. The

clinical history could be collected in a much more collaborative manner to create a more personally owned history which was still clinically relevant and could be built upon during subsequent appointments.

4.2. The creation of the faux notes

The faux notes test the clinical veracity of the three memoir fiction texts. They reveal *Grace and Mary* (Bragg 2013) as providing the most robust and rich clinical information. It is the one which most closely reflects my clinical experience because it draws from UK rather than American or Canadian health care systems.

Medical notes document a patient's journey through the health care system. For a person with a dementia this journey is likely to last a decade and the input of health professional will ebb and flow. There will be intensive involvement with health services at the beginning of the illness to confirm the diagnosis and if anticholinesterase (ACI) medication is prescribed regular monitoring to assess its effectiveness. There may be a further intensive phase if BPSD symptoms become problematic. In the late stages of the illness health care is likely to be provided by General Practice. Only one of the selected texts documents this course with clinical accuracy but each text illuminates an aspect of dementia and may offer a reader clarification, support or insight. The assessment consultation as a precursor to the diagnosis is dealt with in great detail in the didactic fiction as discussed in the earlier section 3.1b. The selected short stories offer an insight to the lived experience of dementia, from the point of view of an elderly spouse caring for a wife now lost to him and a woman in a residential home who is dependent on the ministrations of professional 'carers' for any comfort. These pieces of fiction may not offer the clinical accuracy of *Grace and Mary* (Bragg 2013) or *The Corrections* (Franzen 2001) but they suggest a verisimilitude which could be

useful to professionals and supporters and, by virtue of their brevity and direct style of writing, be readily accessible to both.

It was the creation of the faux notes and the exploration of *Grace and Mary* (Bragg 2013) which clarified, for me, the narrativity of dementia. This can explain its ubiquity in contemporary fiction and cultural penetration and thus answer the research questions of Why dementia? and Why dementia now? References to dementia in the cultural discourse can be plotted on a graph of declining function. The trope of burden relates to the middle to end stages of the illness whereas the greetings card ‘jokes’⁷³ refer to the early stages and points prior to diagnosis when memory lapses may be perceived as both part of ordinary ageing or the precursor of a dementia. The narrativity of dementia creates what Frank calls ‘narrative ambush’ (2010: 58), a catch-all phrase by which he means stories which can ‘break through filters and grids’ (ibid: 59) to leave the reader responsive to a new or alternative stories.

Narrativity is a vexed term. Gerald Prince in his *Dictionary of Narratology* cites seventy nuanced interpretations but defines it as ‘one or more real or fictive events communicated by one or two or several (more or less overt) narrators to one, two, or several narratees’ (Prince 2003: 58). The progression of a dementia is likely to elicit more than one event and will almost certainly involve supporters as both narrators and narratees. The most practical definition of narrative as it relates to dementia remains Aristotle’s definition: a beginning, middle and end. This suggests a trajectory and causal influence. They are also the stages clinicians use when describing the course of the disease. Within each stage of dementia there is a

⁷³ See Appendix 10 for the most egregious examples.

beginning, middle and end as the impairments and behavioural changes make their impact on the person and how they function.

Labov's characterization of narrative is more complex. It requires a complicating action and up to six macro-structural elements: abstract, orientation, complicating action, evaluation, result or resolution and coda (Prince 2003: 59) which a dementia fulfils in the following way.

The complicating action of the dementia is the impact of the disease on the person and those around them and the 'what happens next?' fears of the person and the supporter. Due to the protean nature of dementia 'what happens?' might be slightly different for each person but with a similar trajectory of decline. Each of the dementias portrayed in the selected fiction has a different presentation but each demonstrates the progression of decreasing function. The memoir fiction does this through the sustained course of each novel whereas the literary fiction uses a shorter time scale to explore the experience of the individual with a dementia as they contemplate their future and interrogate their past. Judge Teoh in *Garden of the Evening Mists* (Eng 2012) and Jake in *The Wilderness* (Harvey 2009) use their diagnosis of dementia to review their lives. Each of the selected texts describe 'what happened, and then what happened' in varying degrees of detail and veracity about the illness and use varying timescales.

Abstract is the part of the dementia narrative which summarises the story and answers the question 'What is it about?' Dementia is about decline and change. In most cases dementia is in the context of old age and physical frailty, such as for Mary in *Grace and Mary* (Bragg 2013) and most poignantly for Margaret in 'These are not my clothes' (Kay 2013) because she is apparently alone in the world

with no strong advocate. This situation is not common and when happened upon as a clinician I was always saddened and moved to reflect upon how the prospect of old age, and then frail old age, may have been experienced. This presentation of memory impairment in old age is on the verge of being ‘normalised’ in its cultural anticipation, despite the epidemiology described earlier. The equation between age and decline in dementia helps to explain the appeal of early onset dementia for fiction because it highlights the drama and tragedy of an illness which is out of kilter with the expectations of chronological age.

Orientation identifies the spatiotemporal situation in which the events take place. Prince argues that the constituents of orientation are: ‘Who? When? What?’ Who the dementia affects, at what point in life, and what impact it makes is the core of the clinical history taking. All the sub-genres of the dementia fiction used in this work address who, when and what but it is only the memoir fiction which tackles the full timescale of dementia and the changing emotional impact of the illness on the person and those around them over an extended period.

Evaluation is the set of features which suggest the point of the narrative, the aspects of dementia which suggest that it is worth narrating. That dementia is utilized, even if only *en passant* in the narrative by so many authors so frequently suggests that it is worth narrating as the signature illness of the twenty-first century. The didactic fiction is overt in making dementia the point of the narrative to inform and educate. Lisa Genova in the ‘Reader’s Club Guide for *Still Alice*’ and Susan Lewis in her ‘Dear Reader’ letter on the first page of the book view dementia as an illness which requires more information and knowledge to be made available and the books are written to close a part of the knowledge gap they have

identified. Dementia threatens the integrity of the self which is at the core of the twenty-first century cultural *zeitgeist*. This is depicted in the literary fiction whereby the key protagonists explore memory, memories and remembering as part of maintaining their personhood and efficacy in the world. More frequently the perceived impact of dementia on the NHS, community services and families is cited as the trope of ‘burden’ and the experiences of the people intimately involved with the illness are not valued in this metaphor

That the clinical presentation of dementia is varied, but united by decline, means that the illness is media malleable; it can be made to fit whatever point is being made. Together these attributes conspire to confirm its position as the signature illness of the twenty-first century and thus likely to be represented in contemporary realist fiction.

Considering the narrative nature of dementia reveals the literary fiction as potentially problematical, particularly in relation to clinical authenticity. While the protagonists of *The Garden of Evening Mists* (Eng 2012) and *The Wilderness* (Harvey 2009) do have a diagnosed dementia the narrative arc is less about the course of the illness than the appraisal of memory and remembering. Both protagonists remain insightful and sentient about their predicament and reconciled to their lot.

The Garden of Evening Mists (Eng 2012) is lyrical and metaphor rich. One of the key metaphors is the *horimono*, a tattoo Judge Teoh undertakes to have on her back. This *horimono* is both tangible evidence of her existence, ‘The *horimono* is a part of what happened to me’ (ibid: 340) and of what she will become as her

dementia progresses and she will no longer be able to either articulate or remember her past or present ‘a *horimono* must have an empty area inside it’ (ibid: 336).

Similarly *The Wilderness* (Harvey 2009) is replete with metaphors beginning with a letter ‘e’ missing from a sign as indicative of the start of deterioration, ‘It needs painting back on, somebody should do that.’ (ibid: 25). Jake is an architect whose signature building is a glass house he built for his family. The transparency of this built environment and the potential exposure of the people living within it underpin the novel. That a glass house occurs as a proverb he is no longer able to interpret (ibid: 240) accurately in one of his psychometric tests signifies both cognitive loss and the loss of his past. He is not able to access and use his memories reliably and the reader steadily acknowledges that Jake is the most unreliable of narrators. Entropy is progressive in the text which leaves many unresolved questions. The reader has to anticipate that Jake can no longer answer them reliably but is stuck in a vortex of questioning the nature of why not. He questions about why some memories remain vivid and others fade, ‘What musty corner of the brain keeps these images? What nudges them out?’ (ibid: 226) and queries the nature of forgetting, ‘Fog. That is the weather in your head’ (ibid: 224).

It would not be possible to complete a clinical assessment from either of the literary fiction texts and a DNA reading template would reveal them as being equivalently philosophically complex as *Scar Tissue* (Ignatieff 1993) and having similar problems for clinical use as documented for *Scar Tissue*. Although they meet my criteria of dementia fiction in that the key protagonist has a dementia they novels are about the nature of human existence more than they are about dementia.

That the clinical presentation of dementia is varied, but united by decline, means that the illness is media malleable; it can be made to fit whatever point is being made. Together these attributes conspire to confirm its position as the signature illness of the twenty-first century and thus likely to be represented in contemporary realist fiction.

The pervasive presence of dementia is driven in part by its attributes of cognitive and physical ordinariness and difference, sameness and alterity. Everyone makes memory and language errors as ‘slips of action’ which are usually attributed to haste or stress and largely disregarded. However, if they occur with increasing frequency and impact these same errors *may* be indicative of pathology and thus dementia becomes an ever present possibility. This is made worse because there are no definitive diagnostic tests or preventative measures. Dementia may well be a tragedy for the individual but it may not be an obvious tragedy. A person with a dementia is likely to be physically well, pain free and able to manage social occasions with a degree of competence, if not aplomb, as Mother in *Scar Tissue* (Ignatieff 1993: 45) does when entertaining and, although ‘her laughter is sometimes a beat late’, guests are reluctant to see that there is anything untoward. Alfred Lambert attempts, and largely succeeds in masking his symptoms prior to his ‘fall’ from the ship so only the reader is aware of their intensity and thus the foolhardiness of the cruise. This social presentability in the early stages of dementia, combined with fallible memory, makes it a useful scenario for fiction plots and its use in the range of writing genres discussed in Chapter 1.

Result or resolution is the outcome of the events: what finally happened. Texts, in which the dementia has been researched, rather than observed first hand,

use a disruption, such as the move into care (McHaffie 2010) or sudden death (Lewis 2010) as the resolution to the dementia narrative. Only the memoir fiction addresses the final resolution of dementia realistically as one of prolonged physical and cognitive decline.

Coda is a statement indicating that the narrative is over. *Scar Tissue* (Ignatieff 1993) is unusual in that the coda of the dementia is at the very beginning of the text, 'I do not want to remember her last hour' (Ignatieff 1993: 1) and the narrative is told from a retrospective viewpoint by the narrator. Bragg's coda, 'He felt a deep but tranquil sorrow.' (Bragg 2013: 248) reflects the timbre, not only of John, the son, but the whole novel and, perhaps, Bragg himself.

4.3. What the Triple Analysis reveals

The Triple Analysis of the memoir fiction texts reveals the partiality and limitations of each method of narrative analysis and opens the texts to reveal both what is and is not known about the dementia of the main character.

The clinical history template is designed and used as a precursor for diagnosis and focusses on the signs and symptoms of a dementia, how they have developed and their current impact on every day activities. It is reductive and conflates an assessment of physical health and practical functioning which may not address the main concerns of the person or their supporters. Evidence from the collated assessment of the memoir fiction texts (Section 3.3.2) suggests that the key concerns to the family/supporter in memoir fiction are changes in language and memory which are described in detail in the texts. This is not surprising given their impact on relationships. The clinical template raises the question of whether it was meeting the needs of patients and families when enquiries such as 'Do you

have a downstairs toilet?’ have equal prominence with queries about observed changes of language and memory. In practice these practical questions could be dealt with quickly but it suggests that a pro-forma completed prior to the consultation might collect the practical information more efficiently and thus release time to address more significant issues in the clinic. This is now an option suggested in *Best Practice in Memory Services* <www.england.nhs.uk/wp-content/uploads/2014/08/Best-Practice-in-Memory-Services.pdf> [accessed 24 August 2015]. The practice of a home based assessment as experienced by Mrs Mannering in *Remember Remember* (McHaffie 2010) followed by a consultant appointment in the clinic, minimises this issue but waiting list pressures on memory services means that assessment and diagnosis in a single visit to a clinic is increasingly seen as the preferred option because it is more clinician efficient. Jake in *The Wilderness* (Harvey 2009) continues to attend his Out Patient appointments on his own. However Mado on ‘The Pink Ribbon’ (Byatt 2003) and Margaret in ‘These are not my clothes’ (Kay 2013) are unlikely to be seen in a clinic and probably no longer followed up routinely by NHS specialist dementia services as they are in the final stages of the illness. In the exemplar clinic used in this work there is an ironic retrospective insight. The people attending for a single diagnostic appointment in the clinic were likely to be fitter, younger people, with access to their own transport and who could arrive for a 09.00 start. Mother and Alfred Lambert would have been prime candidates for being seen in the clinic but are the same people whose needs, using evidence comparing the DNA and clinical assessment, are least likely to be met by a single diagnostic appointment because of their complex presentation and family/marital dynamics. Although a one-stop diagnostic memory clinic may be more efficient the memoir fiction suggests that the imperative of the clinical history to be

collected at first contact with a service may not meet the needs of the person with dementia and their supporters in addressing their concerns. The clinical template does not clarify for the person or their family how, or where, opportunities to discuss personally pertinent issues will arise.

The clinical assessment takes the every-day and the mundane seriously but with hindsight leaves supporters concerns unaddressed and with no opening or anticipation for them to be so. Carer groups which offer information and support to people with a dementia may not be the place to discuss heritability or secret thoughts of hastening the death of a parent. Adding more dialogic questioning or a statement at the end of the assessment confirming that future and changing concerns could be aired at follow up appointments would be good practice. This would meet one of the Top Ten Tips from *Best Practice in Memory Services* (Burns et al. 2014) about ‘involving service users and carers at every step’ and makes the argument for more shared documentation between the patient/supporter and the clinician.

Mrs Andgrace’s clinical history suggests a further change to practice: a different assessment for those people with a possible dementia who are already in a care home. Many of the questions on the clinical template are no longer relevant because the person is clearly in the right place with the right level of care.

The stark monologism of the clinical assessment is revealed when compared with the DNA of the memoir fiction. The DNA template reveals different issues and more accurately accesses the clinician’s ‘third ear’ to understand what is ‘really going on’ in the novel. What the DNA of the memoir texts reveal, and the clinical assessments do not, is the felt experience of a dementia in the maelstrom of

everyday life. That the clinical history should focus on the mechanics of that life without any enquiry about what this means for the person or their supporter is a significant deficit.

The DNA clarifies the concerns of the supporting family far more robustly than the clinical assessment. The statement on the clinical template: 'If the person feels they are a carer, complete a carer checklist' is insufficient. The authors writing the memoir fiction clearly cared about their parent but may not have seen themselves as a carer, nor would they have met the current definition that triggers an assessment and payment of state benefits.⁷⁴ The dilemmas for supporters change during the course of the illness. The episodes of John fleetingly contemplating suffocating his mother (Bragg 2013: 247) and Chip managing the pleas of his father to hasten the end of his life are located in the last stages of a dementia. They are not addressed in the clinical history which is elicited at the start of the illness.

Problems with movement predominate in the clinical template but it is the DNA template which reveals Alfred Lambert's hallucinations. The clinical template asks about their presence which, because Alfred is unwilling to talk about them, he denies. In contrast, the DNA asks about the effects of phenomena rather than simply their presence. The hallucinations elicit disbelief in Enid and create disequilibrium amongst the Lambert siblings. Chip is best able to deal with them and enables him to emerge from unreliability into an adult role in the family and be the person to whom his father turns. Such important family dynamics are rarely

⁷⁴ A carer is anyone who helps to look after a person with a disability but to receive Carers Allowance of £61-35 per week at least 35 hours per week must be spent caring for or looking after someone in receipt of AA, DLA or PIP. Carers Allowance is not available to anybody in receipt of the State Pension who provide the bulk of community and family support.

available or disclosed at an initial meeting and may only become apparent in subsequent appointments.

Charon's Close Reading was developed as an essential part of Narrative Medicine's use of stories to encourage clinicians to hear their patients differently. Unlike DNA it pays attention to the structure of the text as well as the content and remains a traditional narrative analysis. It demands a literary interest and sophistication which may not be available in all clinicians or trainee health professionals using fiction as a set pedagogical task or as clinical skills development. Charon's Close Reading is at its most powerful with complex texts. Amongst the examples of authors she uses in demonstrating her Close Reading structure she draws on the work of Henry James, W.G Sebald, Michael Ondaatje, James Joyce and Ernest Hemingway. These are authors whose writing poses more of a challenge to the reader than texts such as *Grace and Mary* (Bragg 2013) or the didactic fiction.

The Triple Analysis emphasises the range of stories within each text. This is most obvious in *The Corrections* (Franzen 2001) and *Grace and Mary* (Bragg 2013) but confirms that *Scar Tissue* (Ignatieff 1993) is less about dementia and more about the narrator's state of mind. DNA does not offer a perfect assessment. Because it is a practice applicable to the genus 'story', and the concepts used in DNA are so open to interpretation they become unwieldy and almost meaningless. Questions such as 'What animates desire?' is a question with an unverifiable answer other than that one offered by a particular reader at that particular time. Despite this it is DNA, rather than the clinical assessment or Charon's Close Reading

which has the potential to reveal ‘the depth and hold of the fear and rage that illness brings’ (Charon 2006: 19).

What the Triple Analysis reveals is that fiction can inform clinical practice without the rubric and imprimatur of Narrative Medicine. The clinical and DNA templates reveal the importance of acknowledging the framing of the questions and provide a reminder for the clinician that questions on any template or pro-forma determine how the story is told, what is told, and what is omitted. This needs to be better acknowledged when the clinical history is used as the seminal information about the patient. The Triple Analysis could be used in health professional teaching to demonstrate the limitations of each template because no template tells the complete story of the patient. It offers a means of demonstrating the dialogic position in practice: that the stories told about a patient, in any form, are incomplete and unfinalised even though the story in the medical notes is reified.

Although the Triple Analysis was carried out on the memoir fiction texts it would have been possible to use the Dialogical Narrative Analysis (DNA) template and Charon’s Close Reading template to create a ‘double analysis’ of the other selected fiction texts. This has been completed informally as part of the research process but not reported because of the number of texts used in the context of this work. It has, however, informed the practical research outcomes such as the patient and supporter information leaflets discussed in section 4.5. Using a Close Reading drill for *The Story of Forgetting* (Merrill Block 2008) reveals the intricacy of the text as it challenges the Close Reading categories of Frame, Form, Time and Plot. Used for the literary fiction it highlights the complexity of these texts and how they address the nature of the self and how dementia threatens this. Although the

didactic fiction and short stories answer the DNA questions they do so with less robustness than the memoir fiction.

The Triple Analysis used for the memoir fiction texts was crucial in developing Augmented Narrative Analysis (ANA) and an alternative structure for a post diagnostic clinical interview discussed in the following section.

4.4. Practical Research outcomes

a) The Development of Augmented Narrative Analysis (ANA)

Training of health professionals involves both academic teaching and a form of apprenticeship which introduces the trainee to the arcane practices of the clinical space. It involves supervised practice and a ‘signing off’ of the skills required.⁷⁵ Some nurse and midwifery teaching⁷⁶ uses Augmented Reality (AR) to provide a ‘real’ account of the patient’s experience and challenge the reactions and communication skills of the students when learning physical techniques. In AR computer generated images are overlaid onto a patient dummy which responds to the nurse’s actions, for instance, with apparent discomfort to cold hands, or too much pressure. The practice allows student nurses to hone their skills and face their first ‘live’ patient with more confidence. In mental health services AR is less feasible and trainee health professionals learn and develop their assessment and interview skills by observation and being observed. Using fiction as a proxy patient develops an equivalent to AR in creating a safe environment to develop clinical competencies in mental health. Morris (2014) has used first person narratives available in the media to develop questioning and reflective practice with student mental health nurses who reported feeling better prepared for practice

⁷⁵ The ‘watch one, try one, do one’ model of medical skill acquisition.

⁷⁶ <<http://www.shu.ac.uk/mediacentre/video-reality-check-student-nurses>> [accessed 7 July 2015]

and more empathic about the lived experience of dementia. ANA extends the preparedness for practice into assessment skills.

The use of *The Corrections* (Franzen 2001) as a medical Master Class text suggested that a fiction text could be used successfully to teach about a specific condition. Augmented Narrative Analysis (ANA) which is based on Franks DNA extends the use of fiction texts to develop assessment skills before a trainee has face to face contact with a patient.

The Triple Analysis revealed the limitations of the clinical template for understanding a patient beyond the collection of symptoms and Rita Charon's Close Reading (2006) template demands a reading commitment and willingness to deal with abstract literary concepts which may not be available to all trainee health professionals. The Dialogical Narrative Analysis promoted by Frank (2010), because it is based on the wide genre of 'story', is the analytic practice which captures most robustly answers to the questions 'What is going on?' and 'What is really happening?' in any narrative. These are the same questions a clinician asks when seeing a patient for the first time. Practicing ANA with fiction, where an illness happens, as it does in life, amidst a mesh of social relationships, opens the clinician to a more dialogical understanding of the situation presented. The Augmented Narrative Analysis (ANA) template uses the questions of Frank's Dialogical Narrative Analysis (DNA) which have been paraphrased for clinical use. Further questions have been added to help the trainee health professional, who may not see themselves as a 'reader', understand the relevance of the task for their learning and skill acquisition. Using ANA alongside the Triple Analysis templates for the same text has the potential to demonstrate to trainee health professionals

how the assessment frames, and may finalise the position of the patient. It prepares the trainee to identify what clinical information might be missing from any assessment and what further questions need to be asked.

The aim of ANA is to provide a structure for assessment and an alternative and more confident clinical ear⁷⁷ in the trainee assessor.

⁷⁷ ANA works beyond dementia fiction e.g. *We have always lived in the Castle* (Jackson 2009) in which the derangement of a sibling is slowly revealed over the course of the novel.

Augmented Narrative Analysis (ANA)

(Name of text here).....is acting as a proxy patient. Please read it as if you were seeing a patient for the first time and making an initial assessment. You may want to read the ANA assessment sheet before you start reading and make notes of relevant page numbers as you read.

What illness or disease process does the novel address?

**What does the story make narratable?*

Where in the book did you start to make a diagnosis / formulation?

What enabled you to do this?

Who is in the most trouble in the novel?

**Who is holding their own in the story, but also, is the story making it more difficult for other people to hold their own?*

How are the different characters in the novel dealing with the situation?

**What is the effect of people being caught up in their own stories while living with people caught up in other stories?*

Is this due to current circumstances or their own backstory?

Is there a character who is frightened? If so, what are they frightened of?

**What is the force of fear in the story?*

What motives do you see in the character(s)?

What animates desire?

Did you agree with the interventions and suggestions made by any health professionals in the novel?

If not-what would you suggest, and why?

What have you learnt from the novel which might inform your clinical practice?

Any other comments ?

Signature:

Date:

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2016

ANA is an extension of Frank’s DNA. It presents an alternative assessment protocol which has an obvious structure and specific questions which need to be answered, unlike Charon’s Close Reading which uses narrative structures as the core of the analysis. Using questions such as Where in the book did you start to make a diagnosis/formulation? and Did you agree with the interventions and suggestions made by any health professionals in the novel? steer the trainee health professional to the relevance of the reading task for clinical practice.

Because ANA is based on DNA it enables trainee health professionals to be in, and experience, a dialogical position with the text as a precursor to the position with a patient. The dialogical position is underused and unacknowledged in

general NHS practice yet has the potential to set the tone for exemplary health care. Developing awareness of the dialogical position at the start of a career, through practising it with fiction, is likely to increase the chance of it becoming an embedded understanding of clinical relationships. The dialogic position is the projection of the self to be the other. It is not merely an empathic response but a completion of the 'other's' horizon, an immersion, not only in point of view but in the totality of the sensory experience. Good supportive care would be inherently dialogic.

Assessment is the start of clinical relationships. The dialogical practitioner would acknowledge that we are immersed as a social being in relationships through which we know ourselves, other people and the world. Dialogism underpins all human functioning and is evident through all our acts. The usefulness of practising an assessment using fiction as a proxy for a patient links the task to other key concepts in care such as attachment and psychoanalytic theory which similarly attest to the importance of relationships and their meaning. The term relationship is somewhat glib and easily said. Bakhtin began to unpick the nature of the ideal relationship in his early work on aesthetics between 1919—1924, collected as *Art and Answerability* (1990) in which he explores the concept of 'architectonics', an activity which describes how relationships between self and other, self and object and self and the world are structured and in which dialogism is nascent.

In this text *Answerability* combines with *Outsideness* as a moral activity which begins after empathy, the living oneself into the experience of the other. It is insufficient simply to imagine the experience but is a more active process because

it is through the return to the self that the boundary between the self and ‘other’ is recognised. Using reading of fiction as a proxy patient in the training health professionals makes obvious the stepping outside the boundary of self-experience before returning to use it in self experience. In the acknowledgement of acceptance of the boundary the empathic experiences derived can begin to form, be processed and used.

The dialogical position is important in initiating the clinical relationship and can be enhanced when used in follow up appointments by clinicians. Using the capacities of socio-narratology as the structure for clinical interview subsequent to diagnosis demonstrates to the patient the clinician’s interest in the meaning of the illness for them rather than just the intensity of their symptoms. It provides a clinical alternative to the standard opener of follow-up appointments: ‘How have things been?’ This proposed interview schedule, which uses Frank’s capacities, offers an even more dialogical position than the initial clinical history because follow-up appointments have fewer audit and bureaucratic constraints.

The thirteen capacities Frank lists in *Letting Stories Breathe* (Frank 2010 pp.28-32) could work as follows: (The suggested line of questioning for the clinician in *italics*.)

Suggested structure for clinical interview: post diagnosis.

Trouble: ‘stories have the capacity to deal with human troubles, but also the capacity to make trouble for humans.

How significant is the diagnosis for you?

What difference does it make to you as a person?

Character: stories have the capacity to display and test people's characters.

How are you managing with the diagnosis?

Who else is affected?

Point of view: stories have the capacity to make one particular perspective not only plausible but compelling.

Does everyone agree with you about this?

Suspense: stories make life dramatic and remind people that endings are never assured.

Have you thought about what happens if things don't go how you anticipate?

Interpretive openness: stories have the capacity to narrate events in ways that leave open the interpretation of what exactly happened and how to respond to it.

How do you explain your condition to the people around you?

Out of control: stories have a capacity to act in ways that tellers do not anticipate.

What difference does your condition make to your life now?

Inherent morality: stories inform people's sense of what counts as good and bad, of how to act and how not to act.

What has been the most helpful behaviour of people?

And the least helpful?

Resonance: stories echo other stories, with those echoes adding force to the present story.

Who else are you in contact with about your diagnosis? How helpful is this?

Symbiotic: stories work with other things — first with people, by also with objects and with places.

How does your condition change practical and social aspects of your life?

Shape-shifting: stories change plots and characters to fit multiple circumstances, allowing many different people to locate themselves in the characters in those plots.

Tell me how you or family members have had to adapt their lives to the diagnosis.

Performative: stories are not only performed: they perform.

What has the diagnosis made you do?

Truth-telling: stories' capacity to report truths that have been enacted elsewhere is always morphing into their more distinct capacity to *enact* truths. (Original italics)

Does your diagnosis and what you have been told about it 'ring true' with you?

Imagination: stories have the capacity to arouse people's imaginations; they make the unseen not only visible but compelling.

What do you most want us to know about your situation?

It is the dialogical position which creates a different assessment ethos and demonstrates a clinician's interest in the patient's experience of their illness. Such an interview has the potential to be profoundly acknowledging of the individual and demonstrate to the patient the keen interest of the clinician in how they are managing to live their lives. It opens up a different conversation about what, if any, support is needed, or might be needed, and facilitates difficult conversations, for instance, about care until the end of life.

Using the range of dementia fiction for ANA is equivalent to the range of people seen within a clinical service; some texts, like patients, are harder work and less easily accessible than others. Reading a range of the selected texts gives trainees access to different presentations of dementia prior to ever meeting a patient. It offers a cheaper and repeatable experience in comparison to hiring of actors for in-vivo clinical assessments and is an accessible model for distance learners.

b). The use of fiction about dementia in patient and supporter information

Crucial to Narrative Medicine is the view that fiction can inform and improve clinical practice and care. A third research outcome is the development of patient/supporter information which uses dementia and memoir fiction which capitalizes on the range of genres and accessibility of the selected texts. It extends the possibility of dementia fiction being used solely in teaching health professionals but extends it into the social realm of patient and supporter. Reference has already been made to the perceived limits of Narrative Medicine but its guiding ethos remains when contemplating how stories might inform patient information. Using the information gained from the exploration of dementia fiction two leaflets have been produced: 'Dementia in Fiction' and 'Fiction about Dementia'. 'Dementia in Fiction' focusses on memoir fiction. The aim is to be clear about what fiction might offer the reader and also the possible dangers in reading the texts because descriptors such as 'bleak' and 'harrowing' are used. The leaflet acknowledges that two of the texts are challenging reads but this is mitigated by the section 'Read this novel for:' which directs the reader to the pertinent sections of the novels. By mentioning two secondary texts, *Elizabeth is*

Missing (Healey 2014), which is based on family experience and *Still Alice* (2009) which has increased in its educative potential since being made into a mainstream film, the range of fiction offered is increased. These are both accessible novels which may offer a connection with a supporter/reader. When combined with the short commentary the aim is to assuage some of the apparent misery attached to reading the main selected texts. The memoir fiction is stark, but honest, in its portrayal whereas the secondary texts mentioned in the leaflet are stories which harbour a different danger for the reader. As a clinician/viewer the film of *Still Alice* did not portray the gruelling nature of support and care for a person with a dementia realistically enough and the limitations of the text have been discussed at various points in this work. Similarly for the clinician/reader the comedic situations described in *Elizabeth is Missing* (Healey 2014), even though based on family knowledge of a grand-parent, present as reported rather than experienced directly. These texts may not offer the confirmatory evidence mentioned in the penultimate paragraph of seeing the supporter's 'thoughts and anxieties there on the page'.

In comparison 'Fiction about Dementia' covers all the selected texts. Again it offers a synopsis and guidance about what the texts might offer. The full academic referencing system was removed after drafting as it looked too over bearing and formal. Enough information is used to allow a bookshop or librarian to locate the text.

The aim of both leaflets, but particularly 'Fiction about Dementia', is to use the range of selected novels to give 'the closest and most intimate access to the minds of others, so that we may build collective life-worlds' (Boxall 2015: 11) and

to offer the key elements of reading — succour, information and reassurance that one is not alone in the world, and that other people have survived the experience. They present stories as ‘guidance systems’ suggested by Frank (2010: 46).

The leaflets demonstrate that all the selected texts may have relevance for the clinic. Although the memoir fiction may have the most significance for health professionals the range of sub-genres, including literary fiction, and short stories, offers relevance to the wide range of potential readers in the clinic. They aim to be realistic and acknowledge that for supporters and carers of a person with a dementia time available for reading may be short and passages have been selected which could be available as copies in the clinic. They do not prescribe fiction but, by using the short cut in the leaflet, ‘Read this for:’ it suggests fiction as offering an alternative view of what may be happening to people in similar situations.

Memoir fiction addresses end of life issues in a manner that many memory and dementia services do not. Dementia is a terminal illness but is rarely treated as such by clinicians at post diagnosis appointments whereas memoir fiction suggests that end of life issues are significant for supporters of people with a dementia. That John in *Grace and Mary* (Bragg 2013) briefly contemplates hastening the inevitable end of his mother’s life may comfort supporters who have had similar thoughts. Fiction may, of course, also remind that it ‘could be worse’.

One of the aspects of clinical practice was how hard it was to predict which patients and supporters would cope with dementia and which would succumb to its pathological reach. Access to fiction and in particular, memoir fiction opens the situations of other families in the same predicament to view without the need for support groups. This is not to denigrate the importance of these, but to

acknowledge that a range of alternative support needs to be made available to meet the varied preferences for carers and supporters. Frank argues that:

stories work best for getting people marching. Stories are not very useful for getting troops into marching formation, but they are rich in capacity for making people willing to march— for making marching seem like a sensible thing to do.

(Letting Stories Breathe, 77)

To pursue Frank's metaphor, the leaflets suggest that fiction can offer a recruiting office for the rigours of care and support for a person with a dementia which can be carried out however personal resources allow. John in *Grace and Mary* (Bragg 2013) is an ideal son, the narrator in *Scar Tissue* (Ignatieff 1993) tries to be but is not, and Chip Lambert in *The Corrections* (Franzen 2001) only finds his capacity to care late in the novel.

A lot of fiction mentions people with a dementia but some books are about a person with a dementia. Some of the books are about giving the reader information, others use the dementia as a literary ploy to explore the nature of memory and are bit more philosophical. All the books mentioned are fiction but some draw on the experiences of the author who had a parent with a dementia.

All fiction comes with a health warning– they are stories which are **made up**. Some of them ring truer than others but you might find some of your thoughts and experiences mirrored in them.

Spoiler alert: the ends of the stories are sometimes mentioned. Dementia is a long illness and some of the books follow the character to their death.

Health warning: reading is a very personal activity and a book doesn't suit everyone. Some people find it helpful to discover that their experiences and thoughts are on the page. There is no right way to manage a dementia, only your way, but you might find some help in some of the books in this leaflet. All the books mentioned are in paperback and will be available from your library. If a book in this leaflet doesn't work for you, stop reading!

Fiction about Dementia

Suggested reading for those caring
for a person with a dementia.
Books in which the main character
has a dementia.

Lakeside Community Trust Memory Service

February 2015

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| <p>Fiction which informs</p> <p>These are books that have been researched. The author may have visited a memory clinic or spoken to people with a dementia and their supporters. They tend to take the reader step by step through the diagnostic process and tell the reader what sort of tests and questions might be asked at an appointment in a memory clinic. They can be a useful guide and a preparation for what to expect.</p> <p>The Forgotten. Susan Lewis. David Kirby MP and his young second wife Lisa are faced with his diagnosis of dementia. David's daughter Rosalind, with a son who has Asperger's has difficulty accepting the relationship. David decides to manage his dementia and explores an assisted dying clinic. If you like Jodie Picoult: you may find this interesting.</p> <p>Remember, remember. Hazel McHaffie. Written by a nurse, this story is about a daughter trying to care for her mother, Doris. The story runs backwards so that you can see why things happen the way they did. Many of the issues patients and carers face, such as medication for difficult symptoms, resuscitation and not wanting to be a burden are aired. It is a bit 'teacherish' but it is useful and honest.</p> <p>Just Alice. Lisa Genova. The book of the film. A Harvard professor develops an early-onset dementia and remains very insightful and articulate about her condition. This may not be true for everyone.</p> | <p>Literary fiction</p> <p>These novels use dementia to explore memory and the nature of who we are. They may not be absolutely accurate in the way dementia is portrayed but they try to tell the reader what it might feel like to have the illness and their struggles with it. The books tend to be very elegantly written.</p> <p>The Wilderness. Samantha Harvey. On the Orange Prize shortlist in 2009. Jake, an architect, widower and in his early 60s develops Alzheimer's Disease. Through the disease he reconnects with members of his family and answers some questions about his past.</p> <p>The Garden of Evening Mists. Tan Twan Eng. On the Booker short list in 2012 this is a beautifully written lyrical book which is about the nature of memory. Judge Teoh has been diagnosed with Primary Progressive Aphasia (PPA), a rare dementia which targets language before memory and creates a garden as way of remembering her sister.</p> <p>Short stories. Sometimes these are more powerful than a long novel. Small episodes tell big stories. These Are Not My Clothes. In Reality, Reality. Jackie Kay. Margaret is in a care home and waits for her favourite carer to buy her a red cardigan. The Pink Ribbon. In The Black Book. A.S. Byatt. A carer visits Mado while her husband goes out shopping. The lives of the couple are told through the loneliness of James.</p> | <p>Memoir fiction</p> <p>These are books written by authors who have a direct knowledge of a parent with a dementia. They can be uncompromising and tell the story of dementia from early stages until death.</p> <p>The Corrections. Jonathan Franzen. Alfred Lambert develops Lewy Body Dementia and the book tells how the past influences each family member's response to the illness. The size of this book can make it seem daunting but it is broken into sections about each family member which makes it manageable. There is some dark comedy and the end is grim but it is a truthful portrayal of this complicated dementia.</p> <p>Mary and Grace. Melvyn Bragg. This is the kindest of the memoir fiction. Mary is based on Bragg's mother who developed Alzheimer's Disease as a very old lady and had to move to nursing care. It is honest about bearing witness to the gradual physical and mental decline of a much loved parent.</p> <p>Scar Tissue. Michael Ignatieff. The narrator's mother develops early onset Alzheimer's Disease. The narrator, who is a philosopher does not handle his mother's speedy decline very well and his life falls apart. Published in 1993 some of the science is out of date but the narrator's feelings about his mother's drift into the inaccessibility of dementia are still valid. The narrator thinks things which are sometimes hard to share with other people.</p> |
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A lot of fiction mentions a person with a dementia and some fiction is about a person with a dementia.

Elizabeth is Missing (2014) by Emma Healey is about an elderly lady who is missing her great pal and fears that something has happened to her. She still lives at home and thinks that she can manage but gets into muddles and has a tendency to overstock on tinned peaches. It is based on the experiences of Emma's grandmother.

Still Alice (2009) has been made into a feature film. It is set in the USA and is about a Harvard professor who develops a dementia in her 50s.

Other authors have woven their experiences of being in a family where a parent has a dementia. The stories are fiction, they are 'made up' but are true to life and reflect many of the anxieties and stresses that carers and supporters have talked about in the Memory Service.

Fiction is not self-help but can be a sort of help. Sometimes an author puts into words what you cannot and suddenly you see your thoughts and anxieties there on the page. It can make things feel a bit less lonely. Fiction may not be for everybody but here is a start.

The books are available in paperback or from your library.

Dementia in Fiction

Suggested reading for those caring for a person with dementia, written by authors who had a parent with dementia.

Lakeside Community Trust Memory Service

February 2015

The Corrections. Jonathan Franzen. 2001.

This is a long novel about an American family in which the patriarch, Alfred Lambert develops Lewy Body Dementia (LBD) with parkinsonian features. The story is about how family members react to the illness. The book is divided into sections which concentrate on each member of the family and give their back story so that we, as readers, can understand the positions they take.

Enid Lambert finds her husband's condition very hard to cope with because it is so variable. She and Alfred embark on a cruise which does not go well. Eventually Alfred is admitted to full time nursing care.

Some of the episodes described are comic but parts of the book are very bleak and the end of Alfred's life (p. 627-653) is painful to read. It pulls no punches but is honest about LBD, which Franzen's own father had. Not everybody in this novel is likeable but the characters are sympathetically drawn and utterly believable. What makes the story moving is that although the family members are sometimes at odds they do care about each other. Nobody in the Lambert family is a saint.

Read this novel for: trying to do one's best for one's parents; living with a retired spouse who is not easy; the importance of good seating (p. 74); problems with eating (p. 86); the impact of tremors (p. 77) and the experience of hallucinations.

One critic described it as 'a big, intelligent and mostly compassionate novel'.
(James Schiff, News & Observer)

Grace and Mary. Melvyn Bragg. 2013.

Melvyn Bragg's mother developed Alzheimer's Disease when she was in her late eighties. This novel is about the lives of two women: Grace and her daughter Mary. Mary's story is based on the life of Bragg's mother and decline as she grew older and frailer. The novel describes a dementia in very old age. Grace's story is pieced together by Mary's son from fragments he discovers or that Mary is still able to tell him and is about the stigma of illegitimacy.

Mary lives in a nursing home and is visited by her son John. Much of Mary's story is about his visits and how he learns to spend time with his mother as her memory fades.

Grace and Mary is a straightforward, well written uncomplicated read. Both the stories blend well and Grace's story throws light on Mary's relationship with John. It is very honest about being the only child of a much loved parent but living far away and trying to do what is best.

Read this novel for: honesty about old age and the hokey cokey (p.81); worries about moving a parent into care (p.21); whether to tell a white lie about being in care (p.46); how being forgetful can mean that some things are always new and pleasurable (p. 48); things to do when visiting (p. 23,97,123,168) and singing (p.144).

One critic said: 'this quiet, unshowy book proves that novels can tell truths that are deeper and truer than the mere fact of memoir.'
(Alex Preston. The Guardian)

Scar Tissue. Michael Ignatieff. 1993.

Scar Tissue is not long, only 199 pages, but it can be quite a challenge. The narrator is a rather annoying, self-obsessed and ultimately self-destructive philosophy lecturer whose mother develops an early-onset Alzheimer's dementia.

In the novel, Mother is an artist and homemaker. She has two sons, one of whom becomes a doctor who has a very different perspective on his mother's illness to that of the narrator. Mother's husband dies suddenly and she has to move to permanent care. What has been very solicitous care becomes obsessive and he supports Mother at the cost of his marriage and his job.

It is an important book because it was the first to describe and name Alzheimer's Disease in a novel and allow it to be written about. Some of the science it describes is now out of date. It is bleak but amongst the narrator's angst and philosophising are the essential truths of trying to be loving and supportive. Despite being well meaning towards Mother the episode leaves him guilty and unresolved about his life.

Read this novel for: becoming a parent for a parent (p. 96); looking for care (p.97); fearing heritability of a dementia (p. 192,199); the reassurance that others have managed to mess up their lives too, despite their best intentions of trying to be good.

One critic said; 'A tough read but worth it.'
(Kirkus Reviews)

The previous section considered the practical outcomes of the research interventions and made reference to increasing the dialogic elements of the clinical history. The following sections explore one of Bakhtin's concepts in more detail as it relates to dementia.

4.5. Theoretical research outcomes: how Bakhtin might inform dementia care

Bakhtin places relationships as the organising centre of a person's world. That dementia is often described as a social illness signifies the importance of relationships surrounding the person with the disease in terms of physical care, emotional well-being and the impact these have on supporters. Bakhtin's recognition of relationships suggests significance for dementia care where the need for certainty of the 'other' in a relationship may be most manifest. Kitwood (1997), Coleman and Mills (2001) and Bender (2003) argue that the maintenance of selfhood in dementia is dependent on a live relationship with at least one other, where there is a felt bond or tie. In fictional portrayals of dementia such *The Garden of Evening Mists* (Eng 2012) and *The Wilderness* (Harvey 2009) this relationship becomes the crux of the narrative. It is possible to argue that only the positive nature of relationships may make the condition bearable. However such positivity can make almost impossible demands on supporters who may find the relationship strained to the extent that hands-on care is relinquished. As the memoir fiction demonstrates, navigating the changing nature of support throughout the course of the disease is complex and can often involve a sense of abandonment by both parties.

The dialogical has been explored earlier in relation to ANA and assessment but Bakhtin's impact extends beyond assessment and into direct professional care

because it makes explicit the combination of respect for and recognition of difference.

The dialogism of Mikhail Bakhtin is integral to Frank's socio-narratology and as a 'moral philosopher, a literary analyst and an eclectic prosaic thinker' (Haynes 2013: 6) his influence has been considerable in the latter half of the twentieth century. Haynes argues that his 'sometimes abstruse musings' (ibid: 3) about 'answerability, outsideness, unfinalizability, dialogue, monologism, polyphony, heteroglossia, chronotope and the carnivalesque' are 'powerful concepts for redefining philosophical aesthetics and theories of creativity' (ibid: 3) and pitches for his influence on theories of art which, I would argue, are matched by his relevance for dementia. Bakhtin's philosophy is one which 'privileges the pragmatic moral and ethical concerns of everyday existence' (ibid: 1), a phrase which summarises the issues relating to dementia and dementia care. A case can be made for all Bakhtin's key concepts to be considered in relation to dementia, for instance, heteroglossia as useful in reimagining changes in language, chronotope in reconstruing the disorientation of time and place which a dementia, eventually, imposes on the person and an understanding of BPSD as being carnivalesque. However only dialogue will be addressed here to suggest an alternative, or at least adjacent, understanding of dementia to that of the medical model of disease and cure. Bakhtin, in contrast, values the experiences of the person.

Before the dialogical position was fully articulated in the essay 'Discourse in the Novel' (1981) Bakhtin played with the concepts of answerability and unfinalizability in *Art and Answerability* (Bakhtin 1990). These became intrinsic to

the idea of dialogism as an ontological understanding. Written amidst the political turbulence of Stalinist Russia *Art and Answerability* was a counter argument to the dominance of theoretical norms and values in the unified social structure then present. Structure and system are antithetical to Bakhtin because they do not reflect the real world, where any structure is temporary and apparent only within a specific space and time. This impermanence resonates with the progression of a dementia.

In the delivery of high standard dementia care Answerability and Outsideness offer the supporter a stance of empathy, but no pretence of ‘knowing’, what the person with a dementia is experiencing. This opens the way to a practice of care which is dependent on supporters or care staff being prepared, and encouraged to be, reflective about their ‘self’ and their relationships at any specific time. Whilst this may be asking much of people employed in the professional care sector on the minimum wage and zero hours contracts (Williams 2015: 35), it is hard to see how good quality care can be offered without it. A frequently used model of institutional care provision is ‘as if me’, meaning to treat someone how you yourself would wish to be treated, which is a reworking of the moral code of ‘Mrs Doasyouwouldbedoneby’ in *The Water Babies* (Kingsley 1863: 133). Bakhtin’s Answerability and Outsideness develops for this trite, but useful, model of care a theoretical understanding of the ‘how’ and ‘why’ of care practices. It places the care provider as enmeshed and within a relationship at any point in time whilst acknowledging that the experience of the cared for person is unique and not necessarily ‘as if me’.

The concepts of unfinalizability, unclosedness and indeterminacy became more fully articulated as dialogism. Used in dementia care dialogism can remind supporters that the person with the illness is always in relation to those around them, that we all remain ‘work in progress’ even as the illness wreaks its havoc and that the meanings we create from the world are specific to us and not necessarily universal. Unfinalizability (Bakhtin 1984: 53), which runs through all Bakhtin’s thinking and writing results from the view that we are all finite human beings and have finite knowledge. What we understand or know are constructions over which potential conflict is inevitable because we cannot see everything. A sense of freedom and openness is experienced by the idea of Unfinalizability when it is accepted as an intrinsic condition of our daily lives. We are open-ended and never complete. Such a view would offer to a model of dementia an emphasis in a continuum of change rather than one solely of decline. As a result it has the potential to increase respect because it demands the acknowledgement that we too are on exactly the same trajectory.

A dialogic response is more suggestive of a shifting, responsive and negotiated care, still person-centred, but with the structure of power defined by ‘with’ rather than ‘for’ or ‘to’ the individual. Kitwood’s ‘Person-Centred Care’, which, although it emphasises the personhood of the individual receiving care remains a system of inequality. Care is delivered ‘to’ or ‘for’ an individual and in Bakhtin’s terms, presents a monologic position. The aim of Person-Centred Care is to make the social and physical environment fit around the person with a dementia, moving at a pace which belongs to that specific environment and create a culture of respectfulness towards the presenting ‘otherness’ of the disease. This, Kitwood argues, acknowledges the essential personhood of the person with a dementia. The

dialogical position emphasises respect for and recognition of difference and in doing so it provides added heft to Person-Centred Care approach which has a limited theoretical base.

Kitwood's position shares a common precept with Bakhtin's dialogic position: that people are in relation to each other and that the environment is a social one. Dialogism extends Kitwood's position from the problems of dementia being driven by malign social relationships to one of the nature of the 'relation' as being never fully known, or being able to be known, and thus not finalised. The truly dialogic position prevents stereotyping and 'essentialising', that is the ascribing of essential and intrinsic truths about a person based on a single feature, that the person has a dementia. Incorporating dialogic understanding into Person-Centred Care can promote a wider ethical and cultural understanding of social relationships. The disease does have a relentless progression but the nature and speed of the progression and how it is dealt with and managed is highly variable, as the memoir fiction confirms.

Bakhtin's dialogic position, because it is not conversation (although it may be) can encompass all the different communicative needs that dementia demands as it progresses. By emphasising the relationship and equality of 'I' and 'other' it places the various therapeutic endeavours in dementia care, from memory training to sensory stimulation as a continuum rather than a prescriptive activity for a particular stage in the dementia.

Changes in the clinical history have already been suggested to create more dialogic practice. Using different questions throughout the course of the illness such as 'As things are at the moment, who is in the most trouble?' opens the

possibility that it may be the supporter rather than the person with the dementia who may be struggling. This would not be uncommon in frontotemporal dementia (FTD) when the diagnosed person may be oblivious to any havoc the behaviour is creating. This open question, used routinely, would allow any 'trouble' to shift through the course of the illness. A second question would be about fear. Frank (2010) asks in DNA 'What is the force of fear in the story, and what animates desire? A question such as 'What do you fear the most?' and 'What is the best that could happen for you now?' may open important but sensitive areas for discussion with the clinician, patients and supporters and are similar to those asked in palliative care. That such questions are now asked routinely in this medical speciality suggests that change may also be possible in dementia services. A dialogical approach to dementia roots any care and support as being for a person rather than simply a patient.

Chapter 5

Summary and Conclusion: *The Discharge appointment*

The structure of this thesis is, in some ways, correlative to the trajectory of a patient's care. The first two chapters are an extended period of assessment, examining the background to the presenting problem and methods and theories to understand it before embarking on any treatment. Chapter 3 contains the various treatment interventions and Chapter 4 their evaluation. This final chapter acts as the discharge appointment, reviewing care and making plans for follow up. At the same time it acts as a meta-narrative telling a story about a range of stories: how dementia is portrayed in fiction and the clinic, where these stories meet and how such a meeting can be used with patients, their supporters and health professionals. The thesis itself is a story driven by review and retrospection rather than professional development. It uses experiences as remembered, with the intention that the thesis contains an equivalent authenticity about reading and practice as memoir fiction shows for dementia.

Autoethnographically I tell stories of how I emerged as a clinician/reader in NHS clinical practice to develop ideas about how fiction might be used creatively in the clinical space. In doing so three key theorists: Arthur Frank, Mikhail Bakhtin and Rita Charon are revealed as retrospectively illuminating clinical practice.

Socio-narratology has been tested in relation to a group of texts which address a health issue of significant cultural concern and one with which as a clinician I have been very familiar. It is not concerned with the literary worth of the texts but their potential to be active in the culture. Using Frank's narrative practice to explore 'how stories **do** their work for people and on people' rather than '**how** stories work' (Frank 2010: 28) offers a means of assessing the usefulness of

fictional stories in the clinical space and move the argument for the use of fiction from the whim described in the autoethnographic vignettes to a stronger theoretical base and promote dialogical practice. The negative outcome of my attempts to use ‘These are not my clothes’ (Kay 2012) as a tool for teaching staff in a unit struggling to provide adequate care might have been more positive if I had been able to demonstrate to commissioners and managers an ANA template and underpinning research outlining for them the impact of the dialogical position for people receiving care.

Frank claims that Dialogical Narrative Analysis (DNA) of socio-narratology should be viewed as a heuristic guide and a method for ‘movement of thought’ (Frank 2010: 72). He gives the researcher the following permission:

Take this set of questions about stories. Do what you want with them. Use some of them in your work; forget others. Modify those you use to fit your scene of enquiry, the better to understand the people you listen to, to make sense to people you hope will listen to you, and be responsible to the people who fund and employ you. Use dialogical narrative analysis to take care of yourself, which sometimes means not using it. But don't say no one ever told you that there is this way of doing narrative analysis. Don't say you never heard that dialogical analysis is an option.

(Letting Stories Breathe, 74. Original italics)

This generosity towards the researcher has enabled me to play and experiment with faux notes and templates. Frank’s direct voice to the reader/researcher and his use of self in developing socio-narratology suggested legitimacy for using autoethnography as the method of incorporating my experiences and the concept of the clinician/reader into the research. It is DNA which gives socio-narratology the breath in the title of Frank’s text. By breath he implies the ‘movement, reciprocity and constant flux’ (ibid: 73) of stories. This resonant and forgiving statement epitomises the difficulties using socio-narratology and DNA because they translate into concepts so loose as to become almost unworkable⁸⁰. They are

⁸⁰ They are reminiscent of what would have been called ‘grand fuzzies’ in my clinical psychology training in the late 1970s.

all encompassing and unboundaried with elusive and slippery implications. Yet, as a reader of stories and as writer of this thesis, I sense what he means by giving stories breath. The writing of the thesis has been one of movement, often halting, occasionally exuberant and sometimes progressing. The current shape has little resemblance to its initial conception and there has been more fun and adventure in the research than I had ever anticipated. My relationship with the selected texts has fluctuated. *The Corrections* (Franzen 2001) can still bear re-reading and I remain frustrated with the narrator of *Scar Tissue* (Ignatieff 1993) for being so self-involved yet still admire the text as an important one for me as a clinician and as the first to tell about and name dementia in fiction. In comparison three of the selected texts will be hastily committed to Oxfam. The work has made me contemplate the worth of the academic endeavour but it has introduced me to methodologies, such as autoethnography which has allowed me to explore my relationship(s) with fiction and to reflect on my own expectations, occlusions, prejudices and preferences, both as a long-standing clinician and as an avid reader. All the theorists I have used, Frank, Bakhtin and Charon have been discovered as part of the research. Together they have allowed me to understand that my response to fiction is the same as my response to patients and practice: What is really happening here?

This chapter could be presented as a synopsis of previous chapters but in the spirit of socio-narratology, breathing, and storytelling, a DNA of the thesis will be used to summarise the thesis and demonstrate how it has answered the research questions.

What does the thesis/story make narratable?

Dementia has a fictional presence unmatched by other illnesses or conditions and this thesis explores how dementia plays out in selected contemporary fiction. The stories told in the selected texts '*enact* realities; they *bring into being* what was not there before' (Frank 2010: 75. Original italics) and make dementia worthy of being discussed in and outside the clinic, and in fiction. A taxonomy of the selected texts

is proposed which reflects the work that dementia does in them. It is suggested that the narrativity and the protean nature of dementia is what makes it useful and beguiling to writers who feel able to use it in a range of ways, such as allegory, satire, plot development and to ground a fictional text as contemporary social realism. The use of dementia in fiction extends the cultural discourse about dementia which in turn affects how and why people present in a clinic.

The thesis deploys the Triple Analysis reading templates to demonstrate how the purpose of reading influences and constrains the information revealed from the text. This research intervention led to the development of the Augmented Narrative Analysis (ANA) reading template as an alternative model of history taking and as a means of developing assessment skills of health professionals. It aims to capture more accurately the range of issues of importance to patients and supporters and enable clinicians able to practice in a more dialogic manner.

The thesis makes a case for Bakhtin's concept of dialogue as it relates to dementia. Frank's theory is underpinned by Bakhtin's dialogism which Clark and Holquist describe as the 'mystery of the one and the many' (Frank 2010: 193). This phrase suggests the immediacy of communication between two persons is extended to include all communication, with everybody, past and potential. Dialogue, in Bakhtin's, terms transforms the speech act, or utterance, into an ethical position because taking account of what has been, and what might be, creates an unknowability which demands an openness to difference, where there is no last word and no finalization. This offers a useful and alternative understanding of dementia. Although radical it can stand alongside, rather than against, the medical model and provide greater heft to the theoretical underpinning for Person-

Centred-Care in dementia. It is a particularly relevant stance because as the disease progresses and the individual is less able to articulate their thoughts it places the experience of the person with a dementia as equally valid with the people providing the care. This dialogical position is a departure from the monological position of the 'un-demented know best' because the felt experience of sufferer/patient is equivalent and equal to that of the carer/supporter and the ethos of care is potentially changed.

Bakhtin developed the theory through his understanding of nineteenth century Russian novels. Rita Charon (2006) takes similar texts and uses them in Narrative Medicine where she develops her drill of Close Reading to promote an understanding of the position of the patient. The three theorists Frank, Bakhtin and Charon, are separate but linked. Each places centrally the experience of the reader and the text as vivid and able to effect changes. This position allows fiction to be incorporated into how the clinician understands and responds to patients.

Who is *holding their own* in the story, but also, is the story making it more difficult for other people to hold their own?

This complex question is hard to answer in terms of this thesis. In his exegesis of the question Frank cites its role as speaking truth to power alongside it as an 'enactment of resistance' (ibid: 77). The research interventions have revealed that the story elicited in the clinic misses the experience of the person with a potential dementia and marginalises the important issues for supporters which are revealed in memoir fiction. The clinical history makes it difficult for the person to demonstrate how they might (or might not) be holding hold their own and changes are suggested to make it more dialogical and better able to answer this question.

Patient Information leaflets which point the reader to helpful passages in texts demonstrate how fiction might help people to hold their own. Changes in the style of clinical questioning could demonstrate more effectively how patients and their supporters might be holding their own.

What is the effect of people being caught up in their own stories while living with people caught up in other stories?

In the suggested taxonomy of the selected texts the didactic fiction is used by authors who are overt in their desire to inform, support and reassure their readers who may be caught up in their story of dementia. They tell stories of dementia which have been researched through observation and as a result focus on the rituals and minutiae of practice the author has witnessed. In comparison the memoir fiction relates the familial experiences of watching a dementia in a parent first hand. The permissiveness of fiction uses the back stories of characters in memoir fiction to reveal why they are 'caught up' and react in the way they do. In doing so the texts create an authenticity and 'ringing true' not present in the didactic fiction. The literary fiction inhabits a middle ground; by exploring a relatively short period in the progression of a dementia the texts demonstrate how their life story affects how they manage their diagnosis and prospect of decline. Judge Teoh builds a garden as her means of creating something lasting to hold her own and Jake rekindles relationships.

The Triple Analysis templates allow the reader access to alternative lenses and thus the different stories within the text. Completing the templates for each text visibly demonstrates to the user the incompleteness of any set of questions to tell the 'full story'. The literary template leaves the clinician seeking more

information about practicalities and impact of the illness on the everyday and the clinical template reveals to the clinician areas of relevance not addressed in the clinical history, such as the fears of heritability of dementia, and, most importantly, who is in trouble. It may well not be the named patient.

What is the force of fear in the story and what animates desire?

Frank argues that ‘stories shape fears and desires’ (ibid: 81) and this thesis aims to explore the circularity of the portrayal of dementia in fiction and the wider culture. While the circle is neither vicious nor virtuous the reflectivity suggests why it is important to have a degree of verisimilitude in the portrayal. The predominance of early onset dementia in fiction is problematical in relation to the epidemiological evidence and develops the trope of dementia as a robber of expectations.

Conversely the increasing portrayals of dementia in fiction as a certain, but whimsical, attribute of growing old minimises the impact of the reality of a genuinely failing memory. Frank points out that desire and fear work in tandem. In fiction which expresses fear about developing dementia it indicates the desire not to have it. Fear and desire are interrelated.

At interviews during their career health professionals are often asked questions about their motivation to enter or continue with the profession. Many responses use the phrase ‘liking people’ or being a ‘people person’. What is probably meant by this is that they like the stories people tell them. When sitting on interview panels one of my stock questions was about what candidates had read or were reading. Candidates often found this unexpectedly challenging. Narrative Medicine offers a formal way of legitimising reading for clinical practice but Charon’s Close Reading demands an interest in narrative structure and textual

analysis which may only be relevant for health professionals choosing this as a clinical option. An alternative use of fiction as an assessment-learning tool has the potential to embed story telling as intrinsic to practice and open clinicians to the range of stories the person/patient might tell and a lead into the practice of formulation as an alternative to diagnosis. Formulation is the creation of a narrative between clinician and patient that offers a rationale for the current problems and a constructive way of working. The created narrative is expected to be active, and offer an agency for change in the same way in which Frank (2010) would see fictional narratives at work.

How does a story help people, individually and collectively, to remember who they are? How does a story do the work of memory?

Frank argues that ‘memoir is the genre of storytelling that self-consciously recollects memories’ (ibid: 84). This thesis has not reviewed dementia memoirs in any detail but has focussed on fictional portrayals of a dementia written by authors who could have written dementia memoirs but instead chose to use their intimate knowledge of the illness in a parent to create fictional texts. This step remove from memoir allows the narrative of illness to have a universality of experience and ability to tell a more compelling and universal ‘truth’ which memoirs cannot. The memoir texts have been useful in creating information leaflets for patients and supporters which draw on this clinical authenticity. Memoir fiction can be read in the knowledge that what is told is rooted in the direct experience of the author but because it is a fictional presentation privileges the reader to simultaneously know, and not know as befits them.

The work has reviewed a range of fiction which addresses dementia directly and analysed it using a range of templates. It has generated a way of understanding dementia care which offers an alternative to the medical model and presented a model of dementia which is culturally prescient by emphasising it as an illness of change rather than one solely of tragedy. These outcomes provide the bedrock for future research and evaluation.

The following points suggest specific areas of work that are required to be done after the groundwork of this thesis:

- Using the Triple Analysis as part of teaching clinical assessment to assess whether it encourages a more questioning attitude in the assessor and a greater interest in the meaning of the presenting problem for the individual.
- Field testing ANA and the post diagnosis structured interview which have a theoretical underpinning of socio-narratological practice with trainee health professionals. The acceptability of the task, texts, and whether any skills pull through into the clinical encounter in terms of increased confidence or development of practice which promotes the dialogic position should be explored.
- The acceptability and the usefulness of the patient information leaflets require evaluation in the clinic or through voluntary bodies. The leaflets for patients and supporters are presented as print ready for NHS ethics board scrutiny. Photocopies of selected pieces could be ‘prescribed’ by the clinician as part of the self-help model. Bibliotherapy is suggested as the first level of service delivery for Cognitive Behaviour Therapy (CBT) and

the information leaflets could be evaluated using the extensive methodologies of CBT research.

In addition the research suggests further interventions and applications which are informed by the research. These include:

- A pro-forma template suitable for sending to patients/supporters prior to the clinical assessment for completion. Such an activity offers the opportunity for increased engagement and a more dialogic practice in the clinic. If the ‘nuts and bolts’ of the clinical history were completed beforehand by the patient and family and returned in a pre-paid envelope the clinician would be able to read this before the consultation. This would mean that the clinician would have access to more information than that provided by the referrer and would be able to address the concerns of the patient and supporters more directly in the clinic. The addition of two DNA questions to the clinical history – Who is in trouble here? and What is the fear? add to the robustness of the assessment by addressing the very individual needs of each patient and their situation.
- The development of a more personal history should be created as a life story to which the patient and family could add in anticipation of the later inability to do so. This builds on the life story work undertaken predominantly by Occupational Therapists as a therapeutic exercise as part of reminiscence and to promote self-esteem. It is an alternative to the memory boxes of care homes and would offer the person with the dementia increased efficacy about how **they** would like **their** story to be told.

In *The Value of the Novel* Peter Boxall suggests that the current position of the novel is that it 'is not to be valued or understood on its own terms, but as part of a wider cultural, social or economic good (2015: 6). The thesis challenges that position through the use of the reader/clinician who values fiction and reading as an activity essential for the maintenance of the self but who simultaneously values the cultural role that it plays. It is a work which responds to the contemporary challenges of the novel in the belief that, like Boxall, it is 'the novel we need, more than ever, to help us to understand [such] communities and to live within them' (ibid: 144). I hope that it meets Ruth Felski's suggestion that reading is a 'coproduction between actors' in which the reader is placed in front of, rather than behind a text, to reveal 'what it unfurls, calls forth, makes possible' (2015: 12). What the work aims to do is understand Felski's three elements: why dementia unfurls the way it does in contemporary fiction, how the texts inform the culture about dementia and how using selected texts can be used to improve health care for people with a dementia and their supporters.

Endpiece

Writing this thesis began by describing the coverage of dementia one weekend in 2013. As I was editing the work dementia was still in the news and mentioned in the leader column in *The Guardian* (15 February 2016). The NHS, it asserted, was ‘creaking under pressures including dementia, alcohol and obesity’. While this may be true it seemed an unholy alliance of conditions and part of the developing soft discourse about fault and responsibility for dementia and reminiscent of what made Susan Sontag so angry about cancer in the 1970s. Fiction may not be able to halt this discourse but it can offer people an alternative. The following day (*The Guardian* 16 February 2016) dementia made another appearance in an editorial in relation to the problems the over 50s have finding rented accommodation as landlords ‘picture an ageing tenant as someone with impending health needs (including dementia) potentially messing up a portfolio of dream tenants.’ Later that week my local paper included piece about creating a ‘dementia friendly national park’ (*Tavistock Times* 18 February 2016).

Dementia remains ubiquitous. The effects of dementia may eventually be ameliorated or delayed but it is unlikely ever to be cured. With the current degree of intensity in the cultural discourse dementia will continue to hover as an existential and financial fear for old age and de facto, appear in fiction.

The work undertaken has left me with certain regrets about my clinical career. Had I been aware of Narrative Medicine whilst practicing I would have explored opportunities for training with Rita Charon. This may have enabled me to formalise the role of the clinician/reader of fiction in medicine and service provision and evaluated it, rather than using it in the quirky and eccentric manner in which I sneaked it in ‘under the radar’. I have discovered that Bakhtin is better

read first hand where his gentle and irreverent world view, perhaps driven by his particular circumstances, is more accessible than in glosses. Frank has been a powerful force in developing my thinking about fiction and in retrospect clinical practice. He introduced me to dialogism as a means of understanding my personal and professional world. Although I always felt that I practised with humanity and decency, an understanding of the dialogic position would have informed my own clinical practice and created a formal conceptual underpinning for the service I developed and managed. It would have been even better.

This work is a story and uses stories. In *History of the Rain* the narrator, Ruth Swain, a reader, in bed, in Ireland, with an undiagnosed illness knows that, ‘We are our stories. We tell them to stay alive or keep alive those who only live now in the telling. That’s how it seemed to me, being alive for a little while, the teller and the told’ (Williams 2014: 3). These sentences encapsulate memoir fiction and Frank’s theory of socio-narratology. Working on the thesis has allowed me to tell a story of exploration: how fiction might contribute to the care of a group of patients whose cultural heft is significant but whose experiences are deemed as nugatory and how utilising the dialogical position in clinical assessment and practice might reverse this position. In doing so it goes some way to ensuring that the experiences of the person with dementia are worthy of value, and respect. Fictional stories of dementia can be the introduction to a new practice of dementia care.

Kate Latham

May 2016

**Appendix 1: Photocopies of the drawings used by Grayson Perry on the
Memory Jar pot**

Memory Jar – a vase about Veronica and her husband,
Christopher, who is suffering from Alzheimer's.

They personified the disease as a third person in their marriage, 'Alzy', who in the final piece I have portrayed as a scissor-wielding demon who is cutting all their family memories, in the form of photographs, to shreds.

Appendix 2: Clinical description of the four main dementias: examples taken from memoir fiction and clinical practice

Each of the dementias has a slightly different course and presentation. An insidious memory loss, particularly of short-term memory, is the most prominent symptom. Often seen by the individual and supporters as a simple symptom of old age as ‘senior moments’ or the ‘mental lagoons’ of self-deprecatory jokes, they make dementia hard to diagnose in the early stages. There is no specific laboratory blood test, brain scan or psychometric questionnaire which can offer a definitive diagnosis despite requests in the clinic. A definitive diagnosis of Alzheimer’s Disease (AD) can only happen at post mortem when the characteristic changes of selective brain atrophy and increased dilation of the cerebral ventricles can be observed and plaques and neurofibrillary tangles are seen at the neuropathological level. However, as Nagy et al. (1995) have shown the picture is complicated. Their quantitative study demonstrated the relevance of strategic density in the frontal and parietal lobes, of tangles and neuritic plaques, but not amyloid plaques, in the presentation of AD.

Vascular Dementia (VaD) is the result of specific changes in the blood supply to the brain, either through the occlusion of a large vessel as a cerebral haemorrhage or from disease of the smaller blood vessels (small vessel disease). The old terminology for this disease, ‘multi-infarct dementia’ (MiD), was more descriptive and useful for clinicians as it enabled discussions about ‘a series of small strokes’ with patients. Such strokes (cerebral vascular events or CVEs) may

be no larger than a pin prick and show no apparent lasting changes but result in cumulative damage. The course of vascular dementia is often more stepwise and fluctuating and the person's insight is said to be better preserved. Post mortems suggest that the differential diagnosis between AD and VaD is insecure and the brain pathology suggests a mixture of brain atrophy, neuropathological changes and small infarcts are at work (Rockwood et al 2000). This position is reflected in *Forgotten*, where, despite being given a diagnosis of AD, David dies following a massive CVE.

Lewy-Body dementia (LBD) is the dementia which is closest to mental illness. It is a complex combination of the Parkinsonian features of slowness and a potential for falls, cognitive changes and psychotic features. These are usually visual hallucinations which present in a fluctuating pattern which makes life for the person and those around them hard to predict and frustrating. The visual hallucinations are usually benign, often of children or small animals, are not usually frightening for the person and have a different quality to the hallucinations of psychosis. In my experience of talking with patients who experience the phenomena they often appear to be driven by the environment. A corner of a square cushion on a sofa elicited a hallucination of a man in an old fashioned coolie hat and patterned curtains were seen as snakes moving up the wall. Both phenomena were described with a calm composure and acceptance. Alfred Lambert in *The Corrections* (Franzen 2001) experiences hallucinations which frighten and distress him but he knows that the phenomena are unreal and is able to say to his son Gary, 'I'm concerned about that something is wrong with my thoughts' (Franzen 2002: 577). Alfred has been diagnosed with 'parkinsonism, dementia, depression, and neuropathy of the legs and urinary tract' (ibid: 651). It is

clear that he has LBD. He does not have Parkinson's Disease Dementia (PDD) because the psychological symptoms are concurrent with the motor symptoms and are present at the lunch in New York with Denise prior to the cruise. Alfred demonstrates classic LBD symptomatology. Due to his tremor he is having difficulty managing the food Denise has prepared, problems maintaining his postural stability and is hallucinating children:

“There are children”, he said, sitting up straighter. “Do you see them? He raised a trembling index finger. “There.” His finger moved laterally, following the motion of the children he saw. “And there. And there.”

(The Corrections, 146)

Enid can only respond, ‘ “Al, those are *sunflowers*,” she said , half angry, half beseeching. “You’re seeing reflections in the window” ’(ibid: 146). Alfred learns, as one of my patients with LBD did, not to talk about the hallucinations to spouses as it made them worried or cross and usually both. The fluctuating pattern of the disease drives much of Enid’s mismanagement of Alfred’s condition as she sees his difficulties predominantly as a lack of will. Of all the dementias it is crucial to get an accurate diagnosis because people with LBD are highly sensitive to antipsychotic medication which, if it used to treat the hallucinations, can be life threatening. Fortunately there is the possibility of some symptom alleviation as it is the dementia most likely to respond to ACI medication. ACI medication is marketed primarily, and was originally only available for, those people with a diagnosis of Alzheimer’s Disease ⁸¹. Only a cynic would suggest that the 55% of dementias attributable to AD compared with the 15% for LBD is relevant in the emphasis in marketing ACI medication for AD rather than LBD where it has more efficacy.

⁸¹ This has now been relaxed.

Frontotemporal dementia (FTD) is a small diagnostic category but comprises 15% of people diagnosed with dementia and who are under 65 (Harvey et al. 2003). The figures demonstrate the tiny proportion of people with FTD but their care causes families and services significant challenges. It is the dementia which drives the myth of personality change or personality reversal in dementia. People diagnosed with FTD are young for any dementia service provision, often of working age and present not with memory changes, which occur later, but usually with behavioural changes to the extent that the families lose the person they used to know. The person with FTD becomes disinhibited in language and behaviour, frequently with a coarseness and lack of social nuance, labelled ‘emotional blunting’ and with no insight into the manner in which they are responding or presenting to the world. Such ‘frontal features’ also occur in the other common dementias as the morphology of the brain changes and the frontal lobes are affected. The result is the ‘challenging behaviour’ described by McHaffie:

This isn't a nice kind of challenging. This is what-on-earth- are-we-going-to-do-with-this-old-lady-kind-of-a-challenge. She can be quite horrible at times, James. I hate to say it, but she can. Vicious even.

(Remember Remember, 100)

Frontal behaviour can turn life upside down as families try to manage this very different person in their midst. FTD is the dementia which puts the greatest strain on social and familial relationships. The behaviours associated with frontal functioning do present in the dementia fiction but there has been no fictionalized portrayal of a frontal dementia. Rachel Hadas, a poet, has written a memoir of her husband, a professor of music at Columbia (2011) which draws on the work of Susan Sontag, Rita Charon and Emily Dickinson as she describes her husband's descent into a territory no longer knowable to her.

Appendix 3: Private Eye cartoons

An oldie writes...

Sir,
As someone recently diagnosed with Mild Cognitive Impairment [MCI] I was initially offended by the second cartoon on p40 in Eye 1410 ("Well, that's good. You haven't got dementia. You're just a stupid old git") – but happy to concede that I could see the funny side of the joke. Nevertheless, I do occasionally feel old and stupid as I deal with the effects of MCI. I am old, but I'm not stupid. How can I get a copy of this cartoon?

DAVID BROWNING,
Huddersfield.

Private Eye, 22 January 2016.

Private Eye, 29 November 2013.

Appendix 4: Socio-narratology's capacities

Definitions of the 'capacities' used in socio-narratology (Frank 2010.pp 28-41, 203)

Trouble — 'What gets a plot moving' (203). 'Stories have the capacity to deal with human troubles, but also the capacity to make trouble for humans' (28). 'Socio-narratology begins with trouble that swirls through stories: it is their occasion, their content, and too often their outcome' (29).

Character — 'Stories have the capacity to display and test people's character' (29). 'Between characters and actors, only characters have character, and the distinctive capacity of stories is to question character: its formation and deformations, its enactments and refusals, its decisive effects, and how it perhaps ought to be other than it is' (32).

Point of view — 'Stories have the capacity to make one particular perspective not only plausible but compelling' (32).

Suspense — 'stories make life dramatic and remind people that endings are never assured...[it] depends on a tension between possible outcomes — some to be hoped for and others to be feared' (32).

Interpretive openness — 'Stories have the capacity to narrate events in ways that leave open the interpretation of what exactly happened and how to respond to it' (34).

Out of control — 'Stories are like the magic spell that Mickey Mouse creates in the "Sorcerer's Apprentice" segment of the film *Fantasia*... [they] have a capacity to act in ways their tellers did not anticipate' (35).

Inherent morality — 'Stories inform people's sense of what counts as good and bad, of how to act and how not to act' (36).

Resonance — 'Storied echo other stories, with those echoes adding force to the present story'. 'Stories are textures of resonance' (37).

Symbiotic — 'Stories work with other things — first with people, but also with objects and with places' (37).

Shape shifting — 'Stories change plots and characters to fit multiple circumstances, allowing many different people to locate themselves in the characters in those plots' (39).

Performative — ‘Stories are not only performed; they perform...Stories *do* things; they *act*.’ ‘Whatever else storytellers are doing — reporting, convincing, instructing, indoctrinating, recruiting, amusing, generating sympathy or antipathy, or simply passing the time — they are always performing, and how they do whatever else they do is affected by the needs of the performance’ (40).

Truth telling — ‘Stories’ capacity to report truths that have been enacted elsewhere is always morphing into their more distinct capacity to *enact* truths. These truths are not copies of an original’ (40). ‘Stories have the capacity to balance multiple truths that have respective claims to expression. The more *dialogical* the truth — or the more polyphonic, in Bakhtin’s sense of blending multiple voices into a harmony in which they never entirely merge but retain some distinctiveness — the greater the capacity of stories to tell the truth that there are multiple truths’ (41).

Imagination — ‘Stories have the capacity to arouse people’s imaginations; they make the unseen not only visible but compelling. Through imagination, stories arouse emotions’ (41).

Appendix 5: The predominant capacities in the selected texts

To develop a typology of dementia fiction Frank suggests telling the stories oneself (Frank 2010: 120). A typology can 'divide stories according to which capacities are paramount, or how stories realize certain capacities in similar ways (ibid: 120). The inset is transcript of the descriptions given, when challenged, to summarise the selected texts and the capacities at play within them. The predominant capacities at are given in bold:

The Pink Ribbon: Ghost. Short story. Couple. Spouse. Amorphous narrative. **6, 1,**

3.

The Story of Forgetting: Metanarrative. Son. Search. Clarity of progress. Clinically resonant. **3.**

The Corrections: BIG. Family. Multiple viewpoints. **12** with a vengeance. **1, 2, 10, 11, 6, 9.**

The Garden of Evening Mists: It isn't about what you think it is about. **1, 10, 7.**

These are not My Clothes: Short story. Uber real. Reflects Francis report. Explores the lived experience. **8, 12, 3.**

The Wilderness: Measured. 3rd person. Dispassionate. Dementia used to reveal the past story. **6, 11.**

Forgotten: Straightforward linear narrative. Un-nuanced. Informs rather than shares. Not veracious. Sanitized. **1, 2.**

Grace and Mary: Veracious. Compassionate. Sainly son. **1, 2, 3, 7, 11, 12.**

Still Alice: Academic develops early dementia. To commit suicide or not while she still can? **1, 10, 11, 9.**

Scar Tissue: Dementia as philosophical conundrum. **1, 3, 5, 6, 7, 9, 11, 12.**

Remember Remember: Cold. Monologic. Didactic. **1, 2.**

Turn of Mind: Did she do it? Clever. **1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 13.**

Appendix 6: World Book Night titles 2011

- Adichie, Chimamanda Ngozi. 2006. *Half of a Yellow Sun* (New York: Alfred Knopf)
- Atkinson, Kate. 2004. *Case Histories* (London: Doubleday)
- Attwood, Margaret. 2000. *The Blind Assassin* (Toronto: McClelland & Stewart)
- Bennett, Alan. 2009. *A Life Like Other People's* (London: Faber and Faber)
- Child, Lee. 1997. *Killing Floor* (London: Bantam)
- Duffy, Carol Ann. 1999. *The World's Wife* (London: Picador)
- Garcia Marquez, Gabriel. 1988. *Love in the Time of Cholera* (New York: Alfred Knopf)
- Haddon, Mark. 2003. *The Curious Incident of the Dog in the Night-time* (London: Jonathan Cape)
- Hamid, Mohsin. 2007. *The Reluctant Fundamentalist* (London: Hamish Hamilton, 2007)
- Heaney, Seamus. 1990. *New Selected Poems 1966-1987* (London: Faber and Faber)
- Le Carré, John. 1963. *The Spy who came in from the Cold* (London: Victor Gollancz,)
- MacIntyre, Ben. 2007. *Agent Zig Zag* (London: Bloomsbury)
- Martel, Yan. 2001. *Life of Pi* (Toronto: Knopf Canada)
- Masters, Alexander. 2005. *Stuart, A Life Backwards* (London: Fourth Estate)
- Mitchell, David. 2004. *Cloud Atlas* (London: Sceptre)
- Mistry, Rohinton. 1995. *A Fine Balance* (Toronto: McClelland & Stewart)
- Nicholls, David. 2009. *One Day* (London: Hodder & Stoughton)
- Pullman, Philip. 1995. *Northern Lights* (London: Scholastic Point)
- Remarque, Eric. 1929. *All Quiet on the Western Front* (London: Little, Brown and Company)
- Sansom, C.J. 2003. *Dissolution* (London: Viking)

Spark, Muriel, *The Prime of Miss Jean Brodie* (London: MacMillan, 1961)

Walters, Sarah, *Fingersmith* (London: Virago, 2002)

Appendix 7: Faux notes for:

**Mrs Mary Andgrace created from *Grace and Mary* (Bragg
2013)**

s

NHS MRS MARY ANDGRACE DOB JULY 1907

Patient Number: 654327
Mental Health: 456321
NHS: 123456

Name Mary Andgrace
Alert Label _____
Visitor _____
SP _____

SECOLOR®

LAKESIDE COMMUNITY TRUST

CONFIDENTIAL



FILING IS EVERYONE'S RESPONSIBILITY

| | RETAIN UNTIL |
|----------------|--------------|
| Clinical Trial | _____ |
| Oncology | _____ |
| Paediatric | _____ |
| Obstetric | _____ |
| Other | _____ |
| Signature | |

Name: MARY ANDGRACE
dob: JULY 1907
NHS: 123456



| ALLERGIES | INFECTION RISKS |
|-----------|-----------------|
| | |

| GENERAL ALERTS/LABELS |
|-----------------------|
| |

Mental Health Directorate
Lakeside Community Trust

Please file in the following order (most recent on top)

NHS data sheet

Then

- Section 1** All referral information-original and subsequent
All CPA documentation including risk assessments.
MMSE
MEAMS
ACE-R
Care plans.
- Section 2** Daily Record Sheet for use by ALL professionals
- Section 3** Investigation details: blood results, ECG, scan results
- Section 4** All specialist assessments eg OT, PT, SALT, Clinical Psychology
- Section 5** Monitoring information and prescription copies
- Section 6** All Mental Health Act documentation
- Section 7** Correspondence
- Section 8** Everything else eg housing, courts, probation, AWOL.

FILING IS EVERYONE'S RESPONSIBILITY

| | | |
|----------------------------|---------------------------------|-----------------------|
| Name: <i>Mary Andgrace</i> | Date of Birth: <i>July 1907</i> | NHS No: <i>123456</i> |
|----------------------------|---------------------------------|-----------------------|

MEMORY SERVICE ASSESSMENT



GP: *Dr GP.* Surname: *ANDGRACE*
 When last seen: *Prev. see Dr Tait April 2009.* First Name: *Mary*
 Present at assessment: *Pr. Senior Carer.* Hospital No: *654321*
 NHS No: *123456*
 Date of assessment: *April 2009* Date of birth: *July 1907*
See in the Nursing Home. Still OK.

Introduction:
 Who we are Who referred you Happy with who is present How long we will be there
 With permission What we will do and consent to assessment Consent to refer on if necessary
 (if possible, something in every box) *Accepted the assr. ? capacity*

Before we start do you know what you want to happen from the assessment?
Not able to state. Says happy to chat.

Current Concerns
 Client view *Says has no concerns*
 What do you think is causing your memory problem? *Don't feel mem. big problem both to age*
 Family view *Has seen see Dr Tait. Phone call. Jan 2009 diagnosed with AD/VAD by Dr Tait. Jan gave details of history*
 Why now? Any new life events
 When problem with memory first noticed? *5+ years ago*
 Has the problem been gradual or stepwise? *Gradual steps*

Family History
 Born & brought up: *Local girl. Lived here all life*
 Family Structure: *Widowed. 1 son.*

| | | |
|-----------------------|---------------------------------|-----------------------|
| Name: ANDORACE | Date of Birth: July 1907 | NHS No: 123456 |
|-----------------------|---------------------------------|-----------------------|

Views of childhood (nil untoward, happy, unhappy):
Says good childhood.

Parents (+causes of death):
Not able to give details.

Employment History

Education: **Says enjoyed school.**

Age of leaving and qualifications: **Says enjoyed school. No details**

Main area of employment: **Only able to say was work.**

Relationships

Marriage (how many times): **1**

Any history of Domestic Violence? **Not reported (from son).**

Children (g children & g g children) names and contact (visits, phone calls, skype)?
1 son, Tom. Knows his grandchildren. Not able to name

Is there someone with a particular carer / supporter role? Who? Name & relationship:
Carers visit ++

Do they struggle to help? (any ill health, live away, work full time)
son London, visits regularly

Do they help with finances?
Phone ++ ++

Do they have a Lasting Power of Attorney? **son has**

Do you have Attendance Allowance? **?**

Is there an Advance Directive? If so who has it? Where is it?
Not aware

CARER (in to. from son)

If appropriate – how many hours per week do you spend in your role as carer/do you receive any help?
NO = reason for admittance to NH

Could the person be left for a weekend?
Who needs 24 hr. care prior to if not

How long could you leave them for?
London

What would be the concerns?
NO.

Would you like a carer's assessment?
NO.

If the person feels that they are a carer complete carer checklist.

Name: Mary ANDERSON Date of Birth: July 1907 NHS No: 1236J6

Do you drive? NIA
 Are family happy to travel with you?
 Any accidents or near misses? If Y details?
 DRIVING-if yes alert them to implications of assessment and diagnosis)

Activities of Daily Living (think initiation, planning and organising, effective performance)

Housing - Do you have any problems with your accommodation? Is it your own home, rented, sheltered etc?
 in NH

Do you have any problems with personal hygiene (bathing/showering)? What are they?
Has full nursing support to on ADLs but accepts

Do you have any problems with dressing? What are they?
Will do it with prompts. Full support given

Do you have any problems with continence? What are they? (constipation, getting caught short etc)
She says no. Staff report faecal + urine. Managed

Do you have a downstairs toilet? NIA 2 floors + regular toilet

Do you have any problems with shopping? What are they?
NA

Do you have any problems with eating (any weight loss)? What are they?
 Needs prompts to continue. Still eats + keels. Uses cup. Needs

Do you have any problems with meal preparation (do you cook like you used to)? What are they? prompts re drink
NIA

| | |
|-----------------------|-----------------------------------|
| What level of ability | Cooks unsupervised |
| | Reduced skills <u>NA</u> |
| | Can no longer cook complex meals |
| | Can make sandwich, cereal, toast. |
| | Meals on wheels |

Can you use the telephone or does this cause difficulties? What are they?
 Can you make appointments? Yes speaks to son when he calls. No help
 Can you take messages reliably? to unholo

| | | |
|-------------------------------|------------------------------------|--------------------------|
| Name: Mary ANDERSON | Date of Birth: July 1907 | NHS No: 123456 |
|-------------------------------|------------------------------------|--------------------------|

Can you do your housework or does this cause difficulties? What are they?
NA

Do you go out regularly? (inc. church, clubs, outings, friends, neighbours, family) Where?
Am pleasant. Mikes & home. Tais in c mp / music

Have you stopped going out or doing hobbies you used to enjoy? If Y why? Memory or other reasons?
Yes

Would you like to take up any of these activities again? Which ones?
No

Do you need help accessing activities? What help?

How far can you walk? **Unable to transfer / walk independently.**
Will help. Not walk unaided.

Do you need a stick/frame etc?
Uses chair for more than few unaided steps

Have you had any falls recently? Explain
None rec. # NOT → 6th admission.

Who looks after your feet?
Home organisers **8th rehab: ? memory loss**

Can you cut your own nails?
Not

Can you get in a car? Use a bus? **No**
Can car still manage → car unaided.

Do you have any problems taking your medication? What are they?
Staff administer.

Can you tell me what medication you take and why? (concordance, understanding, memory, correct)
***State list given by patient, state seen latest script and date.**
Galentamine PR give by Dr Tait

Side effects or allergies?
None reported c with / sm. Staff will report p

Self managing?
No **to response to Galentamine**

Blister pack?
No

Compliant with medication? **Yes**

Do you take any over the counter medication? If so what? **NO**

| | | |
|------------------------|-----------------------------|-------------------|
| Name: Mary ANDORACK | Date of Birth: July 1907 | NHS No: 123456 |
|------------------------|-----------------------------|-------------------|

Physical health
Current physical Problems

Patient view
How is your physical health?
She thinks fine for age.

Have you had any hospital admissions?
Unable to recall. (see mt. letter)

For what & when?
1x got power to admission & NH. Fall at work → Aches

Do you see your GP very often?
NH cell. OT fell horrible to & mobility
massage or home :- memory

When was the last time?
On admission

Do you feel fit and well today? If not please tell me why.
'Yes dear I do'

Do you have any pain?
Joints not

Do you smoke? How many? (consider safety issues and health advice)
Non

Do you drink alcohol? How much?
Non

Do you use any other substances?
NO!

Do you have any giddy turns, or 'funny dos'? (Are they related to epilepsy, heart, diabetes?)
Episode in church (2012) ? TIA

| | | | |
|---------|--------------|----------|-------------------------------|
| Bowels | Incontinence | Heart | Cephalic med. BP / statin GDM |
| Bladder | Incontinence | Lungs | NR |
| Asthma | NR | Diabetes | NR |
| Thyroid | NR | Epilepsy | NR |

*for statin hump
see mt. letter

Did you have rheumatic fever as a child?
Jan thinks not

Have you had any trauma to the head? Any boxing? Any KO? Details?

Have you had any illnesses abroad? (malaria)
None

Do you have any problems with your sight? Details? None significant

| | | |
|----------------------------|---------------------------------|-----------------------|
| Name: Mary ANDGRACE | Date of Birth: July 1907 | NHS No: 123456 |
|----------------------------|---------------------------------|-----------------------|

Do you have any problems with your hearing? Details?
She is able to hear conversation at ordinary volume

Have your eating preference changed? (preference for sweet things, eats anything) Details?
None reported

Do you feel your taste has changed?
None reported

Do you feel the cold more?
Yes.

How do you sleep? **Sleeps well (stays) + she says she does**

Bed time? **By 9.00**

Getting up? **She gets up when she is - if not in bed she gets help**

Do you feel rested?
She says no.

Any recent changes?
Snoring & UR

| | |
|---------------------------------------|----------------------------------|
| Problems with skin? | None reported by smtr. |
| Bruises easily? | NA reported. not visible |
| Cuts? | '' |
| Rashes? | '' |
| Altered Sensation (numbness/tingling) | She says no |
| Pressure Areas (if appropriate) | Smtr report on her |
| Smell (gas) | Poor / none / good / not as good |
| Smoke Alarm? | NTF |
| Carbon monoxide? | |

Have you had your blood pressure and pulse taken recently? **on admission. Smtr monitor per GP request**

If appropriate add new BP for 6 weeks. Please take BP and Pulse.

BP:

Pulse:

Psychological Health

Previous contact with MH services? (pt or family) **None**

Any recent changes to mood? **She says no.**

| | | |
|---------------------------|-----------------------------|-------------------|
| Name: Marilyn ANDERSON | Date of Birth: July 1907 | NHS No: 125456 |
|---------------------------|-----------------------------|-------------------|

Low mood/depressive episodes?
Denies

Thoughts about self harm? (or harm to others – verbal or physical)
"Absolutely not – why should I"

GDS/STORM needed?
No

Can you relax?
Oh yes.

History of anxiety or worries?
None reported

HAD needed?
No

Seen things that others cannot see/hear or believe things others think odd? Details.
No – denied, none reported by staff

OCD symptoms?
Nil

Memory

Changes in language? (quality of conversation, sentencing)
Can be v. chatty or terse. 'surface' – cocktail party

Changes in personality? (check with others present)
Start report she is as ever

Repetitive questions?
+++ but easily reassured

How does your memory affect everyday life?
Not here but +++ or home

If there's a crisis what would you do?

- Main meal yesterday
- Family news and network (remember who's who and what they're up to?)
- TV remote controllers
- ATM
- Own appointments
- Misplacing items
- Central heating
- Household appliances (e.g. kettle, washing machine, cooker, microwave)

} vvv supportive environment – so few req. demands

Any memory disasters?
Had wandered from home

Name: MARY ANDERACE Date of Birth: July 1907 NHS No: 12 3456

Does the family have any concerns about the person's capacity to make sensible and logical decisions about important issues? (moving house, finances) Yes No
 These are: Not able to understand chance / not any not
John has LPA
 Do you have any concerns about the person's capacity?
 These are: understanding
 retaining
 weighing
 communicating in detail

NOW DO ADDENBROOKE'S (ACE-R) OR MMSE TEST

Action

Does the person want to be told if they have a diagnosis? Not addressed at
John aware of diagnosis. not.

Do they give permission for their memory difficulties to be discussed with anyone else? Who?
Yes to John

Onward referrals:

Consultant Y/N
 What are the key issues for clinic? has see see

Social services Y/N

OT Y/N

Carer assessment Y/N

Other? Y/N

Assessment summary or outcome: John is not staff to manage
John's care. Monitor regularly
Phone next

Who else can we talk to about your memory?
My son

Could you come to clinic at short notice? Dr Tait will renew Omms
within.

Print Name: A.M. NURSE Date: April 2009

Signed: Am Nurse NHS No: 12 3456

| Name: Mary Andgrace | | |
|------------------------|---|------------------------|
| | NHS No: 123456 | |
| Date and time of entry | Details of contact and actions taken | Signed and designation |
| April, 2009 | HV No family present. Seen in room. Senior carer present throughout. | |
| HV. | | |
| T.N.H. | Prefers to be called Mrs Andgrace | |
| | MSE | |
| | <ul style="list-style-type: none"> • Tidily dressed. Staff report chooses own clothes. Retains colour coordination. • Gives good eye contact. Social graces ++. • Prosodic variation OK. • Gives name / age / not dots. OK mouth. Knows where she is. | |
| | Name of son ✓ where he is ✓ | |
| | Aware he visits. Not able to say when last / what they did (staff report he took her out) | |
| | Immediate recall for name ✓ | |
| | Date X Month X Year X | |
| | Lunch X - staff prompt ✓ (f x c day) | |
| | Count & from 10 ✓ | |
| | Recall of 3 items 1/3 | |
| | Sentence rept. - X (but close) | |
| | 3 item command - 2/3. | |
| | Newspaper - only able to read headlines. | |
| | Not asked to write. | |
| | Mood | |
| | Subjectively - spirits OK | |
| | Does not present as depressed / sad | |
| | Low mood not reported by staff. | |
| | <ul style="list-style-type: none"> • Hallucinations. • Delusions - staff report with frequently ask to go home. Can be diverted. | Page No: 1 |

| Name: Mary Andrice | | |
|------------------------|---|---|
| | NHS No: 123456 | |
| Date and time of entry | Details of contact and actions taken | Signed and designation |
| April 2009 HV | Seen for assessment in vit. Amary reference from Dr. Tait. See Memory assessment form. Plan: px for galantamine 2 NR Staff will (STAR - 15 months) Telephone contact after 1 week. Visit after 2 weeks | AMNURST MEMORY NURSE AM Nurse April 2009 |
| May 2009 HV | In visit - no side effects re: galantamine. Appears happy. and settled. Repeat memory test next time Plan: visit 4 weeks | AMNURST MEMORY NURSE AM Nurse May 2009 |
| June 2009 HV | Chatty - good eye contact. and more confident - abandoned fr going conversation. Knows what she is doing. Social graces well preserved. Partly gross of day to day life go back for. Not disturbed Staff monitor BP Regular visits from GP PRN Plan: no fu from Memory Nurse Lance Dr Tait will do this as per letter D/C from my case 1000. | AMNURST MEMORY NURSE AM Nurse June 2009. |
| | | Page No: 3 |

| Name: ANDERACE | | |
|------------------------|--|--|
| NHS No: 123656 | | |
| Date and time of entry | Details of contact and actions taken | Signed and designation |
| NOV 2009 HV | Tolerating galantamine - maintenance dose. Mount and actual grades. Plan: continue and speak to Jm - Gm/Hs/HV T call - he feels some improvement Conversation more coherent | Dr Tait Dr TAIT CONSULTANT PSYCHIATRIST |
| July 2010 HV | Continues on galantamine. Staff report more time in bed. T call - sm Bear across music | |
| Jan 2011 HV | ? Seen on a good day Great form Name ✓ Place ✓ History ✓ 10 objects - most recalled No probs reported by staff - activities ✓ T call sm: - memory stable ↓ actual darkness ↑ noise ?? frontal involvement Plan: Gm/Hs review - done ✓ | Dr Tait Dr TAIT CONSULTANT PSYCHIATRIST |
| August 2011 HV | Logmanant ↓ Physically - appears ↑ fall Staff - more time in bed Appetite ↓ - needs prompting + Fluid - ↑ prompting No significant weight loss | |

| Name: <u>KIDGRACE</u> | | |
|-----------------------------------|---|----------------------------------|
| NHS No: <u>123456</u> | | |
| Date and time of entry | Details of contact and actions taken | Signed and designation |
| August 2011 cont'd | Not keen on intervention T/call: sm likely to stop galantamine next visit & efficacy Physical frailty Plan: review 6mths, sooner if req'd | Dr Mitt CONS, PSYCH Dr Lat |
| Jan 2012 ACM 25 Jan 2012 | T/call sm - ?? out in car. Has had recent ch. infection Why not? Renew sm | Dr Mitt CONS, PSYCH Dr Lat |
| April 2012 AV | → aware Staff - more days in bed Van drove - odd tonight day → response to care Will tolerate imip but spits meds. Staff gently persist Staff - more imitable "not like her" Plan: try citalopram liquid 10mg qd speech sm T/call - sm made aware galantamine stopped, citalopram prescribed OK with this Plan: renew 6 weeks | Dr Mitt CONS, PSYCH Dr Lat |
| May 2012 AV | Bed bound. No significant formal contact little response Staff have tol plans in place. End stages - sm aware Staff will let me know if req'd | Dr Mitt CONS, PSYCH Dr Lat |

Mental Health Services for the Older Person,
Lakeside Community Trust.

July 2012.

Mr John Andgrace,
London.

Dear Mr Andgrace,

My secretary has just let me know that you had telephoned to let me know that your mother passed away yesterday evening. I am sorry that I was unable to take your call.

The loss of ones remaining parent is always a significant one but I hope that the knowledge that the care and support you gave your mother over her long and difficult illness was exemplary offers you some comfort.

Please accept my condolences.

Yours sincerely,

Dr Tait,
Consultant Psychiatrist,
Mental Health Services for the Older Person.

Mental Health Services for the Older Person,
Lakeside Community Trust.

May, 2012.

Dr GP,
The Surgery.

Dear Dr GP,

Re: Mrs Mary Andgrace, dob July, 1907.
The Nursing Home, Silloth.
NHS:1234546.

I reviewed Mrs Andgrace yesterday. She does appear calmer on the Citalopram but spends virtually all her days, curled in a foetal position ⁽¹⁶¹⁾ in varying degrees of sleep. Her son says that he thinks she still responds to his voice and touch ⁽²⁴⁶⁾ but she no longer verbalises or sings as she has in the past ⁽²⁴⁷⁾

I think Mr Andgrace is realistic in that we are entering the very final phase of his mother's dementia and that the important issue now is to keep Mrs Andgrace as comfortable as possible. All EOL discussions have been made and documented.

I have not arranged to see Mrs Andgrace again but will of course be happy to do so if you feel that I can help.

Yours sincerely,

Dr Tait.
Consultant Psychiatrist.
Mental Health Services for the Older Person.

April, 2012.

Dr GP,
The Surgery.

Dear Dr GP,

Re: Mrs Mary Andgrace dob. July, 1907
The Nursing Home.
NHS:123456.

I visited Mrs Andgrace at The Nursing Home last week.

There has been a significant deterioration awareness and engagement⁽¹⁰⁰⁾ with now only very rare instances of recall⁽¹⁹⁹⁾. She spends most days in bed⁽²⁰¹⁾ with the occasional day when staff report she looks and sounds "as right as rain"⁽²¹⁰⁾.

Mrs Andgrace's nutritional intake is somewhat variable but she does appear to tolerate the supplementary drinks you have prescribed and she has not lost any significant weight. She is increasingly resistive to personal care and staff use what I call the 'take off and land' approach to addressing this, hoping that Mrs Andgrace will have forgotten that she was irritable and cross when they last approached her⁽²⁰²⁾. It seems to work most of the time and not add to her distress.

Mrs Andgrace has started to spit out her medication⁽²⁰²⁾. Increased irritability is sometimes a feature of distress or depression in dementia and I have started her on a low dose of Citalopram to be given in liquid form. It will take some time to work but I think it is worth a try. If it is not effective there are further options to be considered.⁽²⁰²⁾ I have stopped the Galantamine.

I have spoken to Mr Andgrace about the changes in medication.

I will review Mrs Andgrace in 6 weeks.

Yours sincerely,

Dr Tait.
Consultant Psychiatrist.

cc. Mr John Andgrace, London.

Mental Health Services for the Older Person.
Lakeside Community Trust.

January, 2012.

Dr GP.
The Surgery.

Dear Dr GP,
Re: Mrs Mary Andgrace dob July, 1907.
The Nursing Home, Silloth
NHS : 123456.

Thank you for asking me to bring Mrs Andgrace's review forward.
Mr Andgrace had made me aware that she had a chest infection ⁽¹⁶⁷⁾ from which she had taken some time to recover. He spoke to me about the possibility of taking his mother to view some old family sights on one of his visits given that it will almost have been a year since a 'good day' ⁽¹⁸¹⁾ has coincided with one of his visits and she was happy to have a trip in his car. I cannot see that there would be any harm in this as long as she is physically well enough and you will be more aware of this than I am.

I will pop out and see Mrs Andgrace again in 2 months and will talk with her son about stopping the Galantamine.

Yours sincerely,

Dr Tait.
Consultant Psychiatrist.
Mental Health Services for the Older Person.

cc. Mr John Andgrace. London.

Mental Health Services for the Older Person,
Lakeside Community Trust

January 2011.

Dr GP,
The Surgery.

Dear Dr GP,

Re: Mrs Mary Andgrace dob. July, 1907.
The Nursing Home, Silloth.
NHS: 123456.

I reviewed Mrs Andgrace when I visited The Nursing Home last week and have since spoken to Mr Andgrace on the telephone. At my visit Mrs Andgrace 'scored markedly better than last time on numbers. She was better on association as well. When I asked her who she was and where she came from she was every good. She talked a little about Wigton. She knew she was in Silloth. She remembered more of the ten objects than she has done over the last eighteen months. We are not talking about substantial but we are talking about "marked" ⁽¹²⁴⁾ improvement. I think we should continue with her current maintenance dose of Galantamine.(8 mg bd)
Mr Andgrace agrees that there are some elements of improvement or at least of maintenance in terms of cognition but he has detected a subtle change in his mother's personality. Mary is less aware of social cues, can be rude to others and is more imperious than in the past in a lady whom he describes as "politeness and sympathy had been set in concrete" ⁽¹²⁴⁾ I suspect that this may be the beginning of some frontal atrophy. Mr Andgrace has discovered that his mother has taken to enjoying speedy wheelchair rides through the corridors which I suspect would not have been the case in the past ⁽¹²³⁾ and may hint at a degree of disinhibition.

Mrs Andgrace continues to participate in some activities in the home and spend some time in the sitting room with other residents.

I will review Mrs Andgrace in 6 months.

Yours sincerely,

Dr Tait
Consultant Psychiatrist.
Mental Health Services for the Older Person.

cc. Mr John Andgrace. London.

7

Mental Health Services for the Older Person,
Lakeside Community Trust.

July, 2010.

Dr GP,
The Surgery.

Dear Dr GP,
Re: Mrs Mary Andgrace, dob July, 1907
The Nursing Home.
NHS : 123456.

I visited Mrs Andgrace last week and have since caught up with her son on the telephone.

Mrs Andgrace continues to do well on the Galantamine and is maintaining her mental test scores. Staff report no symptoms of BPSD. Although starting to spend more time resting on her bed she still enjoys going out with her son when he visits. He reports that she responds very actively to old songs and hymns and feels that he had some significant success with a book of Old Wigton photographs when she was able to accurately name some of the sights.⁽⁹⁹⁾

Mrs Andgrace will continue on the maintenance dose of Galantamine. I will review her in 6 months and the Memory Nurse will continue to visit. *see 2010 log*

If there are any problems please let me know.

Yours sincerely,

Dr Tait.
Consultant Psychiatrist.
Mental health services for the Older Person.

cc. Mr John Andgrace. London

6

Mental Health Services for the Older Person,
Lakeside Community Trust.

November, 2009.

Dr GP,
The Surgery.

Dear Dr GP,

Re: Mrs Mary Andgrace dob July, 1907
The Nursing Home .
NHS: 123456.

I reviewed Mrs Andgrace at home in November. Mr Andgrace was informed of my visit and I spoke to him on the telephone afterwards.

Mrs Andgrace has tolerated the Galantamine and is on the maintenance dose. It does appear to have offered Mrs Andgrace some benefits. She has improved her mental test score by a little and her son reports that when he visits he has noticed an improvement in her everyday memory functioning and what he describes as "lapses into normality" although he fears that this may mean that his mother is may be aware of what is happening to her. ⁽⁷⁵⁾ I have reassured him that these sudden flashes of insight are not uncommon in a dementia and were noted prior to medication being available. He confirms what I observed during my visit, that her conversation was more coherent and less repetitive. Given these improvements Mrs Andgrace will remain on her current dose of Galantamine. I will review her in 6 months or sooner if you have concerns. The Memory nurse will continue to monitor her.

Kindest regards,

Yours sincerely,

Dr Tait.
Consultant Psychiatrist.
Mental Health Services for the Older Person.
cc. Mr John Andgrace .London.

5

Mental Health Services for the Older Person,
Lakeside Community Trust.

April, 2009.

Dear Dr Physician in Elderly Care,
Re: Mrs Mary Andgrace, dob July, 1907.
The Nursing Home. Silloth⁽¹²³⁾.
NHS :123456.

Thank you for your referral of Mrs Andgrace to our service.

I visited Mrs Andgrace at the Nursing Home in April. Mrs Andgrace was unable to give me any significant personal history but did know the name of her son and was aware that she was not in her own home. She had no recollection of her recent stay in hospital or of events that have necessitated her admission to The Nursing Home.

Mrs Andgrace does appear to be well placed. She requires full time nursing support to meet her physical daily needs. Staff report that there is some variability in her demeanour⁽²³⁾. She tends to be very sleepy⁽²³⁾ during the day but there are no reported problems of nighttime wakefulness. There are times when she will engage with staff and appear to enjoy some gentle banter and local information. She will of course have known many of them during her long life in the local community. Her speech maintains prosodic variation but is repetitive in content. She does not present as being depressed and responds with pleasure to visits from her grandchildren. Staff do not report any significant symptoms of BPSD and she has settled well in the calmer environment of the home.

I spoke on the telephone to her son to inform him of my intended visit and then afterwards at more length to inform him of the diagnosis and proposed plan of care. He was able to give me a comprehensive personal and medical history and is well informed about the nature and likely course of the disease. He is keen to ensure that Mrs Andgrace has as much stimulation as possible within her physical limitations and variability. There have been times when Mrs Andgrace has lost access to her adult life and family faces and has asked for her own mother which has caused her son some concern⁽⁹⁾ although this state tends to be somewhat transitory and she can be distracted from these concerns. I have reassured him that reminiscing with his mother, by whatever

means- photographs, music, newspapers- is a perfectly valid way of doing this^(23,61,97) It ensures that the person can engage in areas where they are likely still to be able to perform and can be helpful in maintaining self esteem.

Diagnosis:

Given the history and presentation and her performance on the abbreviated mental test I carried out I suspect Mrs Andgrace has a mixed dementia (DSM: F.002).

Treatment:

I have given to the staff a 28 day prescription for Mrs Andgrace for Galantamine 4 mgs bd. and will arrange for one of our Memory nurse to visit the home to start her on this and work with staff to ensure that titration and monitoring checks are in place. If there are no side effects or contra indications I would expect the dose to rise to 8mg bd for a further 4 weeks and then a maintenance dose of 8-12 mgs. The allocated Memory nurse will take out the following prescriptions.

Plan:

I will review Mrs Andgrace in 6 months.

If you have any concerns before this please do not hesitate to let me know.

Yours sincerely,

Dr Tait
Consultant Psychiatrist
Mental Health Services for the Older Person.

Cc General Practioner
Mr John Andgrace . London.

Referral letter beginning to be inserted here
THANK YOU STAPLES

We have not arranged to see Mrs Andgrace again but will be happy to do so at any point in the future.

Many thanks for your help and for taking over the consultant care of this lady.

Yours sincerely,

Dr Physician in Elderly Care
Cc.-General Practitioner.
Mr John Andgrace. London.

ORDER OF FILING

1. Front sheet of patient details
Sheet of patient labels
Details of any patient access requests

FIRST SPINE

2. Allergies Chapter Card
3. Correspondence Chapter Card
(correspondence to be filed in reverse chronological order - latest on top), to include:
4. (a) correspondence to and from other specialities
(b) correspondence to and from therapists/social workers etc
(c) outpatient/inpatient summary
(d) inpatient discharge note
(e) red top referrals
(e) referral letters from GP
(g) copy of A/E card when used as a referral
5. Consent/Living Will Chapter Card to include correspondence from patient detailing his/her wishes regarding treatment
6. Chapter Cards colour coded specialty to follow the filing format detailed in 5.
7. Outpatient/Inpatient/Day Case clinical notes in chronological order (most recent at the back)
To include:

| | |
|-------------------------|--------------------------------|
| (a) clinical notes | |
| (b) operation notes | } |
| (c) anaesthetic records | } with relevant clinical notes |

SECOND SPINE (FIRST CLIP)

1. Pathology report sheets to be filed (most recent sheet in front) in the following order:-
 - (a) Haematology and Immunology mount sheet (red)
 - (b) Clinical Chemistry mount sheet (blue)
 - (c) Microbiology mount sheet (yellow)
 - (d) Histology (no mount sheet needed)
 - (e) Cytology and Sperm Count mount sheet (white)
 - (f) Endoscopy, gastroscopy reports
 - (g) X-rays, Ultrasound & Nuclear Medicine mount sheet (green)
 - (h) Audiograms
 - (i) Growth Charts
 - (j) Electroencephalograms (EEG's)
 - (k) Pulmonary Function tests
 - (l) Electrocardiograms (ECG's)
 - (m) Echocardiograms and Exercise tests
 - (n) Cardiogram
 - (o) Skin Prick Test reports
 - (p) Medical Photographs
 - (q) Post Mortem Reports

SECOND SPINE (SECOND CLIP) - to be filed from front to back

- (a) Microfilms
- (b) Nursing Kardex
- (c) Drug Prescription charts
- (d) Fluid Balance charts
- (e) T.P.R. charts
- (f) Operation check list
- (g) Other nursing records, including nursing intensive care charts etc.

NOTES

1. The nursing notes can be removed and kept in a separate volume at the Central Records Library when notes get too bulky.
2. Further details are provided on the chapter cards.
3. It is the duty of everyone handling notes to ensure that items are inserted

SECOLOR

1

CLIPMAP A4
DOSSIER CLIP A4
CLIP FILE A4
CLIPMAPPE A4



Prod.no.:31031**

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Appendix 8 : Faux notes for:

Mr Alfred Lambert created from *The Corrections* (Franzen 2001)

Patient Number:
Mental Health:
NHS:

Name Alfred LAMBERT
Alert Label _____
Visitor _____
SP _____

NHS Alfred Lambert dob

SECOLOR®

LAKESIDE COMMUNITY TRUST

CONFIDENTIAL

Name: **Alfred LAMBERT**
dob:
NHS:

| | RETAIN UNTIL |
|----------------|--------------|
| Clinical Trial | |
| Oncology | |
| Paediatric | |
| Obstetric | |
| Other | |
| Signature | |

FILING IS EVERYONE'S RESPONSIBILITY



NHS Number: 123456

Hospital Number: 654321

Lakeside Community Trust

Name: Mary Andgrace

Address: The Nursing Home Silloth

Date of Birth: July, 1907

Patient telephone:

Patient Mobile:

Marital Status: Widowed
Religion: Church of England
Patient Status: Informal

NI Number: AB12CD34
Ethnic Origin: British
Social Services number:

Next of Kin: Mr John Andgrace
Address: London
Relationship: Son
NOK Telephone: 0

Mobile Number: 077123456

Carer:
Address:
Relationship:
Carer Telephone:

Mobile Number

Family:
Address:
Relationship:
Carer Telephone:

Mobile Number

Nearest Relative:
Address:
Relationship:
Telephone:

Mobile Number

GP: Dr GP
GP Address: The Surgery

GP Telephone:

Date of 1st contact with any MH provider:

Care Co-ordinator: Kate Latham
Admission Method:
Admission Date:
Discharge Date:
Consultant: Dr Tait

Admission Source:
Ward:
Discharge Method:

| ALLERGIES | INFECTION RISKS |
|-----------|-----------------|
| | |

| GENERAL ALERTS/LABELS |
|-----------------------|
| |

| | | |
|--------------------------------|----------------|---------|
| Name LAMBERT, ALFRED | Date of Birth: | NHS No: |
|--------------------------------|----------------|---------|

MEMORY SERVICE ASSESSMENT



GP: **Dr. Hedg Peth** Surname: **LAMBERT**
 When last seen: First Name: **Alfred**
 Present at assessment: **Mrs Lambert, Gary, Denise, Chip, Mr Lambert.** Hospital No:
 Clinician/reader: **H.R. author** NHS No:
 Date of assessment: Date of birth: **75 years (89)**

Based on information available up to full from ship (390) a Luxury Junk Cedar Cruise (21)

Introduction:
 How long we will be there
 Who referred you Happy with who is present
 With permission What we will do and consent to assessment Consent to refer on if necessary
 (if possible, something in every box)

Before we start do you know what you want to happen from the assessment?

Predominant view: There are things in life that simply have to be endured (207)

Current Concerns: **Morr problems - sports (10), 10 years or so (11)**
 Client view: **Can be variable 'sudden vigor' (25)**
'These shaking hands belonged to nobody but him, and yet they refused to stay his' (77)

What do you think is causing your memory problem?
 Mrs. Lambert date problems from call about Denise's divorce

Family view: **Enid: 'what he has is very mild and almost completely controllable with medication' (20) Denise: 'Dad is sick' (36) - wants him signed up for Coreball (240)**

Why now? Any new life events
Gary: 'wants us to sign up to assisted living' (72)

When problem with memory first noticed?
'this hair should not be on these tracks' (199)

Has the problem been gradual or stepwise?
*** Enid: 'Dad needs to drink a little a his attitude' (206)**

Family History
 Born & brought up:
gr. Jude. Mid-west US.

Family Structure:
lives with wife Enid. Children live east coast

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No: |
|-------|----------------|---------|

Views of childhood (nil untoward, happy, unhappy):

Parents (+causes of death):

Employment History

Education:

Age of leaving and qualifications:

Main area of employment: *Ran Engineering Dept. Midland Pacific Railway (60r (78))
10 yrs. Amateur Metallurgy (39) US patents (83)*

Relationships

Marriage (how many times): *7*

Any history of Domestic Violence?
No. but a 'shouter and a punisher' (25)

Children (g children & g g children) names and contact (visits, phone calls, skype)?
Gary, Denise, Chip

Is there someone with a particular carer /supporter role? Who? Name & relationship:

Do they struggle to help? (any ill health, live away, work full time)
Children distant - NY (Chip) Philadelphia (Gary/Denise)

Do they help with finances? *Wife now does a QT (6)
No longer able to do renably (8)
Gary concerned 'house' 'only large asset' (199)*

Do they have a Lasting Power of Attorney?

Do you have Attendance Allowance?

Is there a Advance Directive? If so who has it? Where is it?

CARER
If appropriate – how many hours per week to you spend in your role as carer/do you receive any help?
Could the person be left for a weekend?
How long could you leave them for?
What would be the concerns?
Would you like a carer's assessment?

If the person feels that they are a carer or provide care, discuss.

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No: |
|-------|----------------|---------|

Do you drive? *No longer - misidentified window crank for door handle (23)*

Are family happy to travel with you?

Any accidents or near misses? If Y details?

DRIVING-if yes alert them to implications of assessment and diagnosis)

Activities of Daily Living (think initiation, planning and organising, effective performance)

Housing - Do you have any problems with your accommodation? Is it your own home, rented, sheltered etc? *Own home Gary feels couple need 'to sell this tucker now, we can't live another day' (199) + they feel assisted living*

Do you have any problems with personal hygiene (bathing/showering)? What are they?
'At, you're lying in the shower' she said, 'That's not the place to sleep'

Do you have any problems with dressing? What are they?
Can dress self (75)

Do you have any problems with continence? What are they? (constipation, getting caught short etc)
'had a final pre-dinner session in the bathroom, his third session was a hour' (336) 'application of second diaper' (363) workshop smells of urine (6) uses Yukon can the ca)

Do you have a downstairs toilet?

Do you have any problems with shopping? What are they?

Do you have any problems with eating (any weight loss)? What are they?

Do you have any problems with meal preparation (do you cook like you used to)? What are they?

| | |
|-----------------------|----------------------------------|
| What level of ability | Cooks unsupervised |
| | Reduced skills |
| | Can no longer cook complex meals |
| | Can make sandwich, cereal, toast |
| | Meals on wheels |

Can you use the telephone or does this cause difficulties? What are they?

Can you make appointments?

Can you take messages reliably?

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No: |
|-------|----------------|---------|

Can you do your housework or does this cause difficulties? What are they?
Takes ages to paint feet (5) Blames the equipment

Do you go out regularly? (inc. church, clubs, outings, friends, neighbours, family) Where?

Have you stopped going out or doing hobbies you used to enjoy? If Y why? Memory or other reasons?
'When he came in role for lunch he found that his father had done no more than remove the old switch plate' (203)

Would you like to take up any of these activities again? Which ones?

Do you need help accessing activities? What help?

How far can you walk?

Do you need a stick/frame etc? *Doesn't use.*
'Shuffled forward with the jerking momentum of a man who knew there would be trouble if he had to stop and start again'

Have you had any falls recently? Explain
'Dad fell down the basement stairs again' (71)

Who looks after your feet?

Can you cut your own nails?

Can you get in a car? Use ~~X~~ bus? *Just - out problems with leaving - not from
 'act of sitting down was a loss of control, a blind backwards free fall' (73)
 Dr H suggests 'high, straight-backed chairs only' (74). MIL. prefers
 Do you have any problems taking your medication? What are they? *has relatives.**

Can you tell me what medication you take and why? (concordance, understanding, memory, correct)
 *State list given by patient, state seen latest script and date.
*'Dr Hedgpeth has been on a new medication' (19)
 'cassary - yellow sp capsule for incontinence, the small pink Turns-like thing for the shakes, the white doling to discourage nausea. The last blue
 Side effects or allergies? Tablet to squelch hallucinations from the small pink Turns-like thing' (381)*

Self managing?

Blister pack?

Compliant with medication?
'I took my pill, I took my pill, I took my pill' (19)

Do you take any over the counter medication? If so what?

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No: |
|-------|----------------|---------|

Physical health
Current physical Problems

Patient view

How is your physical health?

Hard of hearing (5) Motor problems. 'padding at the air with loose-hinged knees' (17). Bi H diagnosed PD (140)

Have you had any hospital admissions?

None

For what & when?

Do you see your GP very often?

When was the last time?

Do you feel fit and well today? If not please tell me why

'I am increasingly bothered by my affliction' (115)

Do you have any pain?

'good days and bad days' (38)

Do you smoke? How many? (consider safety issues and health advice)

Do you drink alcohol? How much?

Do you use any other substances?

Do you have any giddy turns, or 'funny dos'? (Are they related to epilepsy, heart, diabetes?)

| | | | |
|---------|--|----------|--|
| Levels | | Heart | |
| Bladder | | Lungs | |
| Asthma | | Diabetes | |
| Thyroid | | Epilepsy | |

Did you have rheumatic fever as a child?

Have you had any trauma to the head? Any boxing? Any KO? Details?

Have you had any illnesses abroad? (malaria)

Do you have any problems with your sight? Details?

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No. |
|-------|----------------|---------|

Do you have any problems with your hearing? Details?
'he could not hear her shouting back' (5)

Have your eating preference changed? (preference for sweet things, eats anything) Details?

Do you feel your taste has changed?

Do you feel the cold more?

How do you sleep? *sleeps more 'naps deepened' (10)*

Bed time?
 Getting up?
 Do you feel rested?
 Any recent changes?

| | |
|--|----------------------------------|
| Problems with skin? ... | |
| Bruises easily? | |
| Cuts? | |
| Rashes? | |
| Altered Sensation (numbness/tingling) | |
| Pressure Areas (if appropriate) | |
| Smell (gas) | Poor / none / good / not as good |
| Smoke Alarm? | |
| Carbon monoxide? | |

Have you had your blood pressure and pulse taken recently?

If appropriate add new BP for 6 weeks. Please take BP and Pulse.

BP:

Pulse:

Psychological Health

Previous contact with MH services? (pt or family)
N/A reported

Any recent changes to mood?

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No: |
|-------|----------------|---------|

Low mood/depressive episodes?
 'I've suffered from depression all my life' (23)
 'Same flat voice' (48)

Thoughts about self harm? (or harm to others - verbal or physical)

GDS/STORM needed?

Can you relax?

History of anxiety or worries?
 Agitated at prospect of travel (12)
 'My husband gets strange at night, sometimes she said, averting her eyes. Very agitated and difficult' (367)

Seen things that others cannot see/hear or believe things others think odd? Details.
 'My Dr Hedgpeth warned about hallucinations (20)
 'checking his watch in unsanitary' (199) 'whispering conspiratorially that he'd kill a 6th man between the peds' (363)

OCD symptoms?
 'I thought I saw children' No, sunflowers' child said: 'you saw sunflowers' (146)

Memory

Changes in language? (quality of conversation, sentencing)
 hoarse throat 'I am -' (12)

Changes in personality? (check with others present)
 Always been stubborn 'I have made my decision' (176)

Repetitive questions? since returned 'could it get him interested in life' (5)

How does your memory affect everyday life?
 'gets disorientated' (13)
 'a little confused sometimes' but 'He's pretty sharp' (Denise 243)

If there's a crisis what would you do?

- Main meal yesterday
- Family news and network (remember who's who and what they're up to?)
- TV remote controllers
- ATM
- Own appointments
- Misplacing items
- Central heating
- Household appliances (e.g. kettle, washing machine, cooker, microwave)

Any memory disasters?

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No: |
|-------|----------------|---------|

Does the family have any concerns about the person's capacity to make sensible and logical decisions about important issues? (moving house, finances) **Yes** *End/Gary/Denise disagree about Alfred's*

These are: *approach to his estate to end buy out?? re handling*

Are you raising this as a issue of capacity? **NO**, no (this is fully in character' (65)

Do you have any concerns about the person's capacity?

These are: understanding
retaining
weighing
communicating

NOW DO ADDENBROOKE'S (ACE-R) OR MMSE TEST

Action

Does the person want to be told if they have a diagnosis?

Do they give permission for their memory difficulties to be discussed with anyone else? Who?

Onward referrals:

Consultant Y/N
What are the key issues for clinic?

Social services Y/N

OT Y/N

Carer assessment Y/N

Other? Y/N

Assessment summary or outcome:

Who else can we talk to about your memory?

Could you come to clinic at short notice?

Print Name: *KATE LATHAM* Date: *Feb 2015*
CLINICAL READER

Signed: *Kate Latham* NHS No: _____

[Signature]
Specialist

| | ALFRED LAMBERT. OP appv | |
|------------------------|---|------------------------|
| Date and time of entry | Details of contact and actions taken | Signed and designation |
| 26.1.15 | Seen with wife | |
| | Why here? | |
| | Pr. not felt need to be. Summed fm. OK* | |
| | Seeing Dr Hedgpeth already - diagnosed | |
| | E.P.D (40) wife says Dr H says "mind and | |
| | movement completely controlled & meds" (20) | |
| | Pr. disagrees "increasingly affected" (115) | |
| | "I am not well" (115) | |
| | *Can still walk, write dicta (75)) | |
| | What with? | |
| | Main problem is movement | |
| | - padding air with loose hinged knees (17) | |
| | "shuffled forward & jerked movement | |
| | of a man who knew he would be trouble" (21) | |
| | "hands jerk, rapid motions impromptu" (77) | |
| | "knee down was a loss of control & then | |
| | backward motion" (73) | |
| | "hands and lower arms began to dance prom- | |
| | ptly on his lap | |
| | "these shakky heads" (77) | |
| | Tremor variable "he wanted a little - his hand" (!) | |
| | How effect KOL? but "best we are plate to eat" | |
| | How long gap? | |
| | '5 years or so' (141) | |
| | From previous interview | |
| | from previous interview into present & new year | |
| | and he could not get the old shuffling. (206) | |
| | <u>History</u> | |
| | Family: wife first | |
| | Mamed? years | |

| Date and time of entry | Details of contact and actions taken | Signed and designation |
|------------------------|--|------------------------|
| | <p>3 children Gary (banker) w. 3rd child 3 q' childre Chip - janitor Wom Street Bence - restaurant divorced. No children</p> | |
| | <p>Born: Mid Decr. Tough child hood (?) Schooling (?) Employment: Railway engineer. Pacific Mialka 'worked long hours Inventor metallurgist - home lab "chemical stresses" () 2 US patents (40)</p> | |
| | <p>PMIT: nil () new meds (19) Take Haldol 'took my pill, I took my pills (19)</p> | |
| | <p>Mood: Opprobriety - presents as low? grumpy but "face" brightens at discovery of a son among so many strangers (18) Iraq news Subj: Admits to being betrayed by his body 'the first breakdown of the signal system' 75</p> | |
| | | Page No: 2 |

| | Alfred LAMBERT | |
|------------------------|---|------------------------|
| Date and time of entry | Details of contact and actions taken | Signed and designation |
| 20.1.15 | appearance: | |
| | <p>Big his hair was white and thick and sleek like a great bear's and the powerful long muscles of his shoulders which Chip remembered laboured in the spanning of a child, usually Chip himself, still filled the grey tweed shoulders of his sport coat' (19)</p> | |
| | <p>Behaviour: Phobic as passively aggressive NOT much (any) spontaneity/warmth. Twill merges to concrete eyes eye contact</p> | |
| | <p>Cognition: Jays witness comes and goes (records of "bolder up" (25) Overlaid to pers. place, the concrete & Jays memory the Does any problems with decision make Does testimony Insignificant</p> | |
| | <p>Speech: reduced, hesitant & thorny "every sentence became an cover but in the words" (12) "trapped in that space between words" (13)</p> | Page No: 3 |

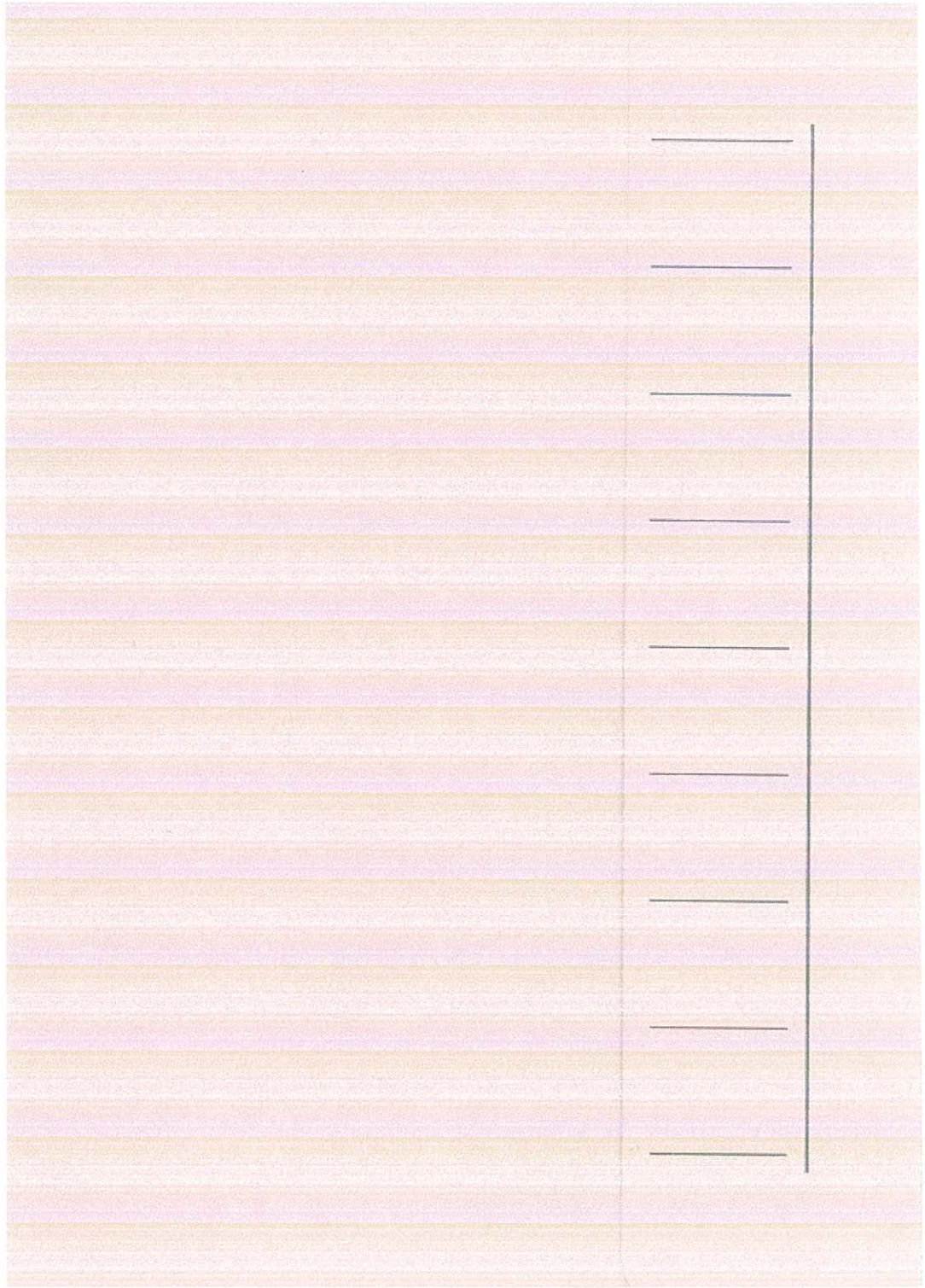
S

| Date and time of entry | Details of contact and actions taken | Signed and designation |
|------------------------|---|------------------------|
| | <p>Thoughts:</p> <p>Admits to strange ones, wanting to elaborate</p> <p>Lees things but does not see her hallucinations</p> | |
| | <p>Insight:</p> <p>Knows he is not the man he was</p> <p>'There are things & life which simply have to be endured' (D.L.)</p> | |
| | <p>Impression:</p> <p>Knows something very ++ but can/would not admit - STOTC school.</p> | |
| | <p>Wife:</p> <p>Lees alone</p> <ul style="list-style-type: none"> Since retirement pretty well stuck in chair & sleep. More withdrawn ++ <u>wants</u> take any guidance. No longer active in workshop Gradual change since retirement. Would not be able to relieve/handle any previously managed tasks. ++ forgetful. Has to be told on the way. No planning. No initiative. No get-up-again. Always has to be re-orientated. Loses things In (Gary) concerned how manage. She feels they are OK - determined by Gary or. Personality - most of how he has changed (see (-ve tests!)) Nighttime. - sleeps up x 2 to PV. | |

Page No:

Conclusion: Independence? drug withdrawal. PD + LBD - ? start after 6
 Plan: ? clear system drug withdrawal. PD + ? LBD into 26.1.

Kate
 Latham
 Ch





SECOLOR

1

CLIPMAP A4
DOSSIER CLIP A4
CLIP FILE A4
CLIPMAPPE A4



Prod. no.: 81031**

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Appendix 9: Faux notes for:

Mother created from *Scar Tissue* (Ignatieff 1993)

Patient Number:
Mental Health:
NHS:

Name Mother IGNATIEFF
Alert Label _____
Visitor _____
SP _____

**LAKESIDE
COMMUNITY
TRUST**

NHS CONFIDENTIAL

RETAIN UNTIL

| | |
|----------------|--|
| Clinical Trial | |
| Oncology | |
| Paediatric | |
| Obstetric | |
| Other | |


Signature _____

FILING IS EVERYONE'S RESPONSIBILITY

SECCOLOR®

Name: *Mother IGNATIEFF*
dob:
NHS:

NHS Mother Ignatieff dob



| ALLERGIES | INFECTION RISKS |
|-----------|-----------------|
| | |

| GENERAL ALERTS/LABELS |
|-----------------------|
| |

| | | |
|----------------------------------|----------------|---------|
| Name: MOTHER IGNATIEFF | Date of Birth: | NHS No: |
|----------------------------------|----------------|---------|

MEMORY SERVICE ASSESSMENT



GP: Surname: **IGNATIEFF**

When last seen: First Name: **MOTHER**

Present at assessment: Hospital No:

Chronic/reader/tox/author NHS No:

Date of assessment: **February 2015** Date of birth: **29.6.60⁽⁴⁷⁾**

Introduction:

to we are Who referred you Happy with who is present How long we will be there

With permission What we will do and consent to assessment Consent to refer on if necessary

(if possible, something in every box) **Based on information available in past Tissue up to the neurology appt. (57) Page nos. in ()**

Before we start do you know what you want to happen from the assessment?

Hb. prompted appt. to neurologist (10). "Scientifically, it is not clear. (34)

Current Concerns

Client view **Doesn't say, narrator feels mother had 'just the old time-boding' (7) about the family history.**

What do you think is causing your memory problem?

Family view

Why now? Any new life events

When problem with memory first noticed?

Has the problem been gradual or stepwise? **It says I had a problem getting words out (20)**

Family History **Grandmother had probable dementia. Institutionalised. (5)**

Born & brought up: **Gov Gov (4) Not able to identify family members (5)**

Family Structure: **Mamed. Doctor/medical researcher (25)**

2 sons: - Narrator Philosophy lecturer.

Hb. Immigrant. Russia. (29)

Has doctorate (in Chemistry) (25)

| | | |
|---------------------------|----------------|---------|
| Name: Mother IGNATIEFF | Date of Birth: | NHS No: |
|---------------------------|----------------|---------|

Views of childhood (nil untoward, happy, unhappy):
Lived with wife within 15 mins. Aitan (17)

Parents (+causes of death):
See earlier summary.

Employment History

Education: Teacher training college

Age of leaving and qualifications:

Main area of employment: Home maker - no 'career' (17)
Emateur painter. Suddenly stopped? reason

Relationships

Marriage (how many times): One

Any history of Domestic Violence?
No but she has smacked 'My father has been smacked several times' (49)

Children (g children & g g children) names and contact (visits, phone calls, skype)?
Narrator - regular + + + visits? over 20 years/ concerned
Doctor - more regular than for? (less involved)

Is there someone with a particular carer/supporter role? Who? Name & relationship:
HB. has taken over household & care. Become 'father and nurse' (42)

Do they struggle to help? (any ill health, live away, work full time)
? IS on (N) depressed

Do they help with finances?
Property transferred to Jms (29)

Do they have a Lasting Power of Attorney?

Do you have Attendance Allowance?

Is there a Advance Directive? If so who has it? Where is it?

CARER
If appropriate - how many hours per week to you spend in your role as carer/do you receive any help?
Could the person be left for a weekend? N.O - Jms visits rather than care done (43)
How long could you leave them for?
What would be the concerns? WORKING (33)
Would you like a carer's assessment?

If the person feels that they are a carer completes carer checklist.

| | | |
|-------------------------|----------------|---------|
| Name: Mona IGNATIEFF | Date of Birth: | NHS No: |
|-------------------------|----------------|---------|

Do you drive?

Are family happy to travel with you?

Any accidents or near misses? If Y details?

DRIVING-if yes alert them to implications of assessment and diagnosis)

Activities of Daily Living (think initiation, planning and organising, effective performance)

Housing - Do you have any problems with your accommodation? Is it your own home, rented, sheltered etc?
Own home. Transferred to home (38)

Do you have any problems with personal hygiene (bathing/showering)? What are they?
I lower her into the bath (47)

Do you have any problems with dressing? What are they?

Do you have any problems with continence? What are they? (constipation, getting caught short etc)

Do you have a downstairs toilet?

Do you have any problems with shopping? What are they?

Do you have any problems with eating (any weight loss)? What are they?

Do you have any problems with meal preparation (do you cook like you used to)? What are they?
Yes. pots left boiling on the stove. After that, a burner left to ~~continue~~ affect on the oven (32)

| | |
|-----------------------|------------------------------------|
| What level of ability | Cooks unsupervised |
| | Reduced skills |
| | Can no longer cook complex meals ✓ |
| | Can make sandwich, cereal, toast. |
| | Meals on wheels |

Can you use the telephone or does this cause difficulties? What are they?

Can you make appointments?

Can you take messages reliably?

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No: |
|-------|----------------|---------|

Can you do your housework or does this cause difficulties? What are they?

Do you go out regularly? (inc. church, clubs, outings, friends, neighbours, family) Where?

Have you stopped going out or doing hobbies you used to enjoy? If Y why? Memory or other reasons?
Suddenly stopped painting "she realizes"

Would you like to take up any of these activities again? Which ones? *instead that she does not know how to go on' (33)*

Do you need help accessing activities? What help?

How far can you walk?

Do you need a stick/frame etc?

Have you had any falls recently? Explain

Who looks after your feet?

Can you cut your own nails?

Can you get in a car? Use a bus?

Do you have any problems taking your medication? What are they?

Can you tell me what medication you take and why? (concordance, understanding, memory, correct)
**State list given by patient, state seen latest script and date.*

Side effects or allergies?

Self managing?

Blister pack?

Compliant with medication?

Do you take any over the counter medication? If so what?

| | | |
|-----------------------------------|----------------|---------|
| Name: MICHAEL IGNATIEFF | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

Physical health
Current physical Problems

Patient view
How is your physical health?
Nonator thinks 'punched, down, ever slightly stopped' (28)

Have you had any hospital admissions?
/

For what & when?

Do you see your GP very often?

When was the last time?

Do you feel fit and well today? If not please tell me why.

Do you have any pain?

Do you smoke? How many? (consider safety issues and health advice)

Do you drink alcohol? How much?

Do you use any other substances?

Do you have any giddy turns, or 'funny dos'? (Are they related to epilepsy, heart, diabetes?)
***NO but weirdly ambidextrous! (21) 'feet would glide
ac' and 'snap back' (27)**

| | | | |
|---------------------------------|--|----------|--|
| <input type="checkbox"/> Joints | | Heart | |
| Bladder | | Lungs | |
| Asthma | | Diabetes | |
| Thyroid | | Epilepsy | |

Did you have rheumatic fever as a child?

Have you had any trauma to the head? Any boxing? Any KO? Details?
**RTA - hit head (concussed). 'My mother's head is flat against the
chrome radio, as if she is listening into
her ear pinned to the sound' (36)**

Have you had any illnesses abroad? (malaria)

Do you have any problems with your sight? Details?

| | | |
|--------------------------------|----------------|---------|
| Name: <i>M/MS IGWATIEFF</i> | Date of Birth: | NHS No: |
|--------------------------------|----------------|---------|

Do you have any problems with your hearing? Details?

Have your eating preference changed? (*preference for sweet things, eats anything*) Details?

Do you feel your taste has changed?

Do you feel the cold more?

How do you sleep?
 Bed time?
 Getting up?
 Do you feel rested?
 Any recent changes?

*Ms asked to her
 'found of noise tip to tip about in their bed room' (42)
 Can't be persuaded to come upstairs - convinced she has
 to stay waiting for someone (42)*

| | |
|---|----------------------------------|
| Problems with skin? | |
| Bruises easily? | |
| Cuts? | |
| Rashes? | |
| Altered Sensation (<i>numbness/tingling</i>) | |
| Pressure Areas (<i>if appropriate</i>) | |
| Smell (gas) | Poor / none / good / not as good |
| Smoke Alarm? | |
| Carbon monoxide? | |

Have you had your blood pressure and pulse taken recently?

If appropriate add new BP for 6 weeks. Please take BP and Pulse.

BP:

Pulse:

Psychological Health

Previous contact with MH services? (pt or family)
None reported

Any recent changes to mood?
'on the time now, she looks frightened' (45)

| | | |
|-----------------------------------|----------------|---------|
| Name: MOTHER IGNAITIEFF | Date of Birth: | NHS No: |
|-----------------------------------|----------------|---------|

Low mood/depressive episodes?

Thoughts about self harm? (or harm to others – verbal or physical)
None reported

GDS/STORM needed?

Can you relax?

History of anxiety or worries?
Less willing to settle at night (see earlier comment)

HAD needed?

Seen things that others cannot see/hear or believe things others think odd? Details.
Nightmare - wanting for someone 'she can't say whom' (42)

OCD symptoms?

Memory

Changes in language? (quality of conversation, sentencing)
'where's that thing... gm... thp... things... with?' (33)

Changes in personality? (check with others present)
No longer conversational in company 'little beyond Yes and No' (45)

Repetitive questions?
Repeats spatula question 'and the 2 third time' (33)

How does your memory affect everyday life?
'I lose track of sixty-three' (44)
'first, the glasses, then the purse. then the shoes' (32)

If there's a crisis what would you do? **Old memories still well preserved (40)**
'she remembers captions of New Yorker cartoons' (40)
'we rig the reels, over and over, in the same sequence' (46)

- Main meal yesterday
- Family news and network (remember who's who and what they're up to?)
- TV remote controllers
- ATM
- Own appointments
- Misplacing items - **SPECS! 'Have you seen my glasses?' (31)**
- Central heating
- Household appliances (e.g. kettle, washing machine, cooker, microwave)

Any memory disasters?
No longer able to set table (44)
'not able to recognize Jack as grandson 'who does he belong to' (45)

| | | |
|-------|----------------|---------|
| Name: | Date of Birth: | NHS No: |
|-------|----------------|---------|

Does the family have any concerns about the person's capacity to make sensible and logical decisions about important issues? (moving house, finances) Yes/No
 These are :

Do you have any concerns about the person's capacity?
 These are: understanding
 retaining
 weighing
 communicating

NOW DO ADDENBROOKE'S (ACE-R) OR MMSE TEST *Mildred (47) 'does so in a child like way, without inflection, unaware that the words are forming no meaning.'*

Action

Does the person want to be told if they have a diagnosis?

Do they give permission for their memory difficulties to be discussed with anyone else? Who?

Onward referrals: *'Urine samples, blood samples, X-rays, CAT scans, PET scans' (SS)*

Consultant Y/N
 What are the key issues for clinic? *What is it? Diagnosis.*

Social services Y/N

OT Y/N

Carer assessment Y/N

Other? Y/N

Assessment summary or outcome:
'predominant senile dementia' (54)

Who else can we talk to about your memory?

Could you come to clinic at short notice?

Print Name: *KATE LATTAM* Date: *July 2015*
CLINICIAN/RENOEX

Signed: *Kate Lattam* NHS No:

Appendix 10: Examples of greetings cards featuring dementia

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