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## **I'm wondering now if I'm the only person who remembers: using film and narrative biography to resist amnesia in dementia studies**

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'I'M WONDERING NOW IF I'M THE ONLY PERSON WHO REMEMBERS':  
USING FILM AND NARRATIVE BIOGRAPHY TO RESIST SOCIAL AMNESIA  
IN DEMENTIA STUDIES

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A thesis submitted in partial fulfilment of the requirements of the Manchester  
Metropolitan University for the Degree of Doctor of Education

Institute of Educational and Social Research  
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The greater part of the post war period has been characterised in intellectual life by a suspicion of questions of reference, and a flight from the links between discourse and history – procedures of avoidance that seem also to be symptomatic of submerged traumatic histories, of which the Holocaust is one.

(Rothberg, 2000: 15)

In memory of my grandfather, William Thomas, Royal Army Medical Corps, 1914-18,  
and my father, Major (by name not rank) David Thomas, Royal Canadian Air Force,  
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the study.

**Abstract:**

This study is grounded in my concerns, as a HE lecturer in Dementia Studies, about the difficulties practitioner-students face in writing reflectively about their work with people who have dementia. I introduced a short fiction film, *Ex Memoria*, into the curriculum, initially as a means of ascertaining whether the use of an arts-based approach would facilitate greater reflection among students more familiar with biomedical perspectives on dementia. The film attempts to convey the experiences of a woman with dementia, a Polish-Jewish refugee from wartime Poland, now living in a London care home. Twenty two students completed either coursework assignments or reviews based on the film. The findings suggest that the psychosocial perspective which underpins the Dementia Studies programme, and has been widely promoted as a corrective to the biomedical ‘standard paradigm’ (Kitwood, 1997), itself contributes to the ahistorical and depoliticized positioning of people with dementia, their families, and professional caregivers. In conclusion I argue that the psychologisation of dementia has contributed to its academic marginalisation. A broader, more transdisciplinary approach is required; one which sets dementia in the context of 20th century history, and thus avoids the social amnesia (Jacoby, 1996) currently affecting dementia studies.

Keywords: Higher Education; dementia studies; film; history; narrative

## **Introduction: History is what hurts....**

When the government...no...the people, ordered it...all the flies and fleas came out of the box we opened...I grew up in all that dust...all the birds...the bees...the humming bees...all the people wishing. My father was nervous...he didn't know what would become of it...who could he trust apart from his children...he heard the people whispering, whispering, whispering...

(extract from the narrative biography of a woman diagnosed with dementia: *Catherine*. Brown and Clegg eds, 2007: 147)

History is what hurts. It is what refuses desire and sets inexorable limits to individual as well as collective praxis.

(Jameson, 1981: 102)

## **Background**

Between December 2004 and September 2005 I was a member of a small advisory group involved in developing the script of a short (15 minute) fiction film entitled *Ex Memoria*. The film attempts to convey something of the lived experience of Eva, a woman in her late seventies and former Jewish refugee from wartime Poland, who now has dementia and is living in a London care home. The intention was to bring the viewer face to face with someone from whom it is easier to look away, whose history it is easier not to know. This thesis provides a detailed study of the film's development, its subsequent introduction into the curriculum of the BSc (Hons) in Dementia Studies, for which I was then course leader, and the responses and reactions to the film of practitioners in the field of dementia care who were part-time distance learners on the BSc programme.

My thesis also charts the difficulties of bringing to the forefront of research a subversive voice which is at odds with both the traditions of the field of study (dementia care), and with the founding ethos of my immediate work environment. At the beginning of the study I was aware that I would be arguing against the former, which is still heavily dominated by the biomedical 'disease model' of dementia. It

took much longer to realise (or to begin to articulate with any consistency) that the psychosocial model which has underpinned my own teaching for the past 12 years might, rather than offering a kind of ‘gestalt shift’ corrective to the biomedical model, also be part of the problem.

In the process of this study I have attempted to follow the advice of Stronach and MacLure (1997: 6) on ‘opening up to interrogation ...the institutional discourses that define the limits of the speaking subject’, both my own and those of the students I teach. My critique of both the dominant biomedical discourse on dementia and its ‘successor science’ alternative, aims to reveal something of their political and historical unconscious (Jameson 1981; Marcherey 1978). I will argue here that what is missing from the current understanding of dementia is a historical dimension of awareness, and that this broadens the field for discussion, problematizes established orthodoxies, and suggests new interdisciplinary (or transdisciplinary) links for teaching, learning and research. If the field of dementia studies would be enriched by a greater interest in social history and critical theory among educators and researchers, then it is also the case that social and critical theory would benefit from a deeper engagement with the nature and experience of dementia.

### *The Ex Memoria project*

The existing draft script of *Ex Memoria* had been written by a film writer/director, Josh Appignanesi, who based the story on his experiences of visiting his grandmother who had dementia, during the final years of her life in a care home. In order to get funding to make the film he and the producer, Mia Bays, had put forward a proposal to The Wellcome Trust through its Sciart funding stream. Sciart projects (now replaced by Wellcome Trust Arts Awards) were intended to involve artists and scientists working collaboratively to explore a scientific subject area using the arts. ‘These projects aimed to stimulate fresh thinking and debate in both disciplines and to reach and engage with diverse audiences on the social, ethical and cultural issues that surround contemporary biomedical science’ (The Wellcome Trust 2007).

Two of my colleagues who were fellow members of Bradford Dementia Group and lecturers in the Division of Dementia Studies at Bradford University had already been

involved at the proposal stage, acting as academic advisors on the scientific side of the project. I became involved myself at the point where the funding was awarded, and it was agreed that I would have the dual role of formal evaluator for the end of project report required by Wellcome Trust, and as an independent researcher carrying out work for my Doctorate in Education (EdD).

Although Wellcome Trust accepted the workgroup readily enough as an arts-science interface there were - in reality - no members of the workgroup who considered themselves biomedical scientists. Bradford Dementia Group, following the work of its late founder Tom Kitwood, has always had a reputation for being deeply critical of the biomedical model of dementia, and has been closely associated with the development of an alternative psychosocial, humanistic approach. The arts-science interface was thus perceived by the workgroup members to lie less *within* the workgroup itself than *between* the workgroup and a practice field, in which biomedical 'neuropathic ideology' (Kitwood, 1997a) is still the dominant discourse.

The role of the University-based workgroup members was, then, to contribute to the development of the script by showing how psychosocial factors (quality of care, social interaction, physical environment) can exacerbate the cognitive problems faced by people with dementia. The main focus of our input was in fine-tuning dialogue and interactions between characters in the existing draft script. This was intended to ensure that the representation of the speech and actions of people with dementia, and the interactions shown between people with dementia and caregivers, would be accepted as authentic by a practice audience. Among other developments, this included the introduction of a number of examples of 'personal detraction' drawn from Kitwood's theory of malignant social psychology (1997a), a keystone of what he termed the 'new culture of dementia care' (Kitwood, 1995).

#### *Kitwood's 'new culture of dementia care'*

Kitwood's alternative way of framing dementia, in which personal and social factors are recognised to play a part in the process of the condition, has been widely accepted as a significant move forward in the field of dementia care practice. Against the biomedical model, which he described as a 'problematic inheritance', Kitwood argued

that much of the ‘problem behaviour’ and apparent symptom progression in dementia can be attributed to insults to ‘personhood’, a status which he believed to be either bestowed on, or withheld from, people with dementia in the context of interpersonal relationships. He reconceptualised problem behaviour as needs-related ill-being arising from insensitive treatment and social exclusion on the part of others, rather than solely from progressive, localised brain pathology. In particular, he identified 17 types of ‘personal detraction’ (Kitwood, 1997a: 46-47) which – when observed frequently in formal dementia care settings - could be taken to indicate the presence of what he described as a ‘Malignant Social Psychology’. This typology of personal detractions has become widely known and used in dementia care practice.

One of my main arguments arising from the data on which this study is based, and other recent work, is that an unfortunate side-effect of Kitwood’s psycho-social model has been to encourage an ahistoric view of those with dementia in which the social and material reality of the events they have lived through is downplayed, whilst their status as citizens with rights remains unrecognised (cf Bartlett and O’Connor 2007). Although Kitwood’s work marked a significant move away from biomedical orthodoxy, his ‘new culture of dementia care’ is based on bodies of psychological or micro-sociological theory (predominantly humanistic, ethogenic and symbolic interactionist) which tend to psychologise dementia at the expense of more broad-ranging historical, socio-economic and political perspectives. Ostensibly he urges us to see each person with dementia as unique, but this is, in fact, to restore (or ‘bestow’, in Kitwood’s own terms) a consolatory uniqueness within the already homogenised community of those diagnosed with dementia. The historical particularity of experience shared by those generations of people who now have such a diagnosis, has already been stripped away.

The vast majority of people who have dementia in the advanced industrial countries of the world are now in their 80s and 90s and came of age during a world war which was perhaps the most cataclysmic event in human history. This is something that has been widely overlooked in studies of the emotional and behavioural manifestations of dementia. In chapter 1 of this thesis I discuss in detail Kitwood’s critique of the standard paradigm, and begin to develop my own argument about the limitations of the psychosocial model he offered as an alternative.

## Using arts-based approaches in health and social care education

I was keen to be involved in the *Ex Memoria* project for a number of reasons, primarily because of the film's potential to be used educationally. Our current distance learning materials were largely print-based with some on-line support, and I wanted to base my thesis on a more innovative, arts-based approach to teaching and learning. The initial training of the nurses and other health and social care practitioners who make up our student group has been dominated by the biomedical model of dementia and this often shows in the language that they use to describe their work with people who have dementia. Often it seems as though this language is used as a kind of distancing technique that limits what practitioners are able to observe in their own area of practice, and thus their ability to interpret what might be happening.

During the initial taught, two-year stage of the EdD course, I had done some preliminary work on the development of reflective and creative writing with students on the Dementia Studies programme, and although this seemed to be welcomed by the participants, I was concerned that it merely burdened them with more written material to grasp. The amount of reading required for the course is a frequent problem mentioned by students. Visual material which presented a different perspective on the person with dementia seemed a valuable alternative to didactic printed material; one which I hoped would be more likely to lead to deep learning.

Although many of the most thought-provoking insights into the experience of dementia can be found in novels, films, poetry and biography, neither biomedical nor psychosocial models of dementia have drawn significantly on the arts in teaching, research or public information. In the education of health and social care professionals generally there is, however, increasing interest in the use of arts-based approaches. Smith et al (2006) suggest the following as some of the advantages of arts-based approaches: developing awareness of the complexity of human experience; promoting sensitivity towards difference; encouraging a more complex appreciation of meanings of illness; making richer connections between personal experience and professional knowledge; and the development of expressive and observational skills. In dementia studies, in addition, there is a need to develop skills in interpreting the

words and actions of people with dementia. Here there is considerable potential for certain kinds of artistic technique, such as those used in surrealist or experimental art, to offer insights into the experience of dementia.

There is some evidence to suggest that using arts-based approaches is beneficial in health and social care education (Staricoff, 2004), and whilst there are fewer sources making reference to film specifically, studies involving the use of film in education of teachers (Bousted and Ozturk, 2004) and social workers (Downey et al, 2003) indicate that there are benefits to using this approach as an adjunct to more formal teaching methods. Bowles (2002) suggests that in our audio-visually saturated culture, film should also be viewed as an important means of teaching about historical events. Blum (1999: 1) suggests that film can play an important role in ‘providing salient cultural imagery of inter-racial co-operation and antiracist activity’, an important consideration in the context of dementia care where both service users and care workers come from increasingly diverse ethnic and cultural backgrounds.

In the context of this study, the need to develop practitioners’ awareness of the social, historical and cultural events which have shaped the life experience of their clients has emerged as a particularly strong theme. A detailed discussion of the rationale for introducing the arts into dementia care education is provided in Chapter 2, but I have also suggested here that there is a need for some scepticism in assuming that arts-based approaches *per se* are preferable to more traditional teaching methods. This argument is developed further in Chapter 3 which explores some of the ways in which mainstream film reproduces orthodox (but inaccurate) views of the nature of memory loss and dementia. Here I also discuss the more authentic representation, in *Ex Memoria*, of dementia as a condition in which long term memory becomes increasingly insistent; hence the film’s sub-title ‘Some memories fade...others keep returning’.

#### *Ex Memoria: narrative and style*

A number of studies recommend the use of film in health and social care education (eg Stuart et al, 2004). As with mental health problems in general, however, existing filmic representations of people with dementia often perpetuate negative stereotypes

(Helsby 2006). This makes their use for educational purposes open to misinterpretation, particularly in the context of distance learning. The *Ex Memoria* project seemed to offer an opportunity to develop a film that would be tailored to our own teaching purposes, and would therefore avoid such stereotypes. I was, moreover, interested to know how practitioner-students on the Dementia Studies programme would respond to a film that used the experimental techniques and imagery outlined in the proposal to the Wellcome Trust; for example, ‘the camera stays locked on the woman’s face as she is wheeled around in her chair. It immerses us in her fragmented reality, her bubble of experience, her lack of control of her environment’. The script also raised issues such as sexuality, trauma, and cultural diversity that are often swept under the carpet in standard sources on dementia care practice. Whilst allowing space for multiple interpretations, it is strongly implied that Eva and her captured brother, are targets of the Shoah<sup>1</sup>, and that Eva herself has adopted a non-Jewish identity and used sexual manipulation in order to survive. Although fictionalised to a considerable extent, *Ex Memoria* also has at its heart a real life ‘missing person’ conundrum, and a personal memoir of emotional depth and complexity (Appignanesi L 2000).

In the film we first see the central character, Eva, walking in a wood as a teenager. By means of off-screen sound effects, including gunfire and German voices, we are made aware that her male companion has been captured and taken away. The remainder of the film takes place in the present day care home where Eva is now living. Events unfold on two levels. First, there are indications that all is not well for Eva in the ‘here and now’. She is isolated and ill-at-ease in the nursing home. Relationships with her visiting relatives are shown as strained and perfunctory, although with moments of ‘near-meeting’. The care home staff, although not intentionally unkind, are dismissive and task-orientated, with the exception of one male caregiver, who – near the end of the film – manages briefly to engage with Eva.

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<sup>1</sup> Although Holocaust is a generally accepted translation of the Hebrew *sho'ah* meaning destruction or annihilation, the terms are not interchangeable. The term Shoah is used to refer specifically to the Nazi programme to exterminate European Jewry. Holocaust is a broader term which incorporates the events leading up to the Final Solution and the many non-Jewish victims who were imprisoned and perished. As will be discussed in Chapter 7, there are important distinctions to be made here when considering the potential scale of post traumatic stress amongst those who now have a diagnosis of dementia.

On the second and deeper level, there are numerous pointers within the film that Eva's experience of dementia is being exacerbated by aspects of the care home environment and interactions with the other characters that remind her of her wartime experience. It can be deduced (although some work is needed here), that the male companion captured in the first scene was Eva's brother, Adek. In her dementia, Eva is still waiting for Adek's return and she mistakes her visiting grandsons for him. We also learn that Eva 'avoided the Warsaw ghetto somehow'. In the final scene, some insight is offered into the strategies Eva may have had to adopt in order to survive in war-torn Poland.

Much of the story in *Ex Memoria* unfolds, then, as implied rather than explicit narrative. In addition a range of film-making techniques are used with the intention of unsettling taken for granted perspectives. Long tracking shots are used to focus the viewer's attention on Eva. Events appear to be played out in almost real time, but at times the cutting and editing process interferes with our own orientation. Other characters and sets are seen off-centre and slightly out of focus behind Eva. Because she is in a wheelchair, keeping the camera at her eye level means that other characters are also often seen only from the chest down, and loom in and out of view. These are all forms of estrangement - *verfremdungseffekt* as Brecht (1964) described it - which have the potential to unsettle viewers by showing a familiar situation from an unusual angle.

#### *Viewers' reactions and responses to Ex Memoria*

In due course the film was shot and produced on DVD. Initially it was difficult not to see this as the end of a process; the transformation of the script into a 'frozen' packaged product. Over time, however, I became aware that – as with the distinction Barthes (1977) makes between work and text – the object which was the material outcome of the development process (the DVD and supporting booklet in its case) existed separately from the ongoing process, the 'methodological field' which was the film's reception, discussion and 're-writing' by those who viewed it.

Through early focus group and conference showings it seemed that viewers reacted differently to film than they would to the same incidents witnessed in everyday life.

For example, there is a very brief scene in *Ex Memoria* in which we see Eva being manhandled onto the toilet by two care workers. They are both wearing disposable aprons and gloves, and Eva appears to be under the impression that she is being sexually propositioned, and perhaps about to be subjected to a sexual assault. The position of the camera outside the bathroom door forces us to adopt the viewpoint of a voyeur, witness to a scene that ought to be, but already is not, private. As a result Eva's privacy is invaded not just by the staff, but by the camera itself. This was the comment of one care home manager on this scene, transcribed from an audio-recorded focus group discussion

Seeing that...in the film...it just made me cringe. It's very hard to watch...because it makes you think 'What *must* she be feeling? What does she think is *happening* to her?' But the worst thing for me is that I know I could walk past on the corridor in my own [care] home while that was going on, and I'd be – you know – going somewhere, some other agenda, twenty other things on my mind, and just think 'Oh, *she's* playing up today'. I'd be more likely to feel sorry for the staff if anything. And that's hard to admit...that it's different because you see it in a film.

Film's potential for bringing to conscious awareness things which are otherwise obscured by familiarity, has been noted since early in its history. Lebeau (2001: 4) quotes psychoanalyst Hanns Sachs, who observed in the 1930s that 'Film seems to be a new way of driving mankind to conscious recognition...it shows us clearly and unmistakably things that are to be found in life but that regularly escape our notice'. The 'discipline of noticing' (Mason, 2002) came to seem particularly apposite in exploring the ways people respond to *Ex Memoria* as, later, did Benjamin's concept of profane illumination (Benjamin 1929; Cohen, 1993) and Segal's work on 'rupture' (1999).

Profane illumination, as described by Benjamin, is a sensory, non-cognitive, apperception similar to Monaco's (2000) concept of 'visceral understanding'. Rupture is a term used by Segal in the context of the encounter with a stranger, within which the taken for granted rules of the familiar world no longer apply. According to Segal, the familiar – that part of our lives which is so mundane that we have ceased to notice it – is ruptured by this encounter. Ironically in this view, it is only when the

normal 'rules of engagement' are revealed as useless, that we become aware of them. As Newman (2006: 215) writes of Augusto Boal's 'theatre of the oppressed', for example, 'When effectively done, it confronts people with unsatisfactory or unresolved versions of their world. In the short term, it can change them from passive onlookers to people literally involved in the scene being acted out. It can stimulate passionate debate'. Mezirow (1991) similarly draws attention to the links between 'disorientating dilemmas' and perspective transformation.

In *Ex Memoria*, Eva ostensibly inhabits a world that is familiar to dementia care practitioners, but one that is 'made strange' by the use of film technique and the revelation of her equivocal character and past. The encounter with Eva may thus be experienced as rupture by some viewers, and at some points in the film. In Chapter 4 this theoretical material is discussed in relation to the introduction of *Ex Memoria* into the BSc (Hons) Dementia Studies programme.

#### *Introducing Ex Memoria into the Dementia Studies curriculum*

The film was introduced into the BSc programme as part of a core second year module *The Social Psychology of Dementia Care*. The students' final assignment for the module was a critical incident analysis which had, in previous years, been based on an incident drawn from each student's own practice experience. I led this module for several years, and had recurrent concerns about the difficulties students experienced in selecting and writing about incidents for analysis. My initial hope was that using the film would enable students to make more detailed and nuanced observations. Although I intended from the outset to use their assignments as data, at this point I was interested in doing so mainly in order to discover how well the film 'worked' as an educational resource. The study was thus initially conceived as an intervention in practice intended to bring about 'improvement' in students' work. It was a considerable time after the delivery and assessment of the module before I was able to start an in-depth analysis of students' assignments, and when I did so I found, interestingly, that they pointed in quite a different direction. Although I had not intended to use a Glaserian grounded theory approach in which 'everything is data' (Glaser, 1998) this is, in effect, what happened and it has led to an almost complete reversal of what I believed for a long time that the project was about. This

has, however, taken me in the direction of bodies of literature that I had not even considered at the outset, and led to a far richer and more invigorating research process. It has also alerted me to the methodological challenges of presenting an argument which is reflexively aware of its own construction as an account of a non-linear process. I have thus attempted to synthesize theory, empirical data and my own reflections throughout the study rather than presenting a more standard-format thesis, subjected to post hoc narrative smoothing (Sarbin, 1986)

First – unremarkably enough - I found that scenes of particular intensity, complexity and – in some cases – ambiguity were foregrounded by viewers (Hakemulder 2007). Unlike the previous assignments for this module based on self-selected incidents, these assignments are almost totally lacking in references to biomedical categories of thinking. On the other hand, there was a consistent tendency for participants to read the actions and interventions of Eva’s family more negatively than the film itself seemed to warrant, whilst at the same time Eva’s own character and intentions were ‘airbrushed’ considerably. It seemed that the imputation either of dislikeable characteristics, or of active agency, to Eva as an older woman, were out of the question for most participants, regardless of the film’s content. This was in marked distinction to personal traits that viewers had been prepared to attribute to the young Eva.

Finally, the tendency to demonise Eva’s family and the care staff increased in accounts where viewers had made little mention of the traumatic nature of Eva’s experiences in earlier life. Where participants had understood the implicit message that Eva’s current experience in the home is disturbing because it provides constant reminders of traumatic wartime experiences, they were less likely to attribute disproportionate blame to interpersonal relationships in the present day context. In addition, there was a significant tendency to overidentify and exaggerate examples of personal detraction (Kitwood 1997a), and to make little reference to lines of dialogue spoken by Eva herself as a way of interpreting the action.

There may be a number of factors at work here, either separately or in combination. Participants may, for example, have lacked confidence in their background knowledge of historical events in wartime Europe. The immersive film-making technique may

have brought about such an increase in empathy for Eva that the viewers' heightened sensitivities led them to be more aware of how even minor slights would be perceived by her. The film is deliberately ambiguous about what happens to Adek in the first scene, and also about what subsequently happened to Eva. Some participants were more forthcoming than others in making interpretations or offering possible scenarios using the clues which *are* provided. Finally, the Dementia Studies course material offers a predominantly psycho-social framework for understanding the experience of dementia. It might, then, be argued that viewers have read the film through a particular lens, that of the person-centred approach to dementia care.

Whichever explanation, or combination of explanations, applies they all point back to emphases or aporia<sup>2</sup> in the Dementia Studies curriculum, and thence to corresponding emphases or aporia in the philosophy that underpins the course. What this, in turn, suggests is that adding a psycho-social discourse to the dominant biomedical discourse in order to arrive at what is now often described as a 'bio-psychosocial' model of dementia is not in itself sufficient. Such a model also needs to take account of the material, historical, social and economic conditions within which people who now have dementia have lived their lives.

In addition to the student assignments mentioned above, a further 10 students completed reviews of the artistic technique and imagery used in *Ex Memoria*. The findings from these reviews appear to demonstrate that when viewers' attention was directed towards particular images or film-making techniques they were more likely to make links between the historical aspects of the film and events in the present day.

Academic colleagues and workgroup members completed interviews and a filmed focus group on their reactions to *Ex Memoria*. I have, however, referred to these additional sources of data only where necessary, in order to support or illustrate a

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<sup>2</sup> Meaning, literally 'pathless' (Gr), the term aporia is used here to signify an 'impasse of meaning' – a point where a text's conscious project is undermined by its internal inconsistencies. In Lacanian theory aporia is associated with the real, with that which resists symbolisation, and perhaps, I would argue (as in Orwell's *1984*) with that which a particular belief system does not permit one to think.

particular point arising from the primary body of data from student assignments. Findings from the primary data are presented and analysed in Chapters 5 and 6.

### **Conformist psychology, social amnesia and the ghettoization of dementia**

Based on the findings of this study, the main argument of my thesis is that whilst Kitwood's work has been an important corrective to the biomedical model it is not in itself sufficiently interdisciplinary to offer the basis for an alternative paradigm or 'new culture' of dementia care. It has tended to psychologise dementia at the expense of more broad-ranging historical, socio-economic and political perspectives.

From an educational point of view it also has the disadvantage of appearing to shift the attribution of blame from the person diagnosed with dementia to providers of direct 'hands-on' care who are, themselves, often marginalised and disadvantaged members of society. Moreover, the person with dementia is presented as too passively dependent on the quality of care that is currently provided, and therefore rendered one-dimensional, without culture, social class, sexuality or gender identity.

The dominance of conformist psychology (Jacoby 1975: 1996<sup>3</sup>) has, I suggest, left Dementia Studies marginalised (or 'ghettoized') as an area outside mainstream critical theory, or more interdisciplinary approaches. It has received little interest, for example in the fields of social theory, philosophy of mind, or semiotics. Ironically, this intellectual disdain for dementia as a subject for critical theorising mirrors the social exclusion and invisibility of people with dementia. Ghettoization is a strong word to use in this context; it is certainly one that needs considerable justification. In Chapter 7 I will explain why I think it is warranted.

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<sup>3</sup> Jacoby's text *Social amnesia: a critique of conformist psychology from Adler to Laing* was first published in 1975, as it's author says, 'amid the dying embers of the new left'. It was reissued in 1996 under the title *Social amnesia: a critique of contemporary psychology*. The 1996 text is identical to the original except for the addition of a new introduction by the author. Page references in this thesis are to the 1996 edition.

All people with a diagnosis of dementia have experienced the major social and political upheavals of the 20th century. This will inevitably affect the way that they experience the onset of symptoms, diagnosis, the provision of services, care environments and the intentions of caregivers. Links between post-traumatic stress and dementia are increasingly being recognised. Much of this work has been done in the context of Holocaust survival. David (2003), for example, identifies numerous aspects of the healthcare system which may trigger traumatic memories for those who have experienced concentration camps, the ghettos, forced labour, or having to remain hidden to avoid capture. Many of these triggers are connected with medical procedures and institutional practices.

By comparison, much less work has so far been done in relation to the experiences of non-Jewish survivors of the Second World War (eg POWs; survivors of bombing raids; child evacuees), or other marginalised groups who now have dementia or are in the at-risk generations. There is little reason to think, however, that their experiences, on an individual basis, are necessarily less traumatic. Economic migrants, prisoners, and victims of domestic violence or sexual abuse have all had traumatic experiences which may well be equally damaging on an individual level. The experience of contact with formal services, psychiatric assessments, hospital admissions, being bussed to a day centre, or moving into some form of communal living facility are likely to reactivate memories of such traumatic events for many more people with dementia than we are perhaps inclined to think.

### *A forgotten Exodus*

Here is one small example – not an unduly dramatic one - from Mass Observation archives. In the autumn of 1940 the East End of London was subjected to repeated bombing raids, and the ‘listening tension’ induced by constantly being on the alert for the sound of aircraft, or the ear-splitting wail of air-raid warning sirens. This appears to have led to a form of mass hysteria, an exodus of people which took place, ‘entirely without planning...[they] went without any plan at all, without money or prospects’ (Inglis, 1989: 85). These were not evacuees, but refugees, mirroring the displacement of populations taking place all over Europe in the 1930s and 40s.

Some six thousand of these refugees from Mile End, Whitechapel, Stepney and Bow converged on Oxford, where they were temporarily housed in a cinema with a capacity audience of two thousand. This rapidly became a ‘foetid, nightmarish shelter’ where some of those contained felt that they were being treated like foreigners, and there was a ‘nasty upsurge of anti-Semitic feeling’. Whether or not those who were whispered against in this way by the townspeople or their fellow refugees were actually Jewish or not seems to have been immaterial. The surroundings quickly became filthy; the sanitation was totally inadequate, and there was no means of disposing of waste which quickly began to decompose. There was an outbreak of boils due to contact with this infected matter. Lighting was restricted, and worst of all there was nothing to do. Apathy and listlessness were reported as among the worst of the problems, the psychological effects of this form of incarceration being even harder to bear than the physical deprivation and discomfort.

Of these six thousand people, the youngest still alive will now be in their seventies, and the oldest in their nineties. A recent longitudinal study suggests that at least 30 per cent of them are likely to have been diagnosed with dementia (Brayne et al, 2006). Memories of this war-time confinement may never have appeared consciously to trouble them, and they may never have talked about it. In dementia, however, long-term memory often remains relatively intact, whilst the ability to discriminate between past and present, reality and illusion is diminished. In this context ‘listening tension’, loud noises, crowded places, invasion of personal space, bad smells, boredom, communal toilets or gloomy lighting might all trigger threatening memories, or perhaps even a literal sense of being back in the same situation. The resulting fear and anxiety may well then manifest itself through various forms of ‘acting out’ of the original experience.

LaCapra (2001: 21), writing in the context of Holocaust survival, suggests that in order to understand the acting out of past trauma

it is important to relate deconstructive and psychoanalytic concepts ...in post-traumatic acting out...one is haunted or possessed by the past and performatively caught up in the compulsive repetition of traumatic scenes – scenes in which the past returns and the future is blocked or fatalistically

caught up in a melancholic feedback loop. In acting out, tenses implode, and it is as if one were back there in the past reliving the traumatic scene.

From the perspective of the biomedical standard paradigm of dementia this ‘acting out’ will be constructed as ‘challenging behaviour’ resulting from damage to localised areas of the brain. From the psychosocial perspective, it is likely to be interpreted as needs-related behaviour resulting from deficiencies in interpersonal relationships in the current context of care provision. In neither case, I would argue, is the historical dimension given due weight or attention.

### *The historical turn and narrative biography*

It can thus be argued that a ‘historical turn’ is now much needed in the field of dementia studies, and that the concept of historical trauma (LaCapra 2001) has much to offer this project. Historical trauma, in the context of dementia studies, might encompass both events that meet the diagnostic criteria for post-traumatic stress disorder (PTSD), and lesser events which continue to provoke unsettling or disturbing emotions arising in situations reminiscent of the original. I do not suggest here that traumatic experiences are causally implicated in the onset of dementia, but – somewhat the reverse - that dementia itself becomes the precondition for a return of the repressed in which earlier traumas are reactivated.

The recorded life histories of people with dementia often have a palimpsestic<sup>4</sup> quality about them, in that the fragments of retained information known to caregivers have been reduced to the normative or banal; so, for example, a suspiciously high percentage of people with dementia have been ‘happily married’ and become the loving parents of devoted children. When people with dementia are allowed to speak for themselves, rather than talked about or ‘written over’, the reality is less comfortable. I met Myra recently in a day centre. Her speech was difficult to

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<sup>4</sup>Palimpsest, n (from Gr ‘palin – again and psestos – rubbed smooth) 1) a piece of writing material or manuscript on which later writing has been written over the effaced original writing 2) something used again or altered but still bearing traces of its earlier form (Oxford Concise English Dictionary 1995: 984)

decipher, but her delivery was forceful and emphatic. She mentioned her second husband. ‘What sort of a man was he, then?’ I asked. ‘Orrible; *bloody* ‘orrible’.

Recent narrative biography work (Brown and Clegg eds 2007) helps to illustrate not only how much people with dementia have to say if someone will listen, but also how interesting, varied, strange, and difficult their lives have been. In the final chapter I draw on material from Brown and Clegg’s book *Ancient Mysteries* to explore the educational potential of the voices of people with dementia as historical testimony; as ‘the wound that speaks’ (Caruth 1996). The narratives I draw on here help to illustrate the concepts of ‘extreme’ and ‘everyday’ trauma as distinguished by Rothberg (2000). Such an approach, I would argue, does not merely help us to ‘humanise’ the biomedical, but brings us into contact with perspectives that defamiliarize official history, and foster new connections between the historical treatment of marginalised groups in society and the current representation of people with dementia.

### **Writing as methodology: bricolage and rhizomatic text**

At the point where *Ex Memoria* had been filmed but not yet widely disseminated. I produced a lengthy record - a thick description (Geertz 1971) - of my own reactions to it. I have drawn on this document at several points in my thesis when reflecting on my interpretation of particular scenes in the film. The most important realisation that came out of this process of writing was, however, the complexity and multi-dimensionality of its themes. These were not just reactions to the film itself, but also reflections back to things that had happened in the workgroup, speculations about the ‘real story’ on which the film was based, things that had happened during the film shoot, and apprehensions about how certain aspects of it might be read or interpreted by others. Themes and connections emerged during the process of writing, almost by a process of free association.

In writing up my thesis, rather than following a traditional format, I have tried to retain this approach; to conceptualise writing as a methodological process of discovery. ‘I write’, as Richardson (1998: 347) says, ‘in order to learn something I

didn't know before I wrote it'. To be consistent with its content, my thesis draws frequently on extracts from poetry, film, literary fiction, biographical material, and on found images. In this I have aspired to Denzin and Lincoln's notion of research as bricolage. 'The product of the bricoleur's labour is...a complex, dense, reflexive, collage-like creation that represents the researcher's images, understandings and interpretations of the world or phenomenon under analysis' (Denzin and Lincoln 1998: 4). My arrangement of text, visual images, and quotations also draws on Benjamin's conviction that writing, similar to montage in film, is a form of action; if we change the position of the objects, different ideas are produced (Cohen 1993).

My original project was conceptualised along the lines of action research. The introduction of *Ex Memoria* into the Dementia Studies curriculum was intended to bring about 'improvements' in students' work. This was an intervention in my existing practice as an educator, teaching – albeit with some misgivings - from a psychosocial perspective. The study then took off in different directions from those I had anticipated. As Deleuze and Guattari (1987) would have it, I pursued 'lines of flight' which make connections between diverse thoughts, ideas, and pieces of data in a rhizomatic configuration. Rhizomatic text is non-linear, intentionally part of the research process, and discursively eclectic. 'Any point of a rhizome can be connected to any other, and must be...A rhizome ceaselessly establishes connections between semiotic chains, organizations of power, and circumstances relative to the arts, social sciences, and social struggles' (Deleuze and Guattari 1987:7). Honan (2006) notes that academic writing often imposes boundaries that convert a research process which is non-linear, messy and iterative into linear and unidirectional text. Reflexive and creative perspectives on the taken-for-granted world are, however, more likely to come about through chance connections and lateral thinking.

Working from *Ex Memoria* as a starting point within a rhizomatic configuration, it is possible to work in any direction, spatially or temporally, to make connections which then become the dominant themes of the research. I have, for example, worked backwards in time from the fictionalised account presented in the film to the real-life memoir on which it is based, and from this to a consideration of the widespread war-related trauma experienced by people who now have dementia. Working laterally I have explored the potential for film and other arts-based sources to challenge existing

orthodoxies around dementia, and argued that there is an urgent need to listen to the first person testimonies of people diagnosed with dementia. Working forward – and by analogy – I have argued that the media and the medical-industrial complex (Bond, 2004) are creating demographic panic around an ever increasing category of older people on the basis of ‘memory disorder’ in ways that are becoming reminiscent, in some ways, of the totalitarian regimes of the mid-20th century.

## **Chapter 1) Problematic inheritances: Kitwood's critique of the standard paradigm and the rise of the psychosocial model of dementia**

### **Introduction**

I worked with Tom Kitwood for four years from 1994 until his early death in 1998 and this was the period during which much of the preparatory work for what later became the BSc (Hons) in Dementia Studies was done. Kitwood's thinking has thus been a significant influence both personally and on the development of my career in Higher Education. In this chapter I will discuss what I take to be the strengths and limitations of his position, as a way of laying the foundations for my later discussion of the assignments based on *Ex Memoria* completed by students enrolled on a module within the BSc course.

In the first part of the chapter I outline Kitwood's robust, though not widely accepted, critique of what he termed a 'problematic inheritance' - the positivistic, biomedical model of dementia. In the second part of the chapter I turn to some of the unresolved tensions and inconsistencies in the person-centred model of dementia he put forward in place of this standard paradigm, and suggest that this model has now itself become a problematic inheritance for those, myself included, who have struggled to move beyond it. In this discussion I place particular emphasis on Kitwood's work on life history.

In conclusion to this chapter I will argue that the current 'global crisis' of dementia is largely a crisis of representation. The biomedical (re)construction of older people with failing memories as victims of Alzheimer's disease has served the interests of neuroscientific researchers, drugs companies and voluntary sector campaigners. It has also been taken up with enthusiasm by the media. The rhetorical use of verbal and audio-visual imagery in the service of either the biomedical or the psychosocial models of dementia thus becomes an important subject for dementia studies.

## **Kitwood's critique of the standard paradigm**

It is today almost impossible to overestimate the extent to which Kitwood's work has influenced the field of dementia care. Before Kitwood the concept of 'dementia care' was, itself, relatively unfamiliar and expressions such as 'the management of the elderly demented' were far more commonplace in research and practice literature. It is still rare to come across new publications on the care of people with dementia which do not cite Kitwood's work on the person-centred approach and the development of a new culture of care provision.

Kitwood's thinking on the nature of dementia evolved as a challenge to what he described as the 'standard paradigm' or 'neuropathic ideology' (Kitwood, 1997a: 36). The dominant discourse on dementia is one in which not only the body, but also now the mind, has been medicalized. As Atkinson (1988, cited in Hughes 2000: 14) notes, this biomedical discourse is

...reductionist in form, seeking explanations of dysfunctions in invariant biological structures and processes: it privileges such explanations at the expense of social, cultural and biographical explanations...[it] implies that diseases exist as distinct entities...[and] that diseases are to be understood as categorical departures from normality.

Kitwood's central thesis was that much of the apparent ill-being, disordered behaviour, and communicative difficulty manifested by people with dementia are not the straightforward result of neuropathology, as tends to be assumed by medical science, but are compounded by the responses and actions of others towards the person diagnosed with dementia. From this perspective, for example, the 'problem behaviour' often described as 'wandering' can be reframed as an expression of an unmet need – the desire for activity, company, or a change of scenery. 'Meaningless speech', similarly, can be re-framed as a failure of interpretation on the part of the listener.

Kitwood did not himself claim to have ushered in a paradigm shift in the framing of dementia, but some of his writing suggests that he did in fact see his alternative model of dementia as one that was a replacement for the standard paradigm

In one gestalt configuration – perhaps the prevailing one at present – the central figure is a process of degeneration...in the gray matter of the brain; psychological and sociological factors fade into the background. Another gestalt, however, equally valid, can emerge; in this the figure becomes an existential crisis of a person, of an embodied, social and sentient being, and indeed a crisis of *an interpersonal milieu* (Kitwood 1990a: 60 emphasis added)

As will be discussed further below, two points are worth noting at the outset. First, Kitwood's suggestion that his own personal – rather than technical - framing of dementia takes the form of a gestalt shift, suggests a binary opposition between two models which are competing opposites. Second, Kitwood introduces the idea that social factors are important in dementia but limits this to the 'interpersonal milieu'. Increasingly, in his later work, this interpersonal milieu was limited to interactions between people with dementia and direct caregivers in formal care settings such as residential homes, day care centres, and hospital wards.

### *The alzheimerization of senility*

Kitwood's critique of the 'standard paradigm', or technical frame of reference, in dementia care has been less widely engaged with or accepted than his views on the improvement of care practice, and in his later work there is some evidence that he downplayed this critique to some extent, yet it has proven to be remarkably prescient. In a series of papers written in the late 1980s and early 1990s Kitwood cast doubt on the evidence underpinning biomedical orthodoxy which suggests that dementia in old age is solely the result of organic brain disease. His critique relates largely to the inadequacy of evidence related to Alzheimer's disease, which is held to account for around 60% of all cases of late-onset dementia. The 'alzheimerization' of dementia is held by Kitwood (following Fox, 1989) to have taken place for social and economic reasons, rather than on the basis of neuroscientific evidence.

The disease identified by the German neuropathologist Alois Alzheimer in the early years of the 20th century was a form of *pre-senile* dementia first observed in a middle-aged woman (Auguste D) aged 51 at the time of diagnosis, who had developed cognitive impairments and was experiencing hallucinations and delusions. After her death six years later her brain was discovered by Alzheimer to have the same kind of changes that were usually found in old age. It seems unlikely that Alzheimer himself wanted to claim this as a new disease category. His colleague, Perusini (1911: 143) wrote that Alzheimer believed what he had discovered ‘[did] not represent anything but an atypical form of senile dementia’ (cited in Porter 1995: 44). It was the head of Alzheimer’s laboratory, Emil Kraepelin, driven by competition between rival research teams all attempting at this time to find organic explanations for mental illness, who actually coined the term ‘Alzheimer’s disease’ in a publication of 1910. As Whitehouse (2008) among others has noted, there was also competition during this period between the newly established neuroscientific research laboratories and the rising psychoanalytic movement which attributed many psychiatric symptoms to repressed memories and desires rather than neuropathology. Kraepelin himself derided psychoanalysis as ‘obviously more art than science.... therefore [it] can never be of general value’ (Whitehouse 2008: 88).

Alzheimer’s disease thus became the name for rare, early-onset instances of a condition which was much more frequent in older people, in whom it was known as senile dementia (or simply ‘senility’). This classification of Alzheimer’s disease, and the distinction between pre-senile and senile dementia remained in place for the following 60 years. Indeed, a standard text on psychopathology of 1970 notes that, ‘Alzheimer’s disease is statistically infrequent and of relatively little interest to students of psychopathology’ (Maher, 1970: 276). Senile dementia, meanwhile, was most frequently considered an inevitable, gradual and natural consequence of ageing rather than a medical condition. As a result it, too, was of little research interest.

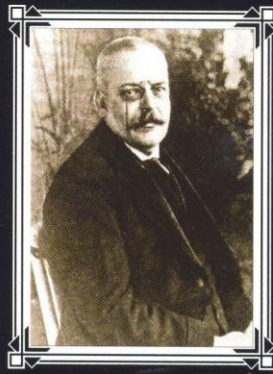
There was a culture of ‘therapeutic nihilism’ around senile dementia during these years, and care was largely viewed as a matter of physical restraint and tending to basic needs. The ageing of the population during the latter half of the 20th century led, however, to markedly increased prevalence of late-onset dementia, whilst simultaneously as Porter (1995: 56) noted, declining family support systems meant

that ‘the elderly are increasingly herded together in old people’s homes, geriatric and terminal wards in hospitals, and in districts specialising in care of the elderly. There they are tended by professionals who...are likely to treat them less as individuals and more apt to view them as psycho-medical cases’.

In the mid 1970s, Alzheimer’s disease (or ‘Alzheimer’s’ as it is now increasingly rendered) was re-created as the fourth largest cause of death in the USA. This was a deliberate ploy by an alliance of scientists and government representatives who wanted to attract more research funding for the study of senile dementia in the face of what was now beginning to be anticipated as a global epidemic of age-related cognitive impairment (Fox, 1989). On the basis that the neuropathology of both pre-senile and senile dementia was the same, the classification of Alzheimer’s disease was now extended to incorporate both early-onset and late-onset cases. Most importantly, in the process, senile dementia became medicalized as a condition that might have a hope of prevention or cure with sufficient investment of research funding. Indeed the budget for ‘Alzheimer’s’ increased from 3.6 million dollars in 1977 to 356 million dollars in 1998 (Katzman and Bick 2000). Whilst this may have appeared to be good news from an investment point of view, the vast majority of this funding has gone into biomedical research on causes and potential cures for Alzheimer’s disease which have not emerged, and comparatively little has been allocated to improving the quality of life of people already diagnosed with dementia.

In the alzheimerization of senile dementia, what appears to have been deliberately overlooked was that the neurological changes held to be characteristic of senile dementia (amyloid plaques and neurofibrillary tangles) are also found to a significant extent in the brain tissue of older people who do not have dementia. These alleged biomedical markers of Alzheimer’s disease may thus be due to the ageing process itself, rather than being causally implicated in dementia. Auguste D’s brain was considered abnormal because it was, in a sense, 30 years older than she was. But the shift that led to the recognition of senile dementia in a woman in mid-life, cannot logically then be reversed to make changes that are pathological at 57 also pathological for someone who actually *is* in her 80s or 90s. Correlation between symptoms of dementia during life and neuropathology discovered post mortem is

‘Before him the disease didn’t have a name.....’ Drug company advertisement.



DR. ALOIS ALZHEIMER

BEFORE HIM,  
THE DISEASE DIDN'T HAVE A NAME

BEFORE ARICEPT,  
IT DIDN'T HAVE A REALISTIC TREATMENT

 **Aricept.**  
donepezil hydrochloride

CONTINUING COMMITMENT TO ALZHEIMER'S

inconclusive. Nor has it been possible for neuroscientists to identify a ‘gold standard’ which can distinguish consistently between brain tissue taken from older people with and without clinical symptoms of dementia (Kitwood 1987: 133). The position has not changed in the 20 years since this article by Kitwood was written.

Even were we to accept that the claimed biological markers play a causal role in the onset of Alzheimer’s disease, a definite diagnosis cannot be given in life because post mortem confirmation of neuropathology is needed. So successful has been the rise of the ‘Alzheimer’s movement’, however, that the term Alzheimer’s is now increasingly used to refer to dementia from all causes. In a world where no living person actually has a confirmed diagnosis of Alzheimer’s disease, the number of cases is increasingly reported to be on the scale of a global catastrophe. A recent report from the US Alzheimer’s Association claims that by mid century 16 million Americans will have Alzheimer’s and ‘someone will develop Alzheimer’s every 33 seconds’. Its CEO is quoted as saying, ‘We must make the fight against Alzheimer’s a national priority before it’s too late. The absence of effective disease modifying drugs, coupled with an ageing population makes Alzheimer’s the health care crisis of the 21st century’ (Alzheimer’s Association, 2007).

There is, moreover, considerable confusion in the way prevalence and incidence figures are presented and interpreted. For example, a recent Department of Health press release claims, somewhat paradoxically, that ‘Currently 600,000 people have dementia in England and yet more than half of these will never receive a formal diagnosis’ (DoH, 2007). This atmosphere of demographic panic is now becoming global. As Howse (2007: 10) has recently remarked, for example, ‘In a country such as China the perceived threat of demographic ageing is that they will grow old before they grow rich – which will seriously hobble them in their efforts to *become* rich’.

Robert Butler, one of the leaders of the US Alzheimer’s movement, admits that concepts like ‘the living death of Alzheimer’s’ have been deliberately promoted in order to create a ‘health politics of anguish’ (Katzman and Bick 2000: 285). It seems, though, that rather than merely drawing attention to the perils of therapeutic nihilism, the aim of this movement has been to promote a pervasive (and largely unjustified)

*optimism* about the possibilities of a medical breakthrough. Kitwood (1997a: 140) noted that, ‘The drug companies for their part know that huge profits are to be made from the medicalization of old age, and that the market is growing as the number of old-old’ people [ie people over 80] increases’. This continues in the present day with major research investment in the development of cognitive enhancer drugs, genome research and stem cell therapy. As Whitehouse (2007: 461) has recently suggested, a variable level of cognitive impairment is to be expected in old age, so the search for a cure for ‘Alzheimer’s’ is ‘tantamount to a search for the neurological fountain of youth’ – a cure, that is, for ageing itself.

### **Kitwood’s dialectical model of dementia**

The alzheimerization of senile dementia is, then, a powerful and ironic example of the kind of social construction that can go on in support of biomedical research. To reveal the machinations of the Alzheimer’s movement is not, however, to alter the reality that many people do develop cognitive impairments of varying degrees in their later years. Here Kitwood’s argument is that neuropathology cannot be the sole determining cause, since the standard paradigm view in which neuropathic change leads to dementia in a straightforwardly linear, causal fashion is undermined by a number of anomalous cases. The first is the existence of cases which appear to have symptoms identical to those of dementia, but which are reversible because they are not due to organic causes (for example, infections, depression, malnutrition or hormonal imbalance). Second are cases where the onset of dementia appears to be related to one or more life crises, such as recent bereavement. Third are instances of a dramatic and rapid deterioration in those with already diagnosed dementia following, for example, a move into residential care. Finally, there are cases of apparent partial recovery from dementia when the person’s emotional needs are being met (Kitwood 1993a). According to Kitwood the standard paradigm has to ‘save the appearances’ by making ad hoc modifications to take account of inconvenient cases such as these, because they undermine its neuropathic determinism. These cases suggest that in dementia there are factors at work other than neurological impairment and that such factors are psychological and social in nature. As Orrell and Bebbington (1995) reported, for example, stressful life events such as relocation are frequently associated

with depressive symptoms in people with a diagnosis of dementia. From a biomedical perspective, however, depressive symptoms in a person with dementia are frequently taken to be evidence of neurological decline.

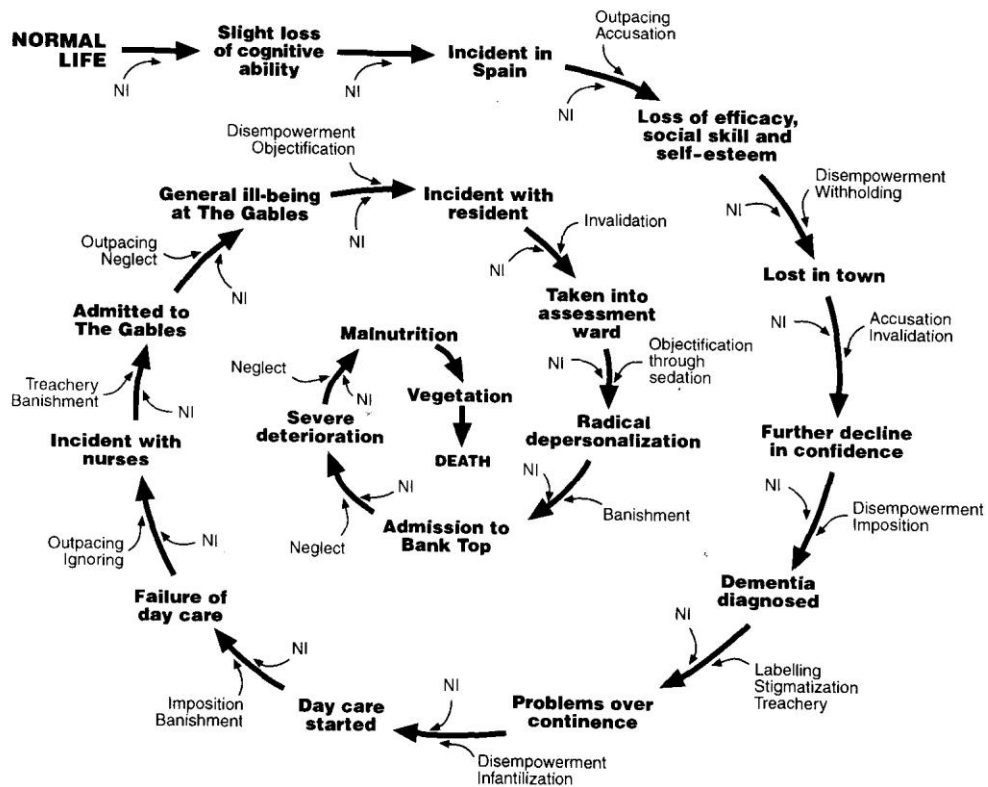
As time went on, Kitwood began to place increasing emphasis on the view that much of the ill-being manifested by people with dementia is the result of negative interactions with those who care for them. From this he developed his concept of a dialectics of dementia - an interplay between neurological impairment and psychosocial factors in the process of dementia. Kitwood's dialectical model of dementia was conceptualised diagrammatically (in relation to the specific case of a woman called Margaret) in the form of an 'involutionary spiral' (see Fig 1 overleaf).

Kitwood used this model to challenge the mind-brain dualism of the standard paradigm, arguing that mental and neurophysiological descriptions refer, in fact, to the same reality and that 'to talk in psychological terms is never to be dealing with a domain that is mysteriously independent of brain function' (1988: 113). In none of his publications did he suggest that neurological impairment plays no part in dementia. Instead he pointed to a relative plasticity and interpenetration between the structure and function of the brain, in which psychological states can be the cause, as well as the effect, of neurological impairment.

Kitwood suggests that there are three undesirable outcomes of the standard paradigm: the exclusion of alternative approaches and the consequent inhibition of development of knowledge about dementia; the exclusion of the person with dementia, and a pervasive pessimism epitomized in images such as "the prison that waits" or "the living death". In a much reproduced aphorism Kitwood suggests that 'our frame of reference should no longer be *person-with-DEMENTIA*, but *PERSON-with-dementia*' (1997a: 7).

I will argue in the following section that Kitwood's own revision of the standard paradigm has become a problematic inheritance in some ways for those who see it as an alternative model which is complete in and of itself. Whilst Kitwood's work has made comparatively little impression on what Bond (2004) refers to as the 'medical-industrial complex', the current dominance of his thinking in the fields of care

Figure 1: The involutory spiral of the dementia process (Kitwood 1997a: 52)  
 NI = neurological impairment



practice and social research has itself worked to exclude alternative approaches. In addition, the person with dementia - although now included in the frame of reference - is presented as a relatively ahistorical and asocial being. To restate this in terms of Kitwood's own rubric the reformulated frame of reference is not so much psychosocial as PSYCHO-social.

For its time Kitwood's work was undoubtedly ground-breaking, but I wish to argue in what follows that whilst his critique of the biomedical model remains masterly, the alternative 'dialectical' model he presented in its place (Kitwood 1990; 1997) is a limited one. The main arguments I wish to put forward against this model relate to what I take to be its ahistoricism and its moralism.

### **The new culture and its discontents**

Kitwood (1993b: 16) developed the following 'equation' to show that 'any individual's dementia may be considered as the result of a complex interaction between five main components

$$D \text{ (dementia)} = P \text{ (personality)} + B \text{ (biography)} + H \text{ (physical health)} + NI \text{ (neurological impairment)} + SP \text{ (social psychology)}$$

These five components were, however, never given equal weighting in Kitwood's work. His main publication on dementia (*Dementia Reconsidered: the person comes first*, 1997a) includes just one page on the impact of physical health on the onset and progression of dementia, and he also wrote increasingly little on biography (or life history). Late in his career, he described the hypothesis underpinning his work as involving only two components, as follows: 'that the process of dementia arises from a dialectical interplay between neurological impairment and social psychology' (Kitwood 1997b).

Whilst life history awareness is acknowledged as an important part of the experience of dementia, the examples offered in Kitwood's published work are - with one exception - divorced from the context of actual 20th century history. He takes a

developmental view of the human life-course which depends for its plausibility on a fixed and unchanging social milieu or 'life as normal', in which, for example, war, persecution, and mass displacement of populations barely feature.

The adapted self is elaborated in many ways, but primarily through the taking on of new roles. Thus it proliferates throughout childhood and adolescence, with each step in the enlargement of skill, opportunity and social life. The process continues into adulthood, as a person enters the world of work (or unemployment), and perhaps takes on new responsibilities such as a committed relationship, parenting or the running of a home. With many people, it seems to be the case that the adapted self reaches its highest level of elaboration in the age period around 40-60, when roles and responsibilities are being added faster than they are being lost. Later life, for many people, brings dismantling of the adapted self. Some major roles, such as that of parent or employee, are relinquished; a lowered income or problems of ill-health may cause a further diminution. (Kitwood, 1997c; 17)

Life history conceptualised in this way, as an individual journey through a series of fixed life stages which are divorced from any actually-occurring, external, historical events or social upheavals, is in Benjamin's term, history as 'homogenous, empty time' (Benjamin 1940 trans 1999: 154). When we think of the period of human history lived through by those who now have dementia this has not, however, been the nature of their lived experience. As Birkett (1991) suggests, the 20th century – like any other phase of human history - was not a polite, neutral background to the development of 'existential monads' divided both from each other and from the events of their epoch. The social history which is our past is woven into us, so that there can be no separation of the person from the historical nexus of events within which he or she has embodied existence. As will be argued in more detail in later chapters, person-centred dementia care, in its current formulation, thus shares many of the hallmarks of conformist psychology that Jacoby (1975; 1996) denounced as 'social amnesia'; it has forgotten history.

### *Malignant social psychology*

As mentioned above, Kitwood believed that negative social interaction contributed to, and exacerbated, the process of dementia. He proposed a list of 17 types of 'personal detraction' he had observed in dementia care settings (see Figure 2), suggesting that when such detractions occur very frequently this is an indication of a 'malignant

Figure 2: Indicators of Malignant Social Psychology/Personal detractions

- 1) *Treachery* – using forms of deception in order to distract or manipulate a person with dementia, or force them into compliance
- 2) *Disempowerment* - not allowing a person to use the abilities they do have; failing to help them to complete actions they have initiated
- 3) *Infantilization* - treating a person very condescendingly, as someone lacking sensitivity might treat a very young child
- 4) *Intimidation* - inducing fear in a person, through use of threats or physical power
- 5) *Labelling* - using a category such as dementia, or ‘organic mental disorder’, as the main basis for interacting with a person and for explaining their behaviour
- 6) *Stigmatization* - treating a person as if they were a diseased object, an alien or an outcast
- 7) *Outpacing* - providing information, presenting choices, etc, at a rate too fast for a person to understand; putting them under pressure to do things more rapidly than they can bear
- 8) *Invalidation* - failing to acknowledge the subjective reality of a person's experience, and especially what they are feeling
- 9) *Banishment* - sending a person away, or excluding them, physically or psychologically
- 10) *Objectification* - treating a person as if they were a lump of dead matter; to be pushed, lifted, filled, pumped or drained, without proper reference to the fact that they are sentient beings
- 11) *Ignoring* - carrying on (in conversation or action) in the presence of a person as if they were not there
- 12) *Imposition* - forcing a person to do something, over-riding desire or denying the possibility of choice on their part
- 13) *Withholding* - refusing to give asked for attention, or to meet an evident need; for example, for affectionate contact
- 14) *Accusation* - blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation
- 15) *Disruption* - disturbing a person's action or inaction; crudely breaking their 'frame of reference'
- 16) *Mockery* - making fun of a person's ‘strange’ actions or remarks; teasing, ridiculing, humiliating, making jokes at their expense
- 17) *Disparagement* - telling a person that they are incompetent, useless, worthless etc; giving them messages that are damaging to their self-esteem

social psychology' in the immediate care environment, or 'organisational culture'. 'The strong word malignant signifies something that is deeply damaging to personhood, possibly even undermining physical well-being' (1997a: 46).

Conversely, Kitwood argued, improving the quality of interpersonal relationships would lead to increased well-being and perhaps even to a degree of 'rementia'. Where the person with dementia continues to be treated by others as a person in the full sense of the word, Kitwood believed, he or she can fare well in spite of even severe cognitive losses. Particularly important here is a preparedness of the caregiver to enter into the person's own version of reality. That is to say that rather than trying to orientate the person with dementia to our own world view we should be able to communicate on the basis of what the person with dementia believes to be happening.

Whilst this approach has considerable appeal, some of its deeper implications are harder to accept. It places immense responsibility on the direct providers of care, whilst simultaneously shifting attention away from, for example, the chronic underfunding of care services, the profit motivation of independent sector care providers, and labour relations under capitalism. It implies that the well-being of people who have dementia depends largely on dyadic interactions between individuals. Pathology (in the form of malignant social psychology) is shifted from the person with dementia to his or her immediate environment and those employed within it. Kitwood acknowledges that caring for people with dementia is stressful, but he makes little reference to the low pay and low status of dementia care work. At times he appears to suggest that the ill-being of people with dementia is the result of a moral failing on the part of their caregivers, and in at least one article this is linked to a discussion of the gendered nature of care work in which he appears to suggest that such moral deficiencies are particularly likely in female caregivers who have had little formal education (Kitwood, 1998a).

When I began working with the Dementia Group I was hugely impressed by Kitwood's erudition, and by his courage in challenging the biomedical model of dementia, a position which sometimes led to attacks on his work. As a working class woman and single parent who had come late to Higher Education, however, I always found myself alienated by the moralistic line in his thinking on care practice. As time

went on, the development of our educational programmes in dementia studies meant that we now had a student body many of whose social and educational backgrounds were similar to my own. Learning about the working conditions many of them experienced and their determination to succeed in Higher Education, often in the face of extreme odds and self-doubt, and not infrequently on a self-funding basis, made me even more uncomfortable about the concept of their ‘moral re-education’.

Caregivers also experience all the indicators of malignant social psychology, both within the workplace and in broader social contexts, particularly if they are members of marginalised groups themselves. Economic migrants are, for example, increasingly over-represented in the direct dementia care workforce. Whilst conditions of employment are worsening, if anything, for direct care staff, the tendency to hold them responsible for deficiencies in dementia care is increasingly prevalent, and there is little current concept of dementia care work as alienated labour.

Kitwood’s model is, moreover, largely synchronic in that it considers only the period from closely before diagnosis to death, rather than involving a diachronic dimension which recognises the person in a ‘whole life’ context. Central to my discussion here, it also involves a question-begging presumption of ‘normal life’ prior to the onset of dementia (see Fig 1, p 35). Malignant social psychology is not, however, limited to people with dementia, nor is it exclusively to be found in the interpersonal milieu. Most people will have experienced repeated instances of personal detraction during the course of their lives and this can perhaps better be considered as an outworking of societal power relationships at an institutional level. So we can identify, in the context of 20th century experience, forms of personal detraction which range from the everyday to the extreme: from *intimidation* by teachers or employers; to the *labelling* of ‘bastards’ and ‘cripples’; the *banishment* of refugees, or the extreme *objectification* of being herded into a cattle truck.

Whilst Kitwood acknowledges that ‘the malignancy is part of our cultural inheritance’ (1997a: 46) he does not elaborate on this, and thus fails to engage with the possibility that a main source of resentment, fear, and anger for people with dementia may be that they have already experienced such a malignant social psychology, and often in a more extreme form, in the schools, factories, barracks, hospitals, PoW camps or

ghettoes they encountered earlier in life. If the concept of malignant social psychology is extended to take in diachronic and socio-historical aspects of experience, the presumption of 'normal life' prior to the onset of symptoms of dementia will, in almost all cases, be revealed as a deficient one.

In the next section I will discuss Kitwood's work on life history, suggesting that having initially attempted, without success, to establish a causal role for negative life events in the aetiology of dementia, he then went on to marginalise the importance of lived experience in understanding the actions and words of people diagnosed with dementia. In switching the focus of his attention from aetiology to care practice, it seems that Kitwood simultaneously turned away from a macro-social explanatory framework.

### **Kitwood's work on life history**

In questioning the theoretical sufficiency of Kitwood's alternative model of dementia – one which seeks to acknowledge the role of the personal and social – it seems appropriate to proceed by following his own example of identifying the anomalous cases and phenomena for which it cannot account. It is striking, for example, given that dementia is fundamentally considered to be a disorder of memory, that Kitwood makes comparatively little reference to the nature, or manifestation, of memory changes in its onset or progression, placing more emphasis on the emotional and affective consequences of stigmatization and deteriorating interpersonal relationships. In particular, Kitwood has little to say about the increasing orientation on the past which characterises dementia, about the frequency with which people who have dementia appear to 'act out' scenes from previous life, or about the urgency they often express about needing to find people or places from the past. As will be discussed further in subsequent chapters, once taken out of its biomedical straightjacket, dementia is above all a *recherche du temps perdu*, but this was never a strong theme in Kitwood's work.

As we have seen, in Kitwood's (1993) 'equation' life history was considered to be one of five key components contributing to dementia. Prior to this he had carried out

a series of 44 psychobiographical investigations in an attempt to establish a causal link between traumatic personal experience and the onset of dementia (Kitwood, 1990b). His aim at this time was to establish that dementia ‘is intimately bound up with the vicissitudes of personal and social life’, but he hypothesised that this was because a person with a poorly developed ‘experiential self’ was predisposed to dementia. ‘It is as if the self, together with its defences, has been subjected to extreme attenuation; then the threats which relate specifically to death and dying fasten onto *psychotic elements that are already present from earlier life*, and their invasion is a relatively easy matter’ (Kitwood 1990a: 74 emphasis added).

What seems to be implied here is that each individual who goes on to develop dementia is already inherently defective in some way. Where biomedical science was beginning to suggest target genes for the newly alzheimerized dementia, Kitwood’s alternative hypothesis was a personality damaged by the micro-social and emotional environment. There is thus a significant tension in Kitwood’s work between his essentially deconstructive approach towards the biomedical model of dementia, and his simultaneous suggestion of alternative causation.

### *The century without a war*

Kitwood published a detailed account of just one of his psychobiographies, and this includes some inconsistencies which raise questions about the kind of life events he was, in any case, prepared to consider significant. Kitwood’s method was to split the person’s life into seven periods of 14 years each and summarise the main life events occurring in each period. This approach has some similarities to the model of eight life stages proposed by the prominent American post-war humanist psychologist Erik Erikson (1982). As Bender (1997) points out, Erikson’s model makes no reference to war, and thus cannot apply to any living person of the 20th century.

When we consider the frequency and degree of war trauma... we note to our surprise that Erikson never comments on the effects of the two World Wars on his theory of life stages... in the Eriksonian liturgy no sounds of gun-fire are allowed to disturb the smooth unwinding, albeit difficult and complex, of a man’s life.

(Bender 1997: 339)

Rose, the woman in question was born in 1904. Kitwood's summary of her life for ages 0-14 (ie 1904 – 1918) is as follows

The family was large; material and psychological impoverishment were intertwined. Rose was the fifth child. Probably she lacked attention and care. Her success at school came to nothing. She suffered a major bereavement. Her first job was one in which she adapted to others' needs. There is little to suggest a strong beginning to an experiencing self (Kitwood 1990a: 70).

It is difficult to avoid the suspicion here that Kitwood selected data to support his hypothesis about the underdevelopment of the experiential self in people who succumb to dementia in later life. Inferences about Rose's 'probable' lack of care and attention, for example, are not necessarily valid simply because she was a member of a large, working class family. On the other hand, it is difficult to think of any form of employment that *does not* involve adapting to the needs of others. There seems to be little here that would lead of itself to a poorly developed experiential self, unless we are to accept, also, that an entire generation and social class were prone to the development of 'psychotic elements', as a result of belonging to large families and working from an early age.

Later in the same article, Kitwood quotes from a letter from Rose's daughter Sarah, the same person who had provided the biographical data, as follows, 'This lady has suffered the bereavement of all nine of her brothers and sisters... caring for the babies of working women during the first world war when only a child herself...' In later periods of Rose's life, however, the deaths of only six brothers and sisters are noted by Kitwood, leaving three unaccounted for. It is impossible not to wonder whether the 'major bereavement' mentioned in the period between 1904 and 1918 was the loss of several male members of the family as the result of the First World War. Whether or not this is the case, it is noticeable that Kitwood does not make any reference to that war or the one that followed it, as 'vicissitudes of personal and social life'.

From Kitwood's whole series of psychobiographical studies, 'critical life events' were noted in 27 out of 44 cases, a fairly inconclusive finding, and from this point on his interest in a precipitating role for life events in the aetiology of dementia began to wane. In Lakatos' (1970) terms it appears to have become a degenerating research

programme. Kitwood's subsequent work continues to refer quite often, in passing, to the importance of life history knowledge in providing care for people with dementia, but the concept of history advanced here tends to be individual and limited to what Smail (1993) describes as the proximal sphere, the person's immediate environment. Kitwood also frequently treats biographical material as though it is a merely allusive or metaphorical response to the current experience of dementia.

### *Lived experience as metaphor*

Three examples are given to demonstrate the importance of life history in Kitwood's main text *Dementia Reconsidered* (1997a: 75). The first of these relates to Janet whose references to trains passing by the residential home - when there are in fact no trains present - is explained in terms of her often having visited her family by train in the past, and wishing she could still do so. Henry who 'had a career as an academic before retirement' is now distressed by his inability to use a computer. Finally, there is Arthur who 'had been a highly respected member of the community and a pillar of his local church...now...he often offends people with his foul language, and some care staff are afraid of him, because when they come close he often punches or bites them'. These examples imply a homogeneity in the class background, ethnicity, and social status of those concerned, suggesting that dementia is the sole tragedy that disrupts a previously unremarkable life. Kitwood's tendency to use fictional examples, or 'vignettes' as he called them, perhaps also contributes to this lack of diversity; as a clergyman-turned-academic he may have tended to formulate fictional examples close to his own experience.

By contrast, two real life examples quoted by Kitwood (1997a: 74) taken from group work carried out by Cheston (1996) both make explicit reference to wartime experience - itself an indication that this is an ongoing preoccupation in situations where people with dementia are encouraged to speak freely. The first is a man whose war service was in the Malayan jungle. He spoke about 'the persistent advance of the vegetation and the constant battle to keep it back'. This is interpreted as a metaphor for the experience of dementia - 'a way for him to talk about his *own* struggle with dementia' (Kitwood 1997a: 74 emphasis added). The second example is of a woman who describes her employer's return from the Second World War - thin and

bewildered - 'looking like someone who had really lost his way'. Again, Kitwood supports the interpretation that this is a metaphor for her own feeling of being 'lost' as a result of dementia. Real experiences of traumatic situations thus have imposed upon them an interpretation which denies their importance as first person testimony.

In the first case, referring to this man's '*own* struggle with dementia' suggests a split with the past, as though the historical experiences he is describing are not merely unimportant, but are not even his own. The Malayan conflict was, even at the time, a secret war and has now largely been expunged from popular memory. Never officially acknowledged *as a war* by the government of the day, it nevertheless involved 545,000 tons of bombs being dropped, the internment of 34,000 people, and the exfoliation of hundreds of acres of land. Hostilities in Malaysia continued for almost 20 years from 1948 to 1966. Until 1960 this was a war fought by conscripts on national service, in itself a corrective to the popular myth that, post-1945, an unbroken peace returned. It is not surprising that having been involved in such a conflict should continue to loom large in someone's memory in a literal rather than metaphorical way. The same image can, of course, be both literal *and* metaphorical, but Kitwood does not appear to consider the traumatic nature of the former.

Kitwood's humanistic perspective and corresponding interest in progress, self-actualisation and the maximisation of well-being also no doubt prevented the turning of his attention to the darker aspects of social and cultural history. In his person-centred philosophy of care it is imperative that caregivers realise that their own approach towards, and interaction with, the person with dementia are paramount in influencing that person's well-being or ill-being; that there is always something that can be done in the here and now that will lead to increased well-being. This is, of course, an important humanitarian aim but it seems, for Kitwood, ultimately to be a moral issue, rather than an empirical one.

In a late publication, Kitwood (1998b) does in fact make one reference to the importance of seeing each person with dementia as a historical being. He goes on to outline a role play exercise in which (as part of the programme for a short course on dementia care) he took on the character of Richard, a man in a residential home about whose life history very little is known. During the course of the exercise the

participants are asked to note down clues about Richard's possible life story. Part of the mystery to be unfolded is Richard's reference to 'Anzio', and his cowering under a table following a loud noise. Commenting on the denouement to this exercise, Kitwood remarks that some participants 'even thought that Anzio was a person and had no inkling that it was the scene of a famous landing in World War II where there was heavy loss of life'. This is the only example I have been able to find in Kitwood's work of an accepted connection between the experience of dementia and the reactivation a traumatic historical event.

## **Representations of dementia**

This chapter raises many epistemological questions related to the representation of people with dementia. The Alzheimer's movement draws on biomedical concepts and images to create a propagandist view of dementia as a scourge, a threat to the economy, an approaching demographic tidal wave. Kitwood's psychosocial model humanises the person with dementia but in a way that simultaneously homogenises 'the person' (singular) as safe, unthreatening, acceptable, but simultaneously somewhat passive and characterless. There are thus many ways that images of people with dementia can be used rhetorically to persuade particular groups of people, or society at large, to adopt a particular viewpoint, or to condone or protest against various forms of social arrangement.

In 2007, for example, considerable controversy arose over a television documentary (*Love's Farewell*, directed by Paul Watson) in which it was alleged – wrongly as turned out to be the case – that Malcolm Pointon, a man with dementia, had been filmed at the moment of his death. A newspaper reviewer had this to say about the film

The fact is there was nothing faked about Malcolm's catastrophic decline into mental illness. Nor was there anything essentially false in the portrayal of how a not-so-old man suffered and died in a way many people die in this country every day... Watson's style doesn't allow for much context but the Alzheimer's Society estimates that 700,000 people in the UK currently suffer from dementia. And that one in three of us will experience it in some form before we die. What Watson's film indisputably and unflinchingly put the spotlight on was the sheer living hell of this condition...

What was ‘essentially false’ here was not the film itself, but the message it was used to convey. Malcolm Pointon was diagnosed with Alzheimer-type dementia at the age of 51, and died aged 67. He conforms to the clinical picture of what might be termed ‘classical’ Alzheimer’s disease, the form of pre-senile dementia that Alzheimer originally identified in 51 year-old Auguste D. There is no doubt that Malcolm Pointon died from a devastating neurological disease; Alzheimer’s disease, of this classical form is, however, exceedingly rare. Less than 0.1% of the population aged 45-64 are diagnosed with any form dementia, and the condition that affected Malcolm Pointon is different both in type and degree from the age-associated memory changes characteristic of late life. On the basis of one rare case, ‘this condition’ is, however, represented as one that will not only affect one in three of the population, but will also determine the manner in which they die.

Examples such as this help to demonstrate the power of the arts and media to influence the ways that dementia is constructed by society. As will be argued later, such constructions are often very different from the impression gained from sources that pay direct attention to the voices of people with dementia themselves. It seems vital, then, that dementia studies should focus on such constructions and the media used to convey them. This subject is taken up in the next chapter in relation to the use of arts-based approaches in health and social care education.

## **Chapter 2) Using arts-based approaches in dementia care education: interpellation and resistance**

Abra was ready ere I called her name

And, though I called another, Abra came (Matthew Prior, 1718)

### **Introduction**

As would be expected from my critique of Kitwood's work in the previous chapter I have had, for some time, an ambivalent teaching relationship with the person-centred approach to dementia care. On the one hand, I am aware of its considerable potential for challenging the perceptions of practitioners whose initial training has been in the biomedical tradition. On the other, it has always had, for me, moralising and homogenising tendencies that I found difficult to live with. Most of the time I managed to subdue my misgivings, but they came into sharp focus during the period that I was working on this thesis, because at the same time I was also co-editing a critical reader of Kitwood's work (Baldwin and Capstick 2007). The critique in Chapter 1 thus represents the articulation of an unease about what I was teaching that had been mounting for many years. These observations are by no means irrelevant to the content of this chapter, which considers the ways in which professional discourses both interpellate, and can be resisted by, those who are called upon to perform particular roles.

At the outset of this study, however, my purported area of concern was the tendency for students on the Dementia Studies programme to reproduce uncritically in their assignments assumptions derived from the biomedical model of dementia. This was often evident in the terminology and concepts that appeared in their written work. I hoped that the introduction of audio-visual material in the form of fiction film would help to encourage different ways of seeing the person with dementia. Beyond this I was interested to find out whether writing in response to a film would be perceived as more interesting and enjoyable by students, and whether this might lead to a more fluid and reflective writing style. To illustrate this initial area of concern I will begin by outlining the background to the BSc (Hons) Dementia Studies course and then go

on to discuss a specific student assignment submitted in the academic year prior to the introduction of *Ex Memoria* into the curriculum.

I will then go on to discuss the arguments that have been put forward for using arts-based approaches generally, to ‘humanise’ subject areas in Higher Education that have traditionally been dominated by medical-scientific perspectives. Recent authors (eg Staricoff 2004; Larkinson 2005; Smith 2006) have suggested that such approaches have many benefits, pointing out, for example, that ‘the capacity for empathy, compassion and sensitivity required for work as an allied health professional cannot easily be taught through pedagogic methods’ (Smith, 2006: 421). There is also to be considered, however, a long tradition of theoretical debate about the possible deceptions of art, and about the challenges of representing both particular groups of people, and historical events.

A third strand of debate, also relevant to my subject area here, is the potential for works of art to create effects of alienation, estrangement, and defamiliarization - devices which disturb our taken-for-granted assumptions by presenting familiar images in unusual ways, by, for example, ‘prolonging the length of perception and emphasising the new meanings and emotional effects of the forms’ (Miall and Kuiken, 1994: 389). It may be argued that drawing on sources that create such effects is particularly appropriate in the context of dementia care education since the condition itself is characterised by confusion and disorientation, and people who have dementia often appear not to experience time in a linear fashion. At the same time, this may be considered a pedagogically risky strategy as it requires a faith in experiential learning, as opposed to more didactic teaching and control over the curriculum.

### **The BSc (Hons) Dementia Studies**

This course is currently the only full undergraduate degree programme in dementia studies offered by a UK university, and is a development of earlier continuing education programmes provided by Bradford Dementia Group at the University of Bradford from the mid-1990s onwards. The curriculum was designed in response to Kitwood’s increasing conviction that accredited programmes of learning and named

University awards were needed in order to raise the status of dementia care work as a specialised field of practice, to change organisational cultures, and to meet the impending demographic ‘crisis of care’.

In Britain the recognition is slowly dawning that there is a vast training and educational deficit, and that none of the existing forms of professional preparation properly address the issues arising in dementia care. The scale of the problem is gigantic, and it should be tackled at the meta-level... This means that it is essential to have specialist courses in dementia care at both first and higher degree levels (Kitwood, 1997a: 143).

This project was not completed during Kitwood’s lifetime, and after his death the development and validation of the dementia studies programme became my main role. The BSc (Hons) has been running since 2001 and a Masters degree was introduced in 2004.

All students on the BSc programme are existing dementia care practitioners who study part-time by distance learning whilst continuing with their usual work role. The majority of the coursework assignments are practice-based and require students to draw on their own experience of working with people who have dementia. More than 80 per cent of students are women, and the majority have a nursing qualification, although the course also recruits from other occupational groups involved in dementia care, such as occupational therapy, social services, and the voluntary sector.

Students who have already completed a Diploma of Higher Education or equivalent enter the course at final-year undergraduate level as a two-year, part-time ‘top-up’ programme. This is a popular route for nurses qualified since training began to be delivered by Higher Education Institutions in the early 1990s, as it enables them to convert a generic nursing or mental health nursing diploma into a specialist degree. Those who qualified longer ago, or have not previously studied in Higher Education, generally enter at second-year undergraduate level and can register for either a Diploma of Higher Education (completed in two years) or a BSc (four years).

Soon after the course started I began to develop an interest in the practice-based written work that students on the course were submitting for assessment. This was, I realised, a rich and largely untapped source of narrative data about practitioners’

experiences of working at the coal-face of dementia care. At an obvious level, it offered fascinating insights into real life care practice. As a result, we began to ask all students, on entry to the course, whether they were open to having extracts from their work used for purposes of educational research.

I came to realise, however, that students' work was often revealing in less immediately obvious ways. As Reynolds (2007) has also noted of practitioners' written work, it showed evidence of a complex interplay between lived experience, earlier training and education, prior acculturation to a practice field, and students' attempts to assimilate what they were now learning on the course. These were practitioners whose previous ways of conceptualising their work had been dominated by biomedical orthodoxy, and who were now expected to engage not only with complex bodies of theory, but also with the challenge to the very nature of their work required by the psycho-social model. In order to explore a specific example of the effects of this internal tension between models of dementia I have analysed below an assignment submitted for the module HD2003D *The Social Psychology of Dementia Care*. It will be helpful first, however, to outline the content of the module and the way it was assessed.

### *The Social Psychology module*

This module aimed to provide students with a basic understanding of five different bodies of psychological theory: behaviourist, cognitive, humanistic, psychodynamic, and symbolic interactionist. Students were encouraged to consider how these bodies of theory lead to different considerations of what it is to be a person. They were also asked to apply each body of theory to the care of people with dementia and to consider how different interventions in dementia care are linked to theory. For example, reality orientation (based originally on the work of Taulbee and Folsom, 1966) is underpinned by ideas derived from cognitive psychology. It involves the constant provision of prompts, reminders, and aids such as large format clocks and calendars, and colour-coding systems. Although this is intended as a helpful way of compensating for memory deficits, it assumes, for example, that the aim of dementia care is to readjust the person with dementia to our version of reality. Concepts such as 'clock-time', which drive working-age adults, are considered equally of concern to

older people who are living at a different tempo. Post (1998: 72) among others, has commented on the 'hypercognitivity' of modern society, and the inappropriateness of considering the losses of dementia from a purely cognitive perspective. His re-writing of Descartes' *cogito ergo sum*, as 'I feel and relate therefore I am', is more in keeping with Kitwood's humanistic approach.

The *Social Psychology* module had always evaluated well. Completion rates were high, and marks tended to be above average. This was, however, partly explained by the first of the two assignments being a short-answer comprehension exercise on which students tended to score highly. The second assignment was a critical incident analysis which required students to identify an incident from their own experience of care practice and analyse it using the psychological theory introduced in the module. Students found this assignment much more challenging, and a frequent comment was that it was difficult for them to pick anything from their own practice experience that 'stood out'. Although the nature of critical incidents was explained in detail in the module, many students wrote comparatively superficially about the care of a particular person with dementia over a period of weeks or months, rather than writing in depth and detail about a particular incident.

These assignments often lacked personal content related to the people involved, and tended to contain little observational or interpretative detail of what was said and done, particularly by the person with dementia. Third person, passive voice accounts were common, as were uses of technical/medical terminology. Suggestions for improving care practice tended to be vague and general, rather than related specifically to the person in question. These tendencies were also noticeable in practice-based assignments for other modules, and had been commented on by colleagues. Although there was a sense, at times, of frustration that students' received ideas were so resistant to change, there is no suggestion here that the problem lies with individual students. As I will discuss further below I believe that students are struggling – and to a greater or lesser extent, aware that they are struggling – with an inherited and inadequate language.

### *Interpellation and resistance*

Potter (1996) notes that we all have existing scripts, or interpretative repertoires - systematically related sets of terms drawing on familiar and frequently used images - that are difficult to change. Communications are made up of existing, taken-for-granted concepts that do not need to be explained to those working within the same context. Hamilton and Manias (2006) carried out an analysis of patients' files and records which showed that there was a predominance of medical, objectifying and bureaucratic language to be found there. Students on the Dementia Studies programme are similarly used to writing and reading about people with dementia in the context of routine assessments and case notes, and this no doubt influences the way they perceive people with dementia as a relatively homogenous group of people about whom there are a limited number of things that can be said, and a limited linguistic repertoire for saying them.

From the standpoint of critical discourse analysis, Fairclough (2001) points out that a dominant discourse (as with the biomedical standard paradigm of dementia) is

subject to a process of *naturalization* in which it appears to lose its connection with particular ideologies and interests and become the common-sense practice of the institution. Thus when ideology becomes common-sense, it apparently ceases to be ideology; this is itself an ideological effect, for ideology is truly effective only when it is disguised (Fairclough 2001: 89).

The ideologies and interests that link the biomedical model of dementia to the medical-industrial complex (Bond 2004) through the use of certain discursive practices, thus, in this view, permeate the situations in which formal dementia services are delivered, but are unrecognisable as such to those who practice within such services because they have taken on the semblance of common-sense.

As Geertz (1983) suggests, common sense is a cultural regime like any other; historically and culturally contingent, 'Common sense is not what the mind cleared of cant spontaneously apprehends' but rather 'what the mind filled with presuppositions concludes' (1983: 84).

The all-pervasiveness, or hegemony, of this discourse in society at large, in media imagery, and in training and education, inevitably has a great deal of influence on the values and beliefs people bring to bear on their work with people with dementia. If the shared language of the workplace stresses the concepts of disease, meaningless behaviour, and inevitable deterioration through fixed stages of neurological impairment, then practitioners are constrained to adopt this language in order to be understood and recognised as part of the professional group. Althusser (1971) conceptualised this as an ‘interpellation’ of the individual by hegemonic discourse. In this view the subject is ‘called into being’ in its entirety by ideology. It was also Althusser (1968) who first suggested that the presence of such a hegemonic discourse could be detected through the practice of ‘symptomatic reading’. Stronach and MacLure (1997: 6) similarly write of the need to ‘open up to interrogation institutional discourses that define the limits of the speaking subject before he or she ever speaks’.

In the sample assignment discussed below, however, I suggest that there is evidence of the struggle of the writing subject to resist such all-encompassing domination by the discourse of the workplace. If I am correct, this tends to support Zizek’s (1989) Lacanian re-working of the notion of interpellation. Here Zizek argues that the object called into being by ideology is never identical with the subject who comes to occupy the pre-assigned place. There will always be an ‘excess’ – a protest against the identity assigned by the Other.

### **Analysis of a report based on a self-selected critical incident**

The assignment in question was selected randomly from among those submitted by students who had given consent for their work to be used for research purposes. My analysis of the text is based on Fairclough’s model of critical discourse analysis (Fairclough 2001). The account is dominated, at least in terms of its manifest content, by ‘common-sense’ views and perspectives, which cloak the presence of the biomedical discourse on dementia. I suggest, however, that there is evidence of latent, or symptomatic, content which can be made to tell a different story.

Students were asked to give the incident they wrote about a title, and the title chosen by this student (*'I still wonder if Mrs B really did remember me'*) suggests in itself an excess arising from the student's desire to be more than the role ascribed to her. As in the lines by Matthew Prior at the beginning of this chapter, then, the person who appears is never synonymous with the person called into being.

The analysis is based on the 500 word narrative account of the chosen critical incident, with which students are asked to begin their assignment. My first reading of it involved the highlighting, transcription and listing of words and phrases (or 'formal elements' as Fairclough describes them) which were foregrounded *for me*. That is, the words and phrases which cause me, as I read, to pause or reflect. When marking assignments, rather than analysing them as data, this often involves reflecting on how to give constructive feedback to the student (for example: querying why a particular word has been used in preference to another; suggesting additional information that might have been given). On second reading, I carried out a further exploration of repetitions, parallels, and 'overwording'. Overwording is defined by Fairclough (2001: 96) as the frequent use of synonyms, or words which are near synonyms, and which may thus indicate 'a locus of ideological struggle'.

The student in question had clearly engaged with the content of the module and her assignment showed considerable evidence of concern for people with dementia, and commitment to improving practice. There is, however, a lack of observational detail related to how things looked or what people said. Speech is reported. Some terms are used in scare quotes, suggesting that the student is aware that there is something not quite right about them, but is unable or unprepared to explain what this might be, or to use other less problematic terms. This has something in common with the deconstructive practice of using a term which is necessary but inadequate 'under erasure'. A term from the hegemonic discourse has been noted as inadequate or deformative; the writer cannot, however, see a way to question the meaning of the word, without using the word itself. As Heidegger put it 'Because the word is inaccurate it is crossed out; since the word is necessary it remains legible' (cited in Spivak 1997). Scare quotes are used then, in this kind of transitional discourse, to indicate a dissatisfaction with the prevailing ideology, which has not yet become an outright challenge.

*Critical incident report: 'I still wonder if Mrs B really did remember me'*

The assignment describes two occasions, four years apart, when the writer met the same woman with dementia in hospital – the first time on an acute medical ward and the second on an orthopaedic ward. The writer (J) suggests that the woman in question (Mrs B) remembered J fondly, due to having been treated kindly by her on the first occasion.

The formal elements identified in this text were as follows

1) *elderly medical patients/elderly lady*

These are initial classification schemes used to allocate the subject of the text to a particular group (in this case old, ill, female, dependent). 'Elderly' and 'lady' are euphemisms whose use implies that to use the term 'old woman' would be disparaging in some way. Such euphemisms indirectly underline the inequalities that they seek to avoid mentioning.

2) *ambulant/"wandering"/wandering*

'Ambulant' is a term used in medical case notes, rather than to write about ourselves or people with whom we identify. Being ambulant (able to walk) is initially viewed as a desirable indication of Mrs B's recovery from the physical illness for which she was admitted to the hospital ward. Mrs B's 'wandering' (used once with scare quotes and once without) describes the same action, but now this has become *undesirable* problematic behaviour related to her dementia.

3) *she constantly tried to leave the ward/ asking for the way out*

There is an emphasis throughout on keeping Mrs B still. Mrs B does not conform to the requirements of a hospital patient either by remaining passive and immobile, or by getting better and going home. This interferes with the real work of the ward.

4) *staff were always trying to get her to sit by her bed/if I spent a little more time with her she would settle/[she] settled back in her chair*

It is implied that members of staff other than the writer should not try to immobilise Mrs B, but simultaneously that the writer is more successful than others in keeping Mrs B 'settled'. The use of the word 'settled' is interesting in this context, as it is an informal, non-medical one. Using this term helps the writer to present keeping Mrs B still as a caring act, rather than a matter of convenience.

5) *"problem" behaviour/ behaviour 'too difficult to manage'*

Scare quotes are used to indicate that the writer recognises to some extent that the perceived "problem" – Mrs B's activity – arose from the unsuitability of the care environment. This is, however, left as an implied reading rather than being made explicit, or rendered in terms other than those used in the dominant discourse.

6) *Four years later... I'm sure she remembered me too*

It is on the whole unlikely that someone with the short term memory loss characteristic of dementia would remember a nurse met several years earlier. J's conviction on this point seems, however, to provide a strong indication of the desire for a transformative role that practitioners involved in this kind of work may have.

7) *home*

The word home is used seven times in this brief account. Mrs B says that she must go home as her husband (who died several years earlier) will be waiting there for her. On both occasions when she is in hospital Mrs B is 'reassured' by being told that she can go home when she is better, but without acknowledging that the 'home' she will be returning to is not the one she is seeking (ie the home where she formerly lived with her husband) but the care home from which she was admitted.

Whilst a different framework for presentation and analysis has been used here, these points were all included in feedback to the student at the time, in a way that

encouraged her to question what was being taken for granted in her writing. I mention this to avoid any suspicion of commenting on a student's work for research purposes in a way that has not been communicated to her in person.

### **Emotional labour and dementia care**

My purpose in exploring the self-selected critical incident above is not a 'before and after' comparison with the assignments based on *Ex Memoria*, but merely to demonstrate that when a foregrounding approach is adopted patterns, repetitions, and parallelisms that might otherwise be overlooked emerge more clearly. On first reading this assignment I had not, for example, realised how much emphasis there was on 'settling' Mrs B; a term that gestures towards an interpersonal relationship, but one which we might more readily associate with fractious infants.

There is an economy of care in which patients and clients have to be kept still, or have their feelings explained away, in order that the staff can go about what is perceived to be the real work of physical care. Normally, ambulant (ie physically recovered) patients would be discharged. People with dementia – who neither get better nor comply with the rules of being a patient - are always threatening to disrupt this economy. What also becomes apparent is that accounts analysed in this way tell more than the students had intended. For example, there appears to be a latent message about how emotionally draining it can be to work with people who *don't remember* what you have done for them.

These needs can foster the development of a personal script or way of seeing in which praise or blame are allocated on the basis of who it is who is doing broadly the same thing. The complementary beliefs that 'I am doing well'/'you are doing badly' can be held intact simultaneously, whilst the conflicting beliefs 'Mrs B is troublesome and needs to be kept still'/'Mrs B is expressing a legitimate right to freedom of movement' cannot. If one consistently takes the latter view it becomes impossible to work within the existing economy of care. If Mrs B is acknowledged as a person, reacting in a way similar to anyone else held against his or her will, and for reasons

that have not been explained or cannot be understood, her plight becomes too painful to contemplate.

In the field of health and social care generally there is a large body of work on the emotional labour of caring. This focuses attention on the need for practitioners who come into contact with people who are frightened, in pain, or non-compliant, to manage their emotions, by either ‘pushing down’ authentic feelings in favour of emotional distance, or by ‘pumping up’ feelings which are not genuinely there in order to appear more empathic (eg Brotheridge and Grandey, 2002). In the field of dementia care specifically, Balfour (2006: 340-341) points to the culture of blame that can quickly materialise in care settings when things are not going well; ‘the staff conveyed the sense that if they found words for their feelings, there was a fear of what would emerge, particularly negative feelings rather than compassionate ones’. Balfour suggests that this fear often takes the form of inter-professional rivalries over role and identity, of a ‘maiming of the capacity to think’ and a retreat into ‘too busyness’ as a defence against thinking about the experience of patients. He stresses the need to provide opportunities for care staff to process their feelings in a way that does not have a negative impact on the care they are able to provide.

If we take these two factors together – the ‘interpellation’ of the environment by the dominant discourse, and the emotional labour of caring – the challenges of this kind of work become increasingly apparent. It is little wonder, then, that the traces of this conflict are often apparent in students’ assignments, in the suppression of their own feelings beneath the acquired language of the dominant discourse. It is not surprising either, that they often appear to struggle with adopting different ways of conceptualising a situation, or that they find reflection disturbing. Programmes of professional education need to be underpinned, then, by an understanding of the struggle that practitioners returning to study are likely to face when asked to look differently at the nature of care practice in their workplace. Arts-based approaches are increasingly promoted in the health and social care field as an alternative approach in which one benefit is the potential for practitioners to explore their feelings outside the immediate environment of the care setting, by engaging with fictional cases.

## **Arts-based approaches in health and social care education: the case in favour**

If biomedical science has provided the dominant discourse on dementia, artistic discourse as found in literary fiction, poetry, drama, film and biography would seem immediately to offer a different register and set of conceptual tools for engaging with this condition. Here, for example, is an extract from a contemporary fictional text *The Madonnas of Leningrad* (Dean, 2006) in which Marina, the central character, reflects on the experience of dementia

One of the effects of this deterioration seems to be that as the scope of her attention narrows, it also focuses like a magnifying glass on smaller pleasures that have escaped her notice for years. She keeps these observations to herself. She tried to point out once to Dmitri the bottomless beauty in her glass of tea. It looked like amber with buried embers of light, and when held just so, there was a rainbow in the glass that took her breath away. (Dean, 2006: 72)

Ian McEwan's (2006) novel *Saturday*, includes a scene in which the central character Henry Perowne visits his mother, Lily, in a care home. McEwan's rendition of Lily's circuitous and evocative speech is drawn from his experience of his own mother's dementia (personal correspondence).

I've got plenty of them cups and saucers. So I can always go out with one of them. But the thing is, the space between people is so tiny – she brings up two wavering hands to show him a gap – that there's hardly enough space to squeeze through. There's too much binding.....If you turn the picture round and take the back off like I did you get such a lot of pleasure out of it. It's all what it meant. And the laugh we had out of it!

(McEwan 2006: 162-163)

In a general overview related primarily to the use of literary fiction and drama, Larkinson (2005) suggests that using the arts in health professional education can foster the development of

*Creative imagination* – an understanding of the other person's reality and experience

*Perspectival vision* - ability to take the other person's point of view

*Sensitivity to language* – interpretation of signs and clues, understanding of hidden meanings

*Capacity to be fully present* – bearing witness

*Emotional engagement* - ‘whole person’ understanding

*Sense of mystery* – a sense of the depth and complexity of life that helps to retain a sense of wonder and curiosity

In a review of the literature on arts and health, Staricoff (2004) further notes the potential for visual arts to help in developing confidence in observational skills. This suggests that visual representations may lead to a heightened awareness which would be advantageous in dementia care practice. Comments from students that ‘nothing seems to stand out’ or ‘nothing much really happens’ in their workplace suggest that they may not be attuned to the micro-level of individual experience; that they tend to overlook a lot of the fine detail of small interactions or revealing comments made by people with dementia. Such incidents are, however, often what provide real insight into the person’s experience.

I remember, for example, watching a woman in a nursing home who was sitting in one of a row of chairs turned away from the window, facing a blank wall, and who was ‘picking’ the flowers off her dress, transferring them carefully to her other hand, and then ‘eating’ them, like sweets, with signs of great relish. Another woman, left on her own in the dining room at the end of breakfast, began ‘walking’ two toast crusts towards each other, apparently acting out some kind of wordless conversation between them as though they were puppets. A man with dementia in a residential home would frequently approach people in state of great indignation because he had been told he was ‘no good to the British army’.

Often such behaviour suggests extremes of role loss and sensory deprivation – the latter described by Perrin (1999) as being literally ‘bored to death. It is well established that sensory deprivation leads to disorientation, confusion, sleep disturbance and, in extreme cases, hallucinations (Zubek, 1969). All of these are also considered to be symptoms of dementia, yet research has shown that people with dementia are frequently left for long periods of time with nothing at all to do (eg Hancock et al, 2005). Such examples also suggest, however, the immense

resourcefulness that people with dementia can often bring to bear in making something happen in the least propitious of circumstances. This will also tend to be overlooked if practitioners are not attentive to the minutia of day-to-day practice.

Mason (2002: 7) makes the important point that what is noticed in the practice domain depends on what is valued and that 'every act of caring and supporting depends on noticing'. Thus, what is not noticed in the first place cannot be acted on or responded to. In a study based on student engagement with a photograph by Diane Arbus (see following page) of a masked woman in a wheelchair, Benin and Cartwright (2006) suggest that the tendency to look away from people who have visible disabilities is a gesture of shame. Tomkins (1995) describes this shame as 'a taboo on looking'. Freud himself suggested that shame is the force which opposes *scopophilia*, or the normal pleasure of gazing at someone attractive to us (Freud 1924 in Gay 1995), and it seems likely that there are various kinds of 'looking practice' which for all of us have been subjected early in life to parental prohibition. Typically, this will have included being told that 'it's rude to stare' at people whose appearance or behaviour are unusual in some way. This may suggest another reason why practitioners tend to avert their gaze from people with dementia as far as possible.

Taylor and White (2006: 944) suggest that in the current education of social workers there is an increasing tendency to a positivistic 'education for certainty'. By comparison, they suggest, social work in the 80s was conceptualised as *art* and the important practitioner attributes were considered to be intuition, imagination, reflection and personal experience. They quote Jordan (1978) who suggests that literature and poetry offer more perceptive insights into human experience than psychology textbooks, and Downie and McNaughton (2000) who argue that assessment of health practitioners might include writing an essay based on the portrayal of doctors in fiction. 'This kind of imaginative teaching can help move professionals towards practising more reflexively, since it exposes them to different ways of representing what they do' (Taylor and White, 2006: 948). Nussbaum (1997) makes a similar point about the value of literature and art in developing 'narrative imagination'. Other sources (eg Van Voorhis, 1998) promote the use of fictional forms including drama, novels, poetry and auto/biography to encourage 'compassionate engagement' in practice.

Estrangement - Diane Arbus, 1970: Masked woman in a wheelchair



In relation to film, specifically, Downey et al (2003: 403) suggest that ‘films, used as case studies, can deepen a student’s engagement with the subject matter and characters, permitting the student to empathize, identify, and develop feelings of closeness, respect, affection, revulsion, fear, [and] anger’. Alexander et al (2005) make similar points about the use of film in ‘narrative medicine’, an approach in which medical students engage with storied accounts of the lives of patients, and where illness – rather than being the main focus of the practitioner’s attention – is viewed instead as an *interruption* to the ongoing plotline.

These sources all suggest that drawing on the arts will have beneficial influences on the development of empathic, compassionate, imaginative and perceptive practitioners. In other words, they take the humanistic view that the arts per se have a civilising, and what Freire (1972) would describe as a ‘concientizing’, effect on the learner. In this they adhere to a concept of emancipatory education, in which educator effort is devoted to the enlightenment of the learner and his or her liberation from mistaken perceptions and ‘inauthentic language’. Freire used stylised drawings of scenes that would be familiar to the impoverished Brazilians he was teaching, in order to encourage them to produce their own ‘authentic’ words for their experience. Newman (2006) explains how Freire would, for example, use a drawing of water standing in the street of a shanty town, and encourage the ‘renaming’ of water, first as dirty water, then as sewage, then as a threat to their children’s health, and so on, until they were able to name it as an example of injustice.

Whilst this is an approach that has many attractions, it is not without its own ideological implications. It is evidently viewed as a move from falsity to facticity, for example, and it also involves an acceptance of the ‘teacher-as-liberator’, and arbiter of ‘authentic’ language. With hindsight, many of my own early attempts to correct, rather than explore, students’ use of language, shared these hallmarks.

## **Art, representation, and ideology**

C P Snow (1956; 1959) first drew attention to the different languages spoken by the arts and sciences over half a century ago, arguing that these were two separate cultures between which communication or synthesis were increasingly impossible. ‘I believe’ Snow wrote, ‘that the intellectual life of the whole of western society is increasingly being split into two polar groups...literary intellectuals at the one pole – at the other scientists’. Although Snow’s work has since gone out of fashion, it seems that little in Higher Education has changed. The requirement for undergraduate and postgraduate degree programmes to be categorised as either arts or sciences is one indication of this, as is the automatic categorisation of health studies courses as science degrees.

Interestingly, however, Snow’s original argument was not that the sciences should be subjected to the humanising influences of art, as has been the case with the resurgent ‘arts and health’ movement in education. Snow saw science as the culture concerned to solve social problems, and scientists as those who ‘have the future in their bones’. He also advocated the rise of a third culture concerned with ‘how human beings are living, or have lived’. This is very different from the current perception that art is invariably ‘a good thing’ and that including the arts per se in the education of scientists, medical practitioners and health and social care workers generally will have a humanising and beneficial effect. As will be discussed further below the potential for art to deceive or misrepresent also needs to be borne in mind.

More recently Carey (2005) has taken up an argument similar to Snow’s, challenging the commonly held idea that the arts are necessarily ‘good for us’. He refers to the tendency for dictators to use art as a way of distracting the masses (Hitler’s programme of arts subsidy was one of the largest in the history of civilization) and draws attention to the kind of artistic snobbery that could allow Bloomsbury Group member, Clive Bell, to ask why, since all artists are by definition aristocrats, they should bother about the fate of humanity. Clover (2006) also draws attention to the cultural supremacism of European ‘high’ or ‘fine’ art which relegated the artwork of subordinate cultures and indigenous peoples to the margins. The current body of

literature on the use of the arts in health and social care education does not, however, tend to problematize art itself by raising questions about the possible distortions to be found in some arts sources. In other words, it may not yet have located itself in relation to theories of representation.

According to Helsby (2006) representation theory has, over the years, passed through three main phases: reflective theory suggested that art merely mirrors back what already exists; intentionalist theory suggested that the intentions of the author should shape the analysis of the work, and constructionist theory focuses on the discursive aspects of the work in producing meaning and controlling or responding to the beliefs that are dominant in society. The arts and health movement currently seems to accept, without criticism, a blend of the ‘art as mimesis’ reflective theory, and the ‘pre death of the author’ intentionalist theory. As Helsby points out, however, most media analysis work within the field of representation theory today takes a constructionist approach, and here the propensity for art to perpetuate dominant ideologies, and to stigmatize and exclude marginalised groups has tended to be a focus of major concern. Even apparently benign representations can be deceptive. The extract from Dean (2006) quoted above, for example, offers a dramatically different and more human perspective on the experience of dementia than does the biomedical model. These are not, however, the words or thoughts of a person who has dementia, and as a result the authenticity of the experience that is being presented here remains questionable.

Whilst little work has been done on the portrayal of dementia in visual media, the representation of people with mental health problems has been problematised, and Dunn (1999) among others has pointed to the immense power such media have to create and perpetuate discriminatory attitudes. As Cassey (2005) notes, this is often because the representation of mental illness in film is angled to suit the needs of the plot and producers (ie the market), rather than to provide a view that is more authentic, but less dramatic or emotionally manipulative.

Three recent feature films related to dementia, for example - *Iris*, *The Notebook*, and *Away from Her* – all tell the story of male spouse carers for female partners with dementia. In each case the representation is of the male partner’s loss, of the burdens of caring for someone who is ‘disappearing’, and of the inexorable progress of

destruction of brain tissue. As will be discussed further in Chapter 3, in each of them – and in varying ways - memory loss is used either as a plotting device, or as a filmic trope, resulting in depictions that may mislead about the memory changes characteristic of dementia.

A recent text by Alexander et al (2006: 62) *Cinemeducation: a comprehensive guide to using film in medical education* describes a scene from the film *Folks* (dir Kotcheff 1992), in which a character with dementia, somewhat stereotypically, burns the house down. Alexander suggests using this scene to facilitate discussion of ‘the most common forms of dementia’ and ‘the office tests that can be used to screen for and/or diagnose dementia’. It seems unlikely that medical students will derive any of the benefits identified by the arts and health movement merely from discussing standard biomedical model questions in the context of a film. What is also needed is a critical engagement with the film itself in terms of its representation of the person with dementia.

#### *Defamiliarization, estrangement and rupture*

The literature on arts and healthcare education makes little reference to the tendency of experimental and surrealist art forms deliberately to reject verisimilitude in favour of a distorted view of the world intended to challenge the reader or viewer’s existing perceptions – to bring about a rupture in the world of taken-for-granted normality. As Eagleton (1983: 187) argues

Such transfigured forms might jolt the audience out of the reassurance of recognition – the self-security which springs from contemplating a world which is familiar...Bertolt Brecht...uses certain dramatic techniques (the so-called ‘estrangement effect’) to render the most taken-for-granted aspects of social reality shockingly unfamiliar, and so to rouse the audience to a new critical awareness of them. Far from being concerned to reinforce the audience’s sense of security, Brecht wants, as he says, to ‘create contradictions within them’ – to unsettle their convictions, dismantle and refashion their received identities, and expose the unity of this selfhood as an ideological illusion.

The shockingly unfamiliar is, of course, often the already secretly familiar – the unheimlich/heimlich<sup>1</sup> - and if this were not the case it is unlikely that the estrangement effects adopted by modernist texts such as those of Brecht, Beckett and Conrad would have any resonance for those who watch or read their work. This is also, no doubt, the level on which the Diane Arbus photograph discussed earlier in this chapter works to trouble and disturb viewers. Freud's (1919) essay on the unheimlich (or 'uncanny') suggests that two dominant influences on our experience of fictional events as uncanny are the context within which the events are experienced (rather than the events themselves), and the character/s with whom we identify. In the next chapter these debates will be developed further in relation to the characteristics of films on dementia, and the educational potential of *Ex Memoria*.

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<sup>1</sup>The English translation 'uncanny' does not do justice to the contradiction inherent in the German terms heimlich (literally 'homely') and unheimlich ('unhomely') which are often used interchangeably in German, suggesting an association between the familiar and the strange.

### Chapter 3) Dementia and memory loss in film: mainstream cinema and Ex Memoria

MAN:           There's a lot of Poles here...?  
HELENA:       Yeah, Poles, you know, Russians, English. *She's* Polish.  
MAN:           Oh, good. So's my mother. Got out just before the war.  
HELENA:       Mum made it through Warsaw. Managed to avoid the ghetto somehow...

(from the script of *Ex Memoria*: Appignanesi J, 2006)

#### Introduction

As mentioned in the previous chapter, films which touch on dementia – either as a central theme or a sub-text - often misrepresent the nature of the condition because they are too dependent on standard paradigm sources, or because they wish to use the theme of memory loss as a plot device. They may also misrepresent, or exclude altogether, the former life of the person who now has dementia and its historical context. In this chapter, I want to consider how contested ideas about the nature of dementia and the definitional problems which surround it feed into films on the subject, and the challenges this raises related to genre, content and message.

In the latter part of the chapter I will argue that *Ex Memoria* offers a different view of dementia, one which is more grounded both in naturalistic observation of a person with dementia and in historical context, but also – and perhaps because of this - potentially more challenging to the viewer than standard filmic treatments of dementia. Here I will use examples and extracts from the film, and the memoir on which it is based, to explore dementia in the context of 20th century history, and its interpretation in terms of Freud's concepts of repression and the uncanny.

Importantly, the theory that will be discussed in this chapter did not inform the script development process. Rather the events shown in the film itself, throw into sharp relief the way that past experience is revived in dementia. This opens up an

understanding of dementia experienced as a trauma which is simultaneously synchronic (of the here and now) and diachronic (related to past experience).

### **The nature of dementia: from cognitive impairment to terminal disease**

As mentioned at the end of Chapter 1, dementia is a term which eludes determinate meaning, and any attempt to complete the statement ‘dementia is....’ inevitably takes us into debates about ontology and epistemology. Unsurprisingly, then, there is no single, accepted definition of dementia; in fact many sources contradict each other on its nature, underlying causes and progression. Definitions of dementia have, of course, changed over time, but in the following section I will focus on four current definitions from different sources. Whilst all have features in common – notably the emphasis that is placed on memory loss - these definitions lie on a continuum between what might be termed ‘soft construct’ and ‘hard construct’ dementia. At the ‘soft’ end of the scale dementia is a syndrome - a form of cognitive impairment common in later life - at the hard end of the scale it is terminal brain disease.

The American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Revised (DSM-IV-R) - the diagnostic ‘bible’ of psychiatry – states that dementia is a clinical syndrome from which nothing can be inferred about underlying causes. The criteria recommended to diagnose dementia are

Evidence of impaired memory (which must be present in all cases) together with at least one of the following: language disorder; impaired movement or handling of objects, when there is no physical disability to account for this; impaired ability to recognise objects, when there is no sensory impairment to account for this; disturbance in ability to carry out complex tasks that require planning, reasoning, organisation, or abstract thought.

(First et al, DSM-IV-R, 1997/2000)

According to DSM-IV-R, a diagnosis of dementia is only justified when the problems are so severe that they interfere with the person’s ability to work or take part in social activities; when there is a significant decline from the person’s previous level of functioning; when there is no evidence of delirium (eg acute

confusion resulting from infections), and when the observed symptoms cannot be attributed to other mental disorder (eg severe depression).

If we turn to the US Alzheimer's Association website, dementia is defined here as follows

The loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient severity to interfere with a person's daily functioning. *Dementia is not a disease itself but rather a group of symptoms that may accompany certain diseases or conditions.* Symptoms may also include changes in *personality, mood, and behaviour*. Dementia is irreversible when caused by disease or injury, *but may be reversible when caused by drugs, alcohol, hormone or vitamin imbalances, or depression* [emphasis added] [www.alz.org/Resources/Glossary.asp](http://www.alz.org/Resources/Glossary.asp)

This definition differs from DSM-IV-R in its association of dementia with underlying disease, in its reference to changes in personality, mood and behaviour, and in the suggestion that dementia may be *caused by* depression. This last point is striking since DSM-IV-R suggests that dementia should not be diagnosed if depression is present. The Alzheimer's Association does, however, recognise that dementia may be reversible depending on the nature of the underlying cause.

The latest definition of dementia provided by the World Health Organization in its International Classification of Diseases (2003) is

*A syndrome due to disease of the brain, usually of chronic or progressive nature, in which there is a disturbance of higher multiple cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded by, deterioration in emotional control, social behaviour or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain* [emphasis added].

In this definition, dementia - whilst still recognised as a syndrome - is related *in all cases* to underlying disease, and the main candidate diseases are named. It is,

however, implicitly acknowledged that in some cases dementia may not be chronic or progressive.

Finally, in the recent UK National Audit Office report *Improving Services and Support for People with Dementia* (2007: 4) we find that

Dementia is a term for a range of *progressive, terminal, organic brain diseases*. Symptoms include decline in memory, reasoning and communication skills, ability to carry out daily activities, and *loss of control of basic bodily functions caused by structural and chemical changes in the brain*. The emotional impact on people with dementia and their families can be enormous, with depression and high levels of stress common [emphasis added].

Here dementia is no longer a syndrome at all, but a range of diseases. All such diseases are progressive (none are reversible), all are organic (resulting from damage to the brain) and, for the first time among these definitions, all are terminal - that is, it is implied that people die from, rather than with, dementia. Depression is mentioned only as a consequence of dementia, rather than a condition requiring differential diagnosis (DSM-IV-R) or a possible *cause* of dementia (US Alzheimer's Association). Most importantly, for the first time, loss of control of basic bodily functions is attributed directly to 'changes in the brain'. This implies that in people with dementia who become incontinent or suffer falls, this is a consequence of neuropathology, rather than an indication of the quality of care and support they receive, or the appropriateness of the drugs they are given.

Inevitably, the purpose for which each definition has been designed will have a bearing on its construction. The diagnostic definition from DSM-IV-R conforms to what I described above as 'soft construct' in that it is cautious, based on clinical observation alone, and works by exclusion of other possible causes of confusion and memory impairment (delirium or depression). The Dementia UK report, which is concerned with social policy and funding of dementia care takes a positivistic 'hard construct' line. In this it owes more to rhetoric - aided by subtle and progressive shifts in terminology - than to new research data. This is an indication that neuropathic ideology owes more to the Alzheimer's movement than it does to

psychiatry. Psychiatry may have medicalised senescence, but it is the Alzheimer's movement that has pathologised it.

### *Memory changes in dementia*

Memory loss is central to popular understandings of dementia, and as would be expected, impaired memory is common to all four definitions given above, although for DSM-IV-R it is a necessary rather than sufficient diagnostic indicator. None of these four sources problematize the concept of memory, however, nor do they specify the particular domains of memory that are affected in dementia. Typically it is a deterioration in short term memory that is one of the first manifestations of dementia, whilst long term memory remains intact for much longer. 'Initially the amnesia is in relation to *recent events*, while recall of more *remote occurrences* remains well-preserved. Relatives often comment on this' (Burns et al, 1995: 37, emphasis added).

The preservation of long term memory in dementia, together with the likelihood that the person's most significant experiences will have taken place in the past, and the reduced ability she or he now has to maintain cognitive control over emotion related to past life, combine to '[force] the affected person farther and farther back into his or her long term memory' (Valle 1998). Muller-Hergl (2007: 11) takes this further, pointing out that 'it is too easy to say that people with dementia live in the past ... actually they live in a boundless present, in which the past is experienced as present'. As Burns et al (1995) note this is something that anyone who has ongoing close contact with someone with dementia will recognise. It is not merely supported by anecdote, however. It is also capable of explanation in neuroscientific terms as a changing dynamic between the neocortex and the amygdala (Goleman, 1995). As neurones are lost in an ageing brain, the cognitive control exercised by the neocortex weakens, allowing freer expression of the emotions associated with the amygdala which have been suppressed in earlier life. Memories – and the emotions associated with them – come flooding back.

Here is an example from fieldnotes I made in a residential home as part of a previous observational study. Throughout the morning Nora had seemed unsettled and had asked staff repeatedly, 'Have they been round with the wages yet?' Now

Nora is standing in the middle of the lounge, rocking on her feet slightly, craning her neck towards the office. She looks very tense. It's as though every fibre of her being is fixed on the office window. The office is locked and empty, the lights have been turned off, but there's enough light from the lounge to be able to see a desk, a filing cabinet, a telephone, health and safety posters. Nora raises her fist; she looks furious, rigid with anger, ready to cry. "The buggers; they've locked up - gone home - and they haven't been round with the wages".

Precisely what Nora was experiencing here is, of course, open to interpretation. Her verbal and non-verbal communication seems, however, to make some interpretations more likely than others. Nora may have been employed in a mill or factory where the wages were distributed manually each Friday; perhaps, like many women of her generation, bringing up children on her own, or in a 'hand to mouth' way. If so, the non-appearance of her pay packet would be deeply anxiety-provoking. Nora's worries may have been based on one or more occasions in the past when she had been unable to buy food or pay the rent. Perhaps, also, her wages had been an assurance that she was self-supporting and could pay her way. Without money she may have feared that she would be evicted; and this fear may have returned in the context of her new state of unwaged dependency in the home. Even for people who never experienced serious debt or homelessness directly, the fear and shame of eviction were a significant form of social control in the lifetimes of people who now have dementia.

Practice examples of this kind abound; very commonly someone with dementia will develop anxieties about, for example, needing to get home in order to feed the children, or needing to find their mother, who has been dead for many years. Dementia is characterised, then, not only by the loss of short term memory, but also by the insistent return of long term memory, and because of this it is more appropriate to talk about memory changes, than memory loss, in dementia. Importantly for my argument later, it is also significant that something in the present day care home *reminds* Nora of a past experience. There is in 'real/present time' a locked office shut off from the lounge, which is reminiscent of her earlier life experience of a locked and inaccessible office separating factory workers from their earnings. Here, rather than an event from the past becoming a metaphor for the present experience of dementia –

as in the examples from Kitwood (1997a) given in Chapter 1 - it is as though the opposite happens.

The resurgence of memories from earlier life suggests that dementia may be particularly open to exploration using a psychoanalytic approach. Psychoanalytic theory sheds a very different light on some of the phenomena commonly observed in dementia. Often, when a person has dementia it is as though the social veneer of what we tend to consider 'civilised behaviour' has been stripped away. As cognitive skills are lost, the underlying unconscious ways of relating and responding become more evident. A psychoanalytic approach would suggest that there is significance in the apparent overemphasis, fragmentation and repetition of speech that are often apparent in dementia. What tends to be described from a medical point of view as perseveration (the 'stuck needle' phenomenon, in which the person constantly returns to the same question or statement), may be understood in psychoanalytic terms as a repetition compulsion (Freud 1920, in Gay 1995: 602), an attempt to resolve, by repeating, some particularly threatening repressed experience.

Quite often, also, something like a transference reaction (Freud 1905, in Gay 1995: 234) may take place. Current carers may be accused of having hurt or deceived a person in some way, for example, when the source of the feelings being expressed lies in the distant past. This can be particularly noticeable because a person with dementia will often relate to a family member as though s/he is someone else; so a niece may be recognised as the person's mother, or a grandson as a long-dead husband. What is happening here may not be simply a process of cognitive decline, but an unconscious attempt to complete some form of unfinished business.

### **Dementia and memory loss in mainstream cinema**

My purpose in exploring differing definitions of dementia and memory impairment in this chapter is to consider how such contested and competing claims find their way into arts and media representations – and specifically film. Such representations then compound, or influence in various ways, popular understandings of dementia. Films aimed at the mass market need to have dramatic appeal and rely on themes that

audiences will find thrilling or moving. Aspects of mental health in general, when represented in film, thus tend to follow well-worn themes of love triumphing over adversity, the madman-criminal, or the presumed link between insanity and genius (Cassey 2005). Greenberg (2003: 807, emphasis added) notes that in its treatment of mental health issues ‘mainstream cinema especially, if not always reliably, foregrounds *amnesia*, multiple personality disorder and other dissociative reactions because of their inherent melodramatic potential’. Baxendale (2004) argues that from the viewpoint of clinical neuropsychology, most amnesic conditions in Hollywood films bear little relation to reality.

If mainstream cinema is at all interested in dementia, then, this is likely to be because exciting things can be done with the concept of memory loss. There have been relatively few mainstream feature films with dementia as a major theme to date, and those that are in existence focus on memory loss as their central trope. These films fall into two clear categories. The first consists of thrillers and action movies featuring male protagonists whose early-onset dementia or traumatically induced amnesia must be overcome in order to complete their quest (*Safe House 1998*; *Memento 2001*; *Memory of a Killer 2005*). In these films memory loss is a sub-plot which adds to the dramatic tension, and it seems unlikely that the makers of films of this genre will be particularly interested in authenticity of representation, provided the storyline works effectively.

The second category consists of romantic dramas in which the central female character has dementia. These films clearly aim for a much greater degree of verisimilitude with real life cases, and have in most cases been conscientiously researched. Unsurprisingly, though, when we consider the differences of ‘expert opinion’ discussed above, each of them presents a distorted view of the nature of memory changes in dementia. I now want to consider in a little more detail three such films that were mentioned briefly in the last chapter (*The Notebook 2004*; *Away from Her 2006*; *Iris 2001*) in order to show how definitional problems related to dementia impinge upon the representation of the characters in those films.

*The Notebook: long-term memory lost*

*The Notebook* (dir. Nick Cassavetes) is a romance, described by one viewer as ‘senile dementia meets Mills and Boon’. Told largely in flashback, the film shows a male visitor recounting to an old woman in a care home the story of the central characters, Noah and Allie. Born on different sides of the Southern US tracks in the 1920s, Noah and Allie fell in love and were then separated by war and parental deceit. Gradually we realise that the man reading the story is Noah, that Allie now has dementia, and that he is reading her their story because she can no longer remember it. As Basting (2005) points out, Allie is, however, able to follow the story being told to her in the present day, and to ask relevant questions about it without any evidence of stumbling over words.

The representation of Allie in *The Notebook* – as someone who is coherent in the present, but has forgotten the most significant events in her past - is thus almost a direct reversal of what would usually be observed in life. A more typical scenario would be one where Allie remembered and talked about the past – particularly events of emotional importance – whilst having relatively little ability to follow what was happening in the present.

*Away from Her: short term memory regained*

*Away from Her* (dir. Sarah Polley) tells the story of a husband (Grant) struggling to cope with his wife, Fiona’s, early-onset dementia. Following her diagnosis they read to each other from standard texts about the bleak prognosis. At one point we are shown an exterior shot of their Canadian lakeside cabin at night with the lights going off in rapid succession to symbolize the death of neurones. Following an incident in which Fiona gets lost away from the cabin, she decides, unilaterally and somewhat peremptorily, that it is time to go into residential care. The nursing home has a no visiting policy for the first 30 days (Polley has acknowledged in an interview that this is not typical in Canadian care facilities, but says it is ‘an important device in the film’). During this time Fiona appears to forget Grant’s existence and forms a strong attachment to another resident, Aubrey, who is mute and wheelchair-bound.

Grant suspects – and we are encouraged to sympathise with him – that Fiona’s ‘forgetting’ of his existence is really revenge for his infidelities with his college students 20 years earlier. When Aubrey’s wife removes him from the care home having run out of money to pay for his care, Fiona declines into apathy and disorientation. In a rather contrived ending, Grant heroically brings Aubrey and Fiona back together, only to find that Fiona now magically recognises him again. Earlier in the film Grant has been warned by a nurse that Fiona will continue to have occasional lucid moments, so this ending can be read as a concealed twist. On the other hand, it leaves the impression of dementia as a form of memory loss that can be magically reversed by the self-sacrificing acts of others.

*Iris: the death that leaves the body behind*

*Iris* (dir. Richard Eyre) is a biopic about the novelist and philosopher Iris Murdoch, who was diagnosed with dementia in her 70s. The most serious of the three films considered here, it has received considerable critical acclaim. More impressive as a film than *The Notebook* or *Away from Her*, the flashback style in which scenes from Murdoch’s final years are intercut with scenes from her Oxford heyday and early relationship with her husband John Bayley is both effective and disturbing. At many points it seems to convey the message that everything about Murdoch’s life is to be understood in terms of it having ended with dementia. McColgan et al (2000) note that obituaries that appeared at the time of Murdoch’s death, almost all referred in some way to the irony of a great mind ‘destroyed’.

*Iris* is based on John Bayley’s memoir of Murdoch, and thus on his own subjective memory and version of reality. The idea of dementia as a ‘death that leaves the body behind’ - in which social death precedes physical death - is a strong theme, and its essential dualism is exacerbated by the near-relish with which the camera lingers on scenes of Murdoch transfixed in front of the *Tellytubbies*, by contrast with flashbacks showing her incisive debating skills at Oxford dinner parties.

Twenty five years ago Pitt (1982: 39) said of dementia, ‘sometimes it seems as if the true self dies long before the body’s death, and in the intervening years a smudged caricature disintegrates noisily and without dignity into chaos.’ This is a view that

continues to be perpetuated in audio-visual media. For example, an episode from a recent TV drama series (*Afterlife*, ITV, 24.9.05) claimed, 'It's Alzheimer's...it's worse than death...The brain dies and the body carries on without it'. This idea of dementia as a living death, the 'death that leaves the body behind', and of the person with dementia as an automaton or zombie is a striking cultural metaphor and one to which I will return later.

For the moment I want to reiterate the point that films such as those discussed above, used uncritically for educational purposes, may well perpetuate misunderstandings about dementia and reinforce stereotypical views. They may, of course, stimulate discussion, and that discussion, if skilfully facilitated, may lead to the development of an increased critical awareness. Mainstream feature films are not, however, necessarily the automatic route to enlightenment that some advocates of arts-based approaches to health and social care education have suggested.

### **Film and collective consciousness: memory loss as a cultural phenomenon**

Whilst films with an overt theme related to dementia are still rare, as Basting (2005) points out, memory loss itself is an increasingly popular theme in Hollywood films aimed at mass audiences. Interestingly, in terms of my thesis, Basting traces the beginnings of this movement in a post World War II wave of imagery where the impetus was to 'forget' that war and pursue the American Dream of the future. Films which form part of this wave of literal and symbolic post-war amnesia include *Random Harvest 1942*; *Deadline at Dawn 1946*; *Somewhere in the Night 1946* and Hitchcock's *Spellbound 1945*, the first film to introduce Freudian psychoanalysis to the mainstream cinema.

A new wave of films related to memory loss followed in the 1980s and 90s. Perhaps in keeping with the shift in perception of Hollywood as a wish-fulfilling 'dream factory' in the post war years, to increasing recognition of the trashiness of 'La-La Land' and the end of the post-war dream, the common themes have now become darker. Often they seem to centre on unease over the real or perceived potential for technology to manipulate human memory. *Blade Runner* (dir. Ridley Scott 1982) is an

obvious example of this type of film. In it, replicants created to do menial work, and with limited life spans, are implanted with memories that convince them they are human, ie *real*, until the time arrives for them to be ‘terminated’. Post (1998: 78), in his critique of the ‘hypercognitivity’ of modern Western society, suggests that *Blade Runner* is an apt allegory for the differential value that society places on those who do, and do not, have dementia. If we believe that memory is what makes us human, Post asks, will it become socially acceptable to terminate those who do not have memories? ‘In future decades, as more people lose their memories, will we find ourselves so burdened by economic and caregiving pressures that nonvoluntary euthanasia of the most deeply forgetful becomes commonplace?’ Whilst this is another example of the somewhat crude misrepresentation of dementia as global amnesia, the question itself, as will be discussed further below, has become an even more urgent one in the years since Post raised it. Cooley (2007), for example, has recently suggested that people diagnosed with dementia are under a Kantian moral obligation to take their own lives in order to prevent the loss of their moral identity as the condition progresses. An Internet search today reveals more than quarter of a million sites on dementia and euthanasia.

Standard definitions and mainstream films locate memory loss within the person and attribute it to neurological impairment. Sources such as those discussed in this section suggest, however, that there is a collective, societal forgetting in film, which corresponds to Jacoby’s (1975; 1996) concept of social amnesia. Basting (2005) suggests that the current plethora of films related to memory loss from accidental, technological or criminal causes (by comparison with the tiny number that are overtly about dementia) is evidence of a repressed fear of dementia in society among the post-war baby boom generation. Whilst baby boomers tend to be thought of as an articulate and powerful group in society, the baby boom generation in the US is also of course the Vietnam generation. Selig (1994) points to the damage to the national psyche arising from the Vietnam war, which he suggests is recognised increasingly not just as having been ‘lost’, but as having been ‘wrong’. Many Hollywood films about Vietnam, Selig suggests, attempt to heal the national psyche through the character of a male hero who remains honourable in the face of the dissolution and ineptitude of older male authority figures (*Apocalypse Now 1979; Platoon 1986*). In this way, Selig argues, ‘a victory can be contrived for a history which is experienced

as a loss, desire can be satisfied while the particulars of social history are sacrificed... This subordination of history to subjectivity permits the reconstitution of a national identity based on moral judgement rather than political actions, an identity *that is fundamentally ahistorical*' (Selig 1994: 5 emphasis added). Vietnam films are, in this view, another vehicle for social amnesia.

### **The provenance of *Ex Memoria***

I want to turn now to *Ex Memoria*, and examine the ways in which it differs, in its depiction of dementia, from the mainstream feature films discussed above and how it helps to contribute to an understanding of dementia as an interplay between past and present, in which time is not experienced in linear progression but through repetition and return. Specifically, *Ex Memoria* is based on personal observation and biographical data. It references historical events which have, in some way or other, shaped the lives of all those in the Western and post-colonial worlds who now have dementia. It raises the possibility that those who have dementia may experience the return of repressed memories of such events. Finally, it draws our attention to the ways in which present day dementia care may prompt the resurfacing of traumatic memories.

The script of *Ex Memoria*, already in existence at the time Wellcome Trust funding was awarded, was not underpinned by any specialist knowledge or existing model of dementia. It took a personal slant on writer/ director Appignanesi's experiences of visiting his Polish grandmother, Hena Borenstejn, in the final years of her life when she was in a Jewish care home in London, and on his attempts to find some way of connecting imaginatively with her.

She could no longer construct the story or image of herself. Her language had disintegrated into fragments of sense and stray words, often spoken in a Polish or Yiddish she had rarely used in 50 years, and addressed to people long since departed... Grandma was someone 'known' who suddenly became unknown – thereby revealing what had been lost in the forms and conventions of social life, namely that she was never known and had always been a stranger (Appignanesi J and Baum 2006: 85-86).

I do not wish to suggest in what follows that I am wholly uncritical of *Ex Memoria*. There are some scenes in the film that I think work less well than they might have done, and some awkward lines of dialogue. The script in its original form, however, already showed an engagement with the experiential nature of dementia not present in the mainstream feature films discussed above – the return of memories, relationships and ways of being that social convention has required the person to suppress. People with dementia, it is noted, are frequently in search of the dead; they wish to *speak* with the dead. Often they mistake the living for the dead, as Eva – the central character in the film - mistakes her grandsons for her lost brother.

Appignanesi's original script was, then, based on a form of naturalistic observation – a detailed phenomenological engagement with what is happening at the minute-by-minute micro-level of one person's experience. Whilst using some artistic licence, *Ex Memoria* is also based loosely on Hena Borenstejn's life story - material which grounds it in a historical past and encourages consideration of lived events as they resurface in the context of dementia. The requirements of assimilation to a new culture, the silencing of wartime experience, the need to keep family skeletons firmly in the cupboard, all emerge here as aspects of repressed experience which return in dementia. Although *Ex Memoria* is a storied version of events, then, it is also based on things 'as they happened' on both interpersonal and historical levels. There is no suggestion that we are being told 'what *really* happened' – indeed the film is deliberately, if not wilfully, enigmatic on this score - but there is a moral concern with the authenticity of representation and memorialisation of a singular woman.

*Ex Memoria* is based on an earlier memoir, *Losing the dead*, written by Hena's daughter about the family's attempts to find out many years afterwards what had become of Hena's older brother, Adek, who disappeared without trace in the latter years of the war. When Hena developed dementia, she became fixated on the idea of Adek's return, frequently misrecognising other people for him. 'It is to happen again and again. She sees her brother here, there and everywhere. He is a restless ghost, unburied' (Appignanesi L, 2000: 78). The search for Adek is carried out in a present day Poland where the past has been mythologised, disowned, re-written. Documents are missing; landscapes are altered; graves remain unmarked. Such absences from the official records and censorings of history are also absences in the accepted history of

dementia. Missing from both the dominant discourse on dementia and its conformist psycho-social corrective is any real consideration of the centrality of the ‘war years’ (the parentheses of 1939-45 are not broad enough to capture them) in the experience of people who now have dementia.

*‘Some memories fade – others keep returning’: the return of the repressed*

In the memoir *Losing the dead*, Hena last sees Adek from the window of a tram in 1943 when she is already a married woman in her mid-20s with a young child. ‘She waves gaily. She points Adek out to the others and for a moment they all wave. They are delighted to see him, but they do not leap off the trolley to embrace him. They do not realise that they will never see him again’ (Appignanesi L, 2000: 173). Although Adek’s real-life loss was traumatic, then, this was something which became apparent only later, by association, and by speculation on the many different fates that might have befallen him. The last sighting is an everyday occurrence which is only later revealed in its true – extreme - significance (Rothberg, 2000).

In the dramatised version, by distinction, the time scale is shifted; the separation between brother and sister shown here is abrupt and violent, taking place soon after the invasion of Poland when Eva (the character based on Hena Borenstejn) is a girl still only in her teens. Here the traumatic nature of the separation between Eva and Adek is very clear. Off-screen German voices, gunshots, the sound of a receding vehicle and Adek’s desperate cry to his sister add to the dramatic tension.

Later in the film we see Eva driven to distraction by the cumulative effect of small coincidences, repetitions and parallelisms between her wartime experience and life in the care home. The sights and sounds of the home – the ghetto Eva *has not* managed to avoid – bring back in all its visceral immediacy the familiar dread of discovery, containment, annihilation. Eva finds the care home where she is now living out her final years so reminiscent of her wartime experiences that she makes a second bid for freedom by offering herself to a member of the care staff she takes to be a high ranking official - whether German or Allied we should perhaps not rush to judge.

In these scenes, there is also a strong sense of the *unheimlich* (or uncanny). The first line spoken by the older Eva in the lounge of the care home is, ‘I think we should go home now...’ Whilst Eva is now in what is euphemistically described as a ‘home’, then, she is not *at* home, and in a doubly ironic sense, the home to which she wishes to return no longer exists. As for many people with dementia in long-term care settings, who become restless at particular times of day and want to go home, the desired destination is now a place in the memory and in the heart only. In a literal sense, of course, someone who repeatedly states the wish to return home may mean, ‘Please take me back to 27 Milton Street where I used to live happily with my family’. Beyond this, however, there often seems to be a desire – as in Eva’s case - to return to a safe place before all the trouble began, a place which now only exists in fantasy; which perhaps only ever existed there.

All people with dementia who have to move into formal care, become to some extent displaced persons, and the experience of this ‘un-homing’ is likely to be exacerbated by anything in the new environment that reminds the person of unpleasant past experiences, or even experiences that were not perceived as disturbing at the time, but which become so because of their untoward repetition. As Freud puts it in his 1919 essay ‘the uncanny is that class of the frightening which leads back towards what is known of old and long familiar’ (Strachey, ed 1953: 220). Looking back at the fieldnote on Nora earlier in this chapter we might see her fear of not being paid at the end of the week as a legitimate source of anxiety but not sufficiently threatening to be considered traumatic. If, however, we think of this as Nora encountering again in the residential home something which is eerily (and at the same time drearily) familiar – the old grinding worry in this new context of having no money, and not being able to pay for things – this perception of somehow having come back to the same place becomes genuinely uncanny, *unheimlich* (*alzheimerlich* we might almost say, in this context). In *Ex Memoria*, similarly, there is a scene where Eva is left sitting alone beside a glass lift, which - for some reason we can only guess at - fills her with deep misgivings. It seems fair to assume, however, that anxieties from her past related to enclosure and visibility coalesce here (see illustration on following page).

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From *Ex Memoria*: Eva beside the glass lift



Many people who lived through the war years will have had directly traumatic experiences of loss, violent separation, and the various compromises made in order to survive that were equivalent to, or worse than, those implied for Eva in *Ex Memoria*. The very extremity of Eva's experience may lead, however, to doubts about its general relevance in understanding the nature of dementia. The challenges of condensing 'Eva's war' to fit the constraints of a short film with a limited budget, to do this with dramatic intensity, and without the need for excessive narration or additional sets, mean that everything has to be conveyed in one scene a couple of minutes long. We see what is happening only through Eva's immediate reactions to off-screen events.

The events depicted in the original script of *Ex Memoria* thus already raised interesting, if as yet inoperational, theoretical questions which will be discussed further in subsequent chapters. The final section of this chapter outlines briefly some of the changes and additions to the script that were made during the advisory workgroup process.

### **Developing the script of *Ex Memoria***

The workgroup appointed to act as advisors on the development of the existing script consisted of three lecturers in Dementia Studies, a representative of the local Alzheimer's Society branch, and two practitioners (one a reminiscence project worker, and one an occupational therapist). The group met twice in December 2004 and January 2005 and the remainder of the discussion was carried on by email over subsequent months leading up to the film shoot in July 2005. In all there were five versions of the script from the point of funding award to film shoot, and – no doubt inevitably – there are still differences between the version of the script used on set and the finished film. Whilst there were numerous changes to the script during the development process, however, the core content and order of events shown in the film in fact altered very little.

Rather than detailing exhaustively here the changes that were made and discussions about them, I propose to pick this up in detail when discussing the findings in a later chapter. Here, I will just comment on three particularly significant aspects of the script development. The first relates to Eva's use of lipstick in the film. One contributor to the first script development meeting felt strongly that a woman with dementia living in a care home would not be capable of forming the intention to put on lipstick, let alone to complete the action – as in the film – without a mirror. Appignanesi was, however, adamant that his grandmother continued to put on bright red lipstick every day, almost up until the end of her life. In the film itself the lipstick theme was actually strengthened, in such a way that it makes a link between Eva's past and her present.

From a biomedical perspective, this underlines the dangers of generalising about the actions of any one person with dementia on the basis of a 'stage' model of cognitive decline. From the arts side of the project, however, it has also since occurred to me that lipstick is a potent symbol in film, and particularly so in film noir. In *Black Narcissus* (dir. Powell and Pressburger 1947) for example, there is a lingering scene in which the application of bright red lipstick is used to indicate the fall from innocence of a nun, Sister Ruth. In some ways what we are given in *Ex Memoria* could be regarded as the before and after of film noir; scenes from a life that we don't usually see. In the first scene Eva is the *femme* who has not yet become *fatale*, and in the rest of the film a much older woman who still believes that she can use her feminine wiles to seduce men into helping her. In this sense there may well have been an artistic incentive to retain the lipstick as a cultural icon of the feminine.

The second sticking point related to the scene just mentioned where Eva makes advances to a young male careworker, apparently under the impression that he is a high ranking official who can help her to get her papers sorted out. The film clearly attempts to present Eva as someone whom staff will find challenging in various ways; we are made to confront her as Jewish, as a refugee, as a non-native speaker of English, as potentially racist, as manipulative. All of this seemed to be accepted within the workgroup without demur. The idea that Eva might make overt sexual overtures and use explicitly sexual language seemed, however, to arouse more

disquiet; in the form, for example, of assertions that people with dementia become uninterested in sex and only want affection.

Whilst there is little published research in this area, Miller et al (1995) claimed that 24 percent of people with dementia became sexually apathetic, whilst Cummings and Victoroff (1990) claimed to have found evidence of increased libido in 14 percent. This would suggest, perhaps, that levels of interest in sex or sexual expression remain relatively unchanged in the remaining 62 percent. Ward et al (2005) have more recently pointed out that the almost constant surveillance in most long term care facilities makes any overt sexual expression almost impossible. This scene in the film is intended to be an indication of the lengths Eva was prepared to go to in order to retain her freedom, but the script is ambiguous about the extent to which this is the result of a traumatic event, as it has her speaking the lines to the careworker 'lasciviously'. In the event, however, this scene was watered down considerably; predominantly, I think, to avoid 'embarrassment by association' for members of the workgroup.

Finally, two main contributions to the script from the dementia studies side were, first, the incorporation of some examples of the speech of people with dementia which came from research interview transcripts and, second, the integration of items from Kitwood's list of types of 'malignant social psychology' (see Fig 2). My impression is that the interview transcript material genuinely enhanced the script. It was taken from life, and showed a variety of ways in which the speech of people with dementia may change, something which is very difficult to get right in dialogue. Some people in the interview transcripts had word-finding problems and were very hesitant, whilst others had what tends to be described as 'fluent dysphasia' – rambling, circuitous speech - in which the form of normal speech is preserved but the meaning is difficult to discern. This latter example was used to good effect for the character, Jenny, one of the care home residents in the film. In a stylistic twist, some of Jenny's 'disordered' speech is then echoed in the mobile phone conversation of Eva's visiting grandson. By contrast, in my own view, the speech of Eva herself convinces less as that of a person with dementia, since it is more syntactically intact and less fragmented or allusive than might be expected. This is, perhaps, why a colleague not involved in the workgroup commented that the acting of the central character was

‘good if you overlook that it was dementia that was being portrayed...she just seems mildly confused’.

The second contribution - the addition of examples of malignant social psychology – whilst it does not detract from the film’s value for general audiences – has, I think, had implications for its educational use in the context of the module *The Social Psychology of Dementia Care*. This emerges as one of the main themes in my later discussion of findings in Chapters 5 and 6.

## Chapter 4) Introducing *Ex Memoria* into the dementia studies curriculum: visuality, ethics and identification

...by focusing on the hidden details of familiar objects, by exploring commonplace milieus under the ingenious guidance of the camera, the film on the one hand extends our comprehension of the necessities which rule our lives: on the other hand, it manages to assure us of an immense and unexpected field of action... With the close-up, space expands; with slow motion, movement is extended... Evidently a different nature opens itself to the camera than opens to the naked eye...

(Benjamin, 1936: 15)

### Introduction

In the previous chapter I suggested – somewhat against the current assumptions of the arts and health movement in education – that mainstream feature films on dementia and memory loss may often work to perpetuate stereotypes and misinform viewers. I also discussed the reasons why I believed *Ex Memoria* might offer a more authentic representation of dementia than many mainstream feature films. In this chapter I want to develop this argument further by focusing specifically on the visuality of moving image. This is also the point in my thesis where I move from theoretical background to intervention in my own practice, and I discuss here the benefits and potential disadvantages I foresaw in introducing *Ex Memoria* into the Dementia Studies curriculum. The question of authenticity is also one of ethics, and ethical considerations of one kind or another are the main subject of this chapter.

First, there is the ethics of visual representation of those with dementia, and the ways in which viewers may identify, fail to identify, or overidentify with the person so presented. *Ex Memoria* - according to the funding proposal to Wellcome Trust - is intended to ‘teach empathy’; that is – according to the Oxford Concise English Dictionary (1995: 442, emphasis added) - ‘the power of identifying oneself mentally with, and so *fully comprehending*, a person or object of contemplation’. Fully comprehending the other is a humanistic, enlightenment project consistent with the aims of the arts and health movement. *Ex Memoria* seeks, however, to bring about this identification by way of rupture, disturbance and the ‘unsettling’ of more familiar ways of seeing. The proposal to the Wellcome Trust suggests that it will present ‘a

vision of dementia that actively, powerfully confounds their assumptions and prejudices'. This raised interesting questions about how it would be received by practitioner audiences who were not (any more than I was myself) practiced film critics, and whose previous encounters with educational film were more likely to have been through didactic and instructional training material.

In addition, I needed to consider the basic research ethics of 'doing no harm' toward students in the conduct of the intervention in my own practice required for the doctorate in education. This intervention involved introducing *Ex Memoria* into the module *The Social Psychology of Dementia Care* and basing an assessed assignment on the film. These assignments were then treated as data. Any decision about changing the nature or content of assessed work which might have implications for students' confidence in tackling the assignment or the marks they subsequently achieved for it clearly had to be based on sound andragogic<sup>1</sup> principles and could not be justified for research purposes alone. There was a possibility that students might find the film confusing or ambiguous to the extent that they could not interpret the action or apply the theoretical material covered in the module. The need to avoid subjecting part-time, working student-participants to additional pressures on their time had also to be balanced against any possible disadvantages of using their assignments as data.

There is also an ethics of authenticity and accountability in my own writing of the research. Particular dilemmas arose over the 'order of telling' and the voice(s) I adopt at each stage. The time of writing research is asynchronous with the time of doing research and the temptations of being wise after the event are very great. At the point where I initially constructed the rationale for introducing *Ex Memoria* into the curriculum I still conceptualised this intervention as an action research project. This would imply that some form of 'improvement' in students' assignments should be discernible as a result of the intervention. I was, however, reluctant to define what might be the criteria for recognising such an improvement. Simultaneously I took it

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<sup>1</sup> Andragogy is a term popularised by Knowles (1984) in order to draw attention to the differences between adult education and the education of children (pedagogy).

for granted that any difference that *was* apparent would be solely the result of the film. Brown and Jones (2001: 99) suggest that action research “begs key questions about where our ideas about what counts as ‘improvement’ come from...these issues are more complex than action research has so far acknowledged”. At the end of this chapter I have identified a point at which my initial, implied project – my use of film as an intervention in practice designed to ‘cure’ participants’ writing of its biomedical persuasions – turns back on itself in a reflexive movement which requires me to re-examine both my own educational practice and the temporality of research writing.

### **Visuality and moving image**

In this first section I discuss the advantages I originally perceived in introducing visual media into the predominantly print-based distance learning programmes we were providing at the start of this project. An obvious and pragmatic one was the capacity for moving image to break up the reams of written-word material that Dementia Studies students receive in the form of set books, core study material, learning support material, and reading lists. In addition students also receive generic print-based material from both the School of Health Studies and the central University, much of which – because it is aimed at full-time school leavers – is irrelevant to adult, part-time, distance learners and may even have an alienating impact. I suspect that some students feel overwhelmed from the outset by ‘text-overload’, and that this material all too rapidly takes on a similar status as ‘things that should be read’, but which offers little stimulus actually to do so. Students may thus make little distinction between the centrally important case study on page 58 of their latest course module, and student handbook information about facilities at the sports centre.

Using moving image as an alternative way of presenting case study material thus seemed an attractive option to the static, print-based approach. It seemed likely that students who saw reading as a course-related chore would have more positive associations with film, not only as the visual representation of a practice setting, but also because of its association with pleasurable leisure activities. Miles and Plate (2004) among others, point to film’s potential for creating identification with the other

through the intensity of the visual experience itself, and MacDougall (1998: 262) suggests that in film ‘we achieve identification with others through a synchrony with their bodies made possible in large part by vision’. Mullarkey (2007: 54) takes this further, suggesting that filmed fiction, specifically, creates an identification with its characters – an experience of feeling real emotion towards people who are not real – through the perception of *movement*, which is what ‘makes people come alive for us, not just in make-believe, but at a very present and real level of our perception’.

As mentioned in chapter 2, when students were asked to base assignments for *The Social Psychology of Dementia Care* on self-selected incidents from care practice they often struggled to identify a specific critical incident, or to be able to recall it in sufficient detail. Using film, they are provided with an incident that can be watched several times in order to draw out its details and engage with the sequence of events in depth. The intensive focus on a specific person with dementia – the foregrounding of her experience by visual and auditory means – might be expected to encourage a greater awareness of the impact of moment-by-moment care. Observational studies of dementia care practice (eg Hallbiorg et al, 1995; Ward, 2005) indicate that episodes of verbal or non-verbal communication between caregivers and people with dementia are generally brief in duration, and tend to be restricted to the exchange of greetings, or to giving task-orientated instructions or routine information, such as the time of the next meal. Even though it is a short film, *Ex Memoria* thus demands a much longer period of engagement, and a greater intensity of encounter, than would routinely happen in day-to-day care environments.

Additional advantages I anticipated were that students would be able to discuss the actions of fictional care staff without having to reveal real life incidents which might be felt to reflect badly on themselves, their colleagues or their workplace. This would go some way towards meeting Balfour’s (2006) recommendation that caregivers should be enabled to express feelings arising from their work in such a way that their own emotions do not affect the quality of care they are able to give. Academic staff assessing the assignment would also know what the student had seen, and - when giving feedback - would be able to refer students to specific events or interactions whose details they may have overlooked.

Many aspects of the rationale for adopting *Ex Memoria* as the basis of a coursework assignment were thus based on considerations of its visuality. Whilst postmodernism has often been described as the ‘linguistic turn’ because of its critical attention to the centrality of the word (*logos*) and text, a number of writers have argued that the increasing dominance of the visual image (*ikonos*) in postmodern culture demands a visual or pictorial turn.

### *The visual turn*

Debate about the primacy of visual imagery in the modern age goes back at least to the work of Benjamin (1936) whose essay on the *Work of art in the age of mechanical reproduction* has been an influence on many later writers. Benjamin suggests that film enriches perception in much the same way that the Freudian notion of parapraxis (jokes, slips of the tongue and so on) can enlighten our understanding of what is happening beneath the surface of a conversation; ‘for the entire spectrum of optical, and now also acoustical, perception the film has brought about a similar deepening of apperception’ (1936: 14). Benjamin’s work is cited by Berger (1972) as an inspiration for his own seminal text, *Ways of seeing*. Berger (1972: 7) points out that ‘seeing comes before words...It is seeing which establishes our place in the surrounding world; we explain that world with words, but words can never undo the fact that we are surrounded by it’.

More recently, Mitchell (1994) suggested that a transition is taking place from a culture dominated by the book, to one dominated by cinema, video and other forms of pictorial representation. Devereux and Hillman (1995) predicted a time when university students would understand the world predominantly through the representations of the visual media, with written texts and books in a subordinate role. Bowles (2002), whilst noting a traditional hesitance on the part of historians to use film as a teaching resource, also argues that the dominance of cinematic images in today’s audio-visually saturated culture will inevitably continue to grow. As discussed in the next section, however, things become considerably more complex when we consider the different set of associations and contexts within which each person encounters a film.

In a recent publication, Jamieson (2007) supports the notion of the primacy of the visual, based fundamentally on the direct physiological connection between eye and brain. Sight, he reminds us, is a *sense* – belonging to nature – in a way that language is not. Jamieson is, however, careful to point out that the apparent ‘innocence’ of seeing – the notion of an unmediated one-to-oneness between eye and world - is illusory, and he quotes Barthes (1973) on the dangers of assuming that visual images can ever have the innocence we associate with nature. As Barthes suggested, in accepting any image as ‘natural’ (or given) we ignore its history and all the culturally and ideologically contingent ways in which it can be construed. It is interesting to note here that the call for a visual turn ultimately requires recourse to the all-pervading *logos* if we are to do anything *with* images beyond merely registering their existence. Hence the vast array of books, reviews and journal articles devoted to film studies today.

#### *Denotation and connotation*

Barthes (1977) distinguishes between denotation (in this case what is represented in a film – its intended reading) and connotation (the way its meaning is interpreted on the basis of the viewer’s lived experience and unconscious associations). Although what is denoted in *Ex Memoria* is the same in each copy of the DVD provided to students, at a *connotative* level no two people will ever see the same film. As Jamieson (2007: 70) puts it, there is a ‘proliferation of connoted meanings that visual images can set in train...at the tacit level, below that of consciousness...a maze of pathways which have not been envisaged by the image maker’.

My own reactions to the first scene in *Ex Memoria* show several instances of this form of connotative meaning. For example

Having watched the film several times, I started to think about its broader religious and ideological connotations. Here are Eva and Adek (in one script version he was, briefly, called Adam until the association was pointed out) in a kind of pre-lapsarian Eden. Eva is presented as paradoxically naïve but knowing – a proto-temptress, about to fall from innocence. This fall is somehow linked to Adek’s own ‘fall’ (his capture) whilst Eva herself goes on to survive ‘somehow’ by stealth. Has Eva betrayed her brother to the Nazi serpent? Has she eaten fruit from the wrong kind of tree?

At the beginning of the next scene, in the lounge of the nursing home, the first member of staff to enter crosses the room and picks up – from somewhere behind Eva – *a half eaten apple*...

And elsewhere

There are fairy tale elements here...the young girl walking through a wood carrying her bag of goodies; the 'wolf' hiding behind a tree...Then we come to the grandmother's house. Is it more frightening to find out that grandmother and wolf are one and the same, or that grandmother and young girl are the same?

Connotation is, of course, culturally relative and viewers familiar with different creation myths, folklore or oral histories would be likely to draw on these traditions – consciously or otherwise - to produce different connotative meanings. It seems likely also that my political commitments and stance on gender inequalities will have coloured my dislike of the way the younger Eva – intended to be 16 but played by a considerably older actor - is presented to the camera in the first scene. In this scene Eva, believing herself unobserved, checks her appearance in a compact mirror and practices a seductive walk (see illustration on the following page)

My recorded reactions included the following

Young Eva seems to be a bit of a caricature. Her pouting and preening are rather studied - almost like a mime act. I felt uncomfortable with this when I first watched it. There's something unpleasantly voyeuristic about watching somebody who – whilst believing she can't be seen - is simultaneously putting herself 'on display'. Whilst we watch Eva looking at herself in the mirror; Eva imagines herself seen by invisible admirers...

Berger (1972: 51) points out that the mirror has often been used as a symbol of the vanity of women, when 'The real function of the mirror was otherwise. It was to make the woman connive in treating herself as, first and foremost, a sight'. The way

From *Ex Memoria*: Young Eva in the wood.



Eva is presented in this first scene, direct to camera, ‘offers up her femininity as the surveyed’. The camera’s treatment of young Eva in this scene perhaps pre-figures the intensity of the forced encounter with her older self in the remainder of the film. In the next section I discuss how aspects of the ‘film as a film’ may help or hinder viewers’ engagement with it, and the risks this may involve in the context of practitioner education.

### **Using arthouse film in an educational context: what are the risks?**

The original script of *Ex Memoria* was not written with practitioner education in mind, and whilst the funding from Wellcome Trust was for projects intended to increase public awareness, this was quite broadly defined. My decision to use what is essentially an arthouse film in a specific educational context is one that I have to take full responsibility for. This decision was influenced to some extent by my views on the nature of teaching and learning in adult education, which I take to be a non-didactic exchange between equals. Although I have no reason to think that care practitioners are less likely than anyone else to be able to engage with a film that is deliberately ambiguous and open to interpretations, I was also aware that there were a number of risks in introducing *Ex Memoria* into the curriculum.

The film’s avoidance of standard cues such as voice-overs or subtitles to provide context may, for example, make it difficult for students to work out what was happening in the first scene, or where and when the action was intended to be taking place. Eva’s appearance in the first scene is, intentionally, Aryan and assimilated. Her Jewishness can only be deduced from the one line in the script that refers to her avoidance of the Warsaw ghetto. Some Polish and German phrases are used without interpretation, and whilst all the characters with speaking parts are given names in the end credits, a number of their names are not actually used during the film. I realised rather belatedly that this makes it difficult for viewers to link specific lines of dialogue with the characters who speak them. As will be discussed further below, this meant that I had to make some decisions, as an educator, about how much extra-filmic information to provide students with.

### *Making the familiar strange: mise en scène in Ex Memoria*

As with all films there is in *Ex Memoria*, not just a narrative (or implied narrative) to be considered but also the film ‘as a film’, its *mise-en-scène* or ‘repertoire of elements’: that is the set, lighting, costumes, props, camerawork, and the directorial style with which these elements are presented (Monaco, 2000). Much of *Ex Memoria*’s effect was intended to be achieved by using techniques which estrange us from familiar, everyday perspectives. Estrangement effects were first used in the theatre by Brecht to transform taken-for-granted aspects of social reality into the shockingly unfamiliar, and so to provoke in his audience a new critical awareness of the mundanities of everyday life. Brecht was uncompromising about the purpose of his work – which was to create contradictions in the spectator; to ‘expose the unity of selfhood as an ideological illusion’ (Eagleton 1983: 187). Estrangement effects are evident, for example, in the following aspects of camerawork, sound use, set, and imagery in *Ex Memoria*

*Camera work* - Because the camera remains at Eva’s eye level throughout most of the film the source of sounds and voices is often uncertain. From Eva’s position it isn’t always possible to tell who is speaking, or who is being spoken to. The viewer’s unsettlement is invoked by a cinematic experience which is, in itself, somewhat ‘dementia like’. *Ex Memoria* is also unusual in that it does not include any ‘point of view shots’ (sometimes known as ‘subjective camera’) which enable viewers to see what a particular character is seeing. As discussed further below, this means that although we see Eva, we do not see things from her subjective viewpoint.

*Audio tracks* – Much of Eva’s experience is conveyed through the sound editing. Audio effects are heightened in volume and slightly distorted in places. Sounds along the corridor of the care home include groaning, shouting, and a hectoring male voice. We can’t tell whether these sounds are coming from people in the adjoining rooms or from a TV or radio. The sound of Eva’s breathing was edited into the film afterwards at high volume to accompany some scenes where she is in a state of emotional arousal.

*Set* – The film was made on location in a working care home. Whilst this was not itself an unduly institutional care setting, certain features have been foregrounded to

create an atmosphere of unhomeliness: so the camera shows us, for example, lengthy ill-lit corridors and people slumped asleep in armchairs. There are lingering views of eerie lifts and hoists, the ‘moving and handling’ paraphernalia of homes for the physically infirm.

*Imagery* – There is a (perplexing to many) scene late in the film in which a bird flies into shot and lands on the back of the wheelchair which Eva has recently vacated. This is the one overtly surreal moment in the film. It might be considered to be a symbolic reference back to the birds startled by gunfire in the first scene, but for some viewers it may raise questions about how much credence we are being asked to give to the other events that are shown. Might the whole film sequence be a dream or a hallucination?

The extent to which such techniques might help or hinder viewers’ engagement with the film was difficult to anticipate; there is, however, a potential tension between the aim of ‘teaching empathy’, and the film’s presentation of Eva as someone radically ‘other’.

#### *Heteropathic identification: empathy and estrangement*

Silverman (1996) points out that idiopathic identification is a frequent reaction to Hollywood film. This form of identification is aspirational; it can be represented in terms of Lacanian theory as ‘want to be’, or *manqué á être*. For the duration of the movie at least, we can have the illusion that we are, if not actually the hero or heroine, able to share his or her feelings and experiences. To this idiopathic form of identification, Silverman counterposes the concept of *heteropathic* identification. Here empathic awareness comes not only from respect for the other, but from the realization that the experience of the other *is not one’s own*. In this view, empathy resists the dictionary definition given at the beginning of this chapter which suggests that complete comprehension is possible; now the other demands my respect precisely *because* he or she is ultimately unknowable.

Drawing on Levinas’ (1961) concept of the face-to-face encounter, Miles and Plate (2004) also suggest the need to look outside Hollywood for films which bring us

closer towards a heteropathic identification with the other. This is, they suggest, more likely to happen in response to independent films that do not conform to the aesthetic standards of capitalist/industrialist film. Appignanesi and Baum (2006: 88) directly cite Levinas as an influence on the face-to-face encounter with Eva in *Ex Memoria*.

The conceit of the film is as follows: for 15 minutes with almost no cuts, the camera is locked onto the face of an old woman [with] dementia....The shifting backgrounds, nurses and family visitors flit in and out of her domain as half-seen shades...This is a cinema of immersion whose aim is to bring the 'face-to-face encounter' directly to the audience. *The viewers will be compelled to look closely at a face from which they would normally avert their gaze.*

(Appignanesi J and Baum, 2006: 87, emphasis added)

The intended 'bewilderment' of the viewer in the face-to-face encounter with Eva is the result of what Levinas terms 'radical alterity'; the notion that the Other is ultimately unknowable, a stranger. Levinas uses the unusual term 'alterity' in preference to the more familiar 'otherness', precisely because the Latin 'alter' means 'the other of two'. The relationship Levinas refers to as the 'face-to-face' is thus perceived as a strictly dyadic encounter between individual self and individual other. It does not involve the recognition of the collective 'other' of politically marginalised or dispossessed groups that Brecht, for example, sought to highlight through his use of estrangement techniques.

Central to Levinas' view of the significance of the face-to-face encounter is, moreover, that it is never symmetrical or reciprocal. The face of the other (characterised as a stranger, widow or orphan) Levinas argues, demands my respect and responsibility, but has itself neither power *nor* responsibility. The 'Levinasian conceit' of *Ex Memoria* may, then, come close to Kitwood's (1997a: 8) notion of personhood as a status that is given to the person with dementia by others in a kind of unidirectional, messianic gesture, 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust'.

Zizek (2006) argues that Levinas' claim that we are morally responsible for the other 'depoliticizes those we would be ethical towards' – that it is an 'ethical ideology'

which creates an imbalance between the self and the other, in which the other is vulnerable, because in need of my recognition and respect in order to exist as a human being. This imposes *upon* the other the status of a victim, and implies that ethics consists of a unilateral decision by the relatively powerful self to accord human rights to the impotent other, rather than a confrontation of the material causes of injustice or inequality.

My record of my own reactions to *Ex Memoria* includes the following note

I had difficulties during the script development phase in envisaging how this ‘immersive’ approach would work...I was also concerned about the implications of the ‘clinical (or anthropological) gaze’, which might objectify Eva and make her an oddity.

The unusual camerawork in *Ex Memoria* – the lack of subjective point of view shots; the lingering tracking shots and their potential objectification of Eva – may thus have implications for the kind of identification viewers develop with Eva.

### *The Social Psychology of Dementia Care*

The title of the module into which I planned to introduce *Ex Memoria*, it should be explained, does not refer to ‘social psychology’ in the usual sense; a sub-division of psychology pertaining to individual behaviour in social contexts. Rather, it reflects Kitwood’s theory that the psycho-social ambience surrounding people with dementia is responsible for their emotional and mental state. The module included material on the Rogerian humanistic approach which informed Kitwood’s person-centred approach, and on the more ‘classical Freudian’ material on repression, repetition and transference which I added during subsequent revisions of the module.

The module within which *Ex Memoria* was to be introduced was, then, already one which might be considered to ‘speak with a forked tongue’ due to the uneasy juxtaposition of humanistic and psychoanalytic approaches to dementia and dementia care presented within it. With hindsight, it seems obvious that the resulting data from student assignments would be a product of this mix of components and messages, rather than merely a response to the film itself. At the time, however, I did not

anticipate these complexities, and as will be discussed further, it was largely my struggle with the data that led to the turning point on which my thesis hinges. At this point in the process, however, there were also a range of pragmatic decisions I needed to make about introducing the film into the module and these are outlined in the following sections.

### **Introducing *Ex Memoria* into the curriculum**

An immediate concern to be addressed before the module began was whether *Ex Memoria* should stand alone as the basis of the assignment in question. The film's confusions, ambiguities and lack of closure were intended to be an important part of its overall effect as a work of art. It would, however, be unethical to risk the film being so incomprehensible to students that they lost marks on the assignment based on it. The final DVD package includes a booklet with background information and suggestions on the film's use for staff development, including questions to guide discussion. At the time the *Social Psychology* module started, however, this additional material had still to be produced, and only the DVD was available. In my research role I would have preferred in many ways to have students' unmediated responses to the film, but in order to reduce the risk of anxiety or confusion for participants I added material explaining the background, splitting it into six 'scenes', and providing - in order of appearance - the names and roles of the characters in each scene (eg 'Helena, Eva's daughter'; 'Grace, a member of the care staff'). This additional information can be found in Appendix 1.

I also carried out a mapping exercise to ensure that the material in the film would offer students sufficient opportunity to apply the theoretical material covered in the module, and came to the conclusion that it did. As part of this process I made my own assessment of the number of instances of Kitwood's 17 types of personal detraction in *Ex Memoria*. By my own judgement there were eight clear examples of personal detraction in the film, some of which had been added intentionally as part of the script development process.

### *Student assignments as 'advertent' data*

I discussed some of my reasons for becoming interested in student assignments as data in Chapter 2. Whilst this does not seem to be a widely used approach in educational research involving adult learners, Lamont Hill (2006) used students' work to provide a critical source of data for his study of an evening education programme and Brown (1996) discusses the use of students' writing on classroom practice as data within practitioner research enquiry. For purposes of this study, continuing with such an approach to data creation had both pragmatic and ethical advantages. It was a way of obtaining rich data without making additional demands on the time of working, part-time students. It would not have been possible to interview distance learning students face to face because of the time and resource implications, and the kind of evaluative questionnaire used for the report back to the Wellcome Trust, whilst useful for processing and analysing large volumes of data, cannot provide the kind of qualitative detail that may be found in a 2000 word assignment. In addition this is not 'grey' or inadvertent data, since all students had consented at the outset to its use for the particular research purpose in question.

Having made these preparations I handed module leadership over to a colleague and had no direct teaching involvement with the students enrolled on it during its delivery. The project was carried out in accordance with the British Educational Research Association revised ethical guidelines for educational research (BERA, 2004). Ethical approval for the project was granted by the School of Health Studies Ethics Panel at the University of Bradford in May 2006. I contacted each student individually by letter asking his or her consent to participate in the project. Copies of the information letter and consent form are included in Appendix 2.

### *Participants in the study*

At the beginning of the 2005-06 academic year 19 students were registered for the module HD2003D *The Social Psychology of Dementia Care*, of whom 15 were white British, two Zimbabwean and two black South African. By the Semester 2 start date for the module, however, five of these students had withdrawn and one had deferred the module until the following year. The five students who withdrew included all

four who belonged to minority ethnic groups. This limited the scope for exploring how the film might be interpreted by viewers with varying cultural backgrounds, particularly those who may not be familiar with 20th century European history.

The dementia care workforce is an increasingly multi-cultural one, and this is reflected in the casting of *Ex Memoria*. Members of direct care staff are often recruited from the most disadvantaged socio-economic groups, where black and Asian people and recent economic migrants from Eastern Europe are over-represented. In order to address chronic understaffing in this field of work, there is also an increasing tendency to recruit qualified staff from overseas (Gerrish and Griffiths, 2003). Recruitment onto Dementia Studies courses does not reflect the cultural diversity of the workforce, however, and the relatively high attrition rate among students from minority ethnic groups who do apply may itself suggest that they are not well-supported in the workplace. Whilst there is no selection procedure – all applicants who meet the entry criteria are currently offered places - the course places high demands on students whose first language is not English, and the University currently provides no language support for students in this situation. This is unquestionably another factor in the attrition rate.

The 13 remaining students due to begin the module – three male and ten female – were asked for consent to their assignments being used for research purposes. All but one student (who started the module late following a road traffic accident) consented to this. All 12 students who consented to taking part completed and passed the module, and all were provided with a certificate of research participation recording their contribution to the project (See Appendix 3).

At the end of the academic year, students currently registered on the Dementia Studies programme who had not taken the *Social Psychology* module during that year were invited to take part in the study. Exceptions were those who had assignment resubmissions to complete over the summer, those who were currently intercalating, and those who had ongoing mitigating circumstances. The consent procedure was identical to that described above, but these students were asked to write a guided critical review of *Ex Memoria*. Although producing a review involved students in

additional non-coursework related writing this was to be done during the summer break and the process was entirely voluntary.

Of 40 eligible students, 20 agreed to take part. Students were able to complete their reviews anonymously if they wished, and two did so. An administrative system was set in place so that anonymous respondents could still receive the certificate of research participation. Ten students reviewed the support material provided with the DVD package which had by then been produced. These reviews informed the report back to Wellcome Trust but data from them have not been included in this study. The remaining ten students completed reviews of *Ex Memoria*, with particular reference to the artistic techniques and imagery used in the film (See Appendix 4 for participant information sheet). In total then this study is based on substantial pieces of writing produced by 22 participants, all of whom were required to engage with *Ex Memoria* in considerable detail. Although I have treated the data from student assignments as the main source of data on the film's use for educational purposes, the student reviews have been used as a source of supplementary data on particular points raised in the discussion of findings.

Before moving on to the chapters on data presentation and discussion of findings, however, I want to draw attention to a methodological turning point that I reached during the time that I was attempting to analyse this data.

### **The reflexive turn: inadvertent data and lines of flight**

Myerhoff and Ruby (1992: 307) describe reflexivity as

a possibility that loosens us from habit and custom and turns us back to contemplate ourselves just as we may be beginning to realize that we have no clear idea of what we are doing. The experience may be exhilarating or frightening or both, but it is generally irreversible... Reflexive, as we use it here, describes the capacity of any system of signification to turn back upon itself, to make itself its own object by referring to itself: subject and object fuse.

During the period that the intended data for this project was being collected *Ex Memoria* was also being shown and distributed more widely at conferences and in

other public contexts. The Wellcome Trust evaluation, which I coordinated and wrote up, involved the distribution and return of several hundred evaluation forms which included some Likert-scale questions, but also left space for brief qualitative responses to the film (Capstick 2007a; 2007b). When shown in group contexts the film also invariably generated a lot of discussion, much of which I recorded in field notes. From the outset, then, there were questions about what counted as data for my thesis. I made a conscious decision to limit the research for my EdD to a small group of students doing a specific module because I thought this would ensure that ‘the story’ had clear (and clean) parameters. I also wanted to take an in-depth approach to a relatively small number of participants.

At this stage I was also very fixed on the potential of visual imagery to enhance awareness of practice issues, and I had given much less thought to the film’s implied narrative. This seemed, however, to be what preoccupied viewers most. A commentator at one conference was, for example, quite vociferous in her view that the events Eva had experienced in the past were so extreme that the film’s message could not be generalised to other people with dementia. Many other viewers, on the contrary, cited similar examples of the return of traumatic past events in the context of dementia; a grandfather – now long dead - who had gone back to the trenches of the Somme; a father reliving forced labour on the Burma-Siam railroad; a mother still searching for a child drowned in infancy.

Around this time I also discovered the work of David Clegg, director of the Trebus Projects. Edmund Trebus was a Polish war veteran – featured in the BBC documentary *A Life of Grime* (20.4.99) who filled his home with things that other people considered to be rubbish, the detritus of history, convinced that eventually a use would be found for them. The Trebus Projects named for him are a range of arts-based approaches to working with people with dementia, which struck me as being different from anything I had come across before. The people involved in these projects were not the stereotypical ‘cuddly old dears’ frequently used to popularise the concept of person-centred care. The book of narrative biographies, *Ancient Mysteries* (Brown and Clegg eds 2007) in particular, chronicles some very chequered, eventful and, sometimes insalubrious, lives. No attempt had been made, however, to censor or sanitise what the contributors said. Whilst I was struggling to make any sense of my

‘official data’ – the student assignments and reviews - I was therefore also beset by the real voices of people with dementia; people whose experiences were just as strange and surreal as anything shown in *Ex Memoria*.

A dilemma arises in writing up research that pursues such rhizomatic ‘lines of flight’, (Deleuze and Guattari 1987) because what has emerged by the end of the process did not inform its early stages. My thesis as I originally planned it would not, for example, have included the critique of Kitwood’s work. Whilst this now appears near the beginning of the study, it is the result of my having looked at the data from student assignments in a different light once the concept of social amnesia became a central one. Until I became aware of the ways other viewers constructed the narrative of *Ex Memoria*, I could not work out what to look for in the data from student participants. Most significantly, although I was already aware of Jacoby’s work on social amnesia (1975: 1996) it only really became a critical perspective for my purposes here in the context of Catherine’s story, told in *Ancient Mysteries*. My discussion of Catherine’s story comes later, in Chapter 8, but may not have appeared at all had I not been struck by the irony of a woman with dementia recounting what seem to be fragmented memories of the Holocaust, and wondering if she is ‘the only person who remembers that incident’ (Brown and Clegg eds 2007: 143).

In order to demonstrate reflexivity in the writing of research, then, some form of doubling back becomes necessary. The temporality of the narrative – its chronological ordering – is inevitably disturbed. The temptations are either to write with guilty sophistication a ‘cooked’ (or ‘overwritten’) narrative which suggests that everything eventually found out was known at the outset, or, alternatively, to write a *faux naïf* account which interjects breathless amazement at its own processes of discovery (‘at this point I found...’; ‘I was surprised to discover...’) as though the researcher were a *tabula rasa* with no prior commitments or opinions.

In writing up this research – and referring to myself in the process of writing it - I have tried to avoid either of these strategies. As Denzin (1997) notes, a certain amount of ‘messiness’ is needed in order to develop a text which ‘announces its politics and ceaselessly interrogates the realities it invokes’; ‘messy texts [are]...many sited, intertextual, always open ended and resistant to theoretical holism’ (Denzin

1997: 224). I am thus interposing these comments at the point in my description of the process of *doing* the research where this ‘turning point’ became unavoidable. That is, at the point where my official data would not answer my somewhat hesitant research questions, whilst the unintended sources would not keep quiet. In the end, *Ex Memoria* proved to be less an isolated intervention in a bounded methodological field, than a catalyst for a much more wide-ranging and rhizomatic study. In the process, however, it has drawn attention to the profound ethical dimensions of society’s response to people diagnosed with dementia and the directions such responses may take in the next 40 years or so, until prevalence of dementia in the Western world is predicted to peak around the mid-21st century.

My analysis of student assignments and reviews based on *Ex Memoria* is presented and discussed in Chapters 5 and 6. In Chapter 7, I return to the broader, extra-filmic context and the implications of social amnesia in the post-War world.

## **Chapter 5) Analysing students' narrative accounts of *Ex Memoria*: syuzhet, style and fabula**

In fiction film, narration is the process whereby the film's syuzhet and style interact in the course of cueing and channelling the spectator's construction of the fabula (Bordwell, 1985: 5)

### **Introduction**

The 12 student assignments which form the main body of primary data for this study are each approximately 2000 words in length and consist of a primarily descriptive 500 word narrative account summarising the content of *Ex Memoria*, followed by a 1500 word analysis in which students link the theoretical material covered in the *Social Psychology* module with the events shown in the film. In this chapter I have focused only on the first part of the assignment - the narrative synopsis of *Ex Memoria*. I outline below the process by which the initial narrative accounts were analysed in order to discover how students construct a storyline from the events shown in the film. The longer and more analytical sections of the assignments are the subject of Chapter 6.

In Chapter 2, I presented an analysis of a single narrative account using critical discourse analysis (Fairclough 2001). The incident analysed there was one selected by the student from her own observation of real life practice on a hospital ward. As mentioned above, a disadvantage of using self-selected incidents as the basis of the assignment for the *Social Psychology* module was that assessors had no access to what students had seen, making it difficult to give feedback that suggested alternative interpretations or approaches. A perceived advantage of using *Ex Memoria* was that it was possible to cross-reference the content of students' narrative accounts with the incidents, interactions and dialogue in the film in order to know how much had been observed. Since students would not be able to provide an analysis of aspects of the film they had either not noticed at all, or not considered sufficiently relevant to include in their synopsis, I decided to start by categorising the elements of the film that appeared most frequently in these accounts.

The 12 narrative accounts were analysed using the structuralist method known as foregrounding (eg Hakemulder, 2007) and the associated concepts of fabula, syuzhet and style in film analysis (Bordwell, 1985). Following this approach, I explore the ways that participants have worked from the narratively ordered elements in the film (its syuzhet) in order to construct a fabula for analysis. This primary organisation and analysis of data showed that there were patterned regularities (Wolcott, 1994) in students' responses to the film. Four elements of syuzhet mentioned with particular frequency by participants and discussed further below were: Eva's lipstick; the gunshots in the first scene; Eva's misidentification of her grandsons, and the intervention of the male staff member, Martin, in her attempted 'escape'.

The ten additional student reviews were then analysed in order to check whether aspects of the film's style appeared to have contributed to the foregrounding of these four elements, and whether reviewers had made consistent reference to any additional cinematic devices or aspects of *mise en scène*. Whilst there were a number of correspondences here, some of the recurring themes and tensions in students' assignments suggested that extra-filmic influences had played their part in the application of theory to the events shown in the film and that their analysis thus required a process of 'reading against the grain' (Jameson 1981) which has been followed in Chapter 6.

### *First impressions of the data*

I had access to the anonymised data from student assignments following the end of year exam board in July 2006. At that point I remember starting to read them with great enthusiasm, but quickly developing a sense that there was 'nothing there' to interpret; that they were not going to yield up any striking insights. On reflection, I suspect that I was still hoping that that these assignments would prove to be markedly 'better' in some way than the assignments based on incidents students had selected themselves in previous years, thereby vindicating my enthusiasm for arts-based and audio-visual approaches to teaching dementia studies.

On first reading, it was certainly noticeable that there was little, if any, use of language or concepts derived from the biomedical model of dementia in this body of

work. No-one, for example, suggested that any of Eva's actions were related to a 'stage' of dementia or that Eva should be kept still and quiet for her own good; nor did they construct her accusations of stealing against care staff, her attempt to escape, or her sexual advances towards Martin as 'problem behaviours' arising from her dementia. Instead, these viewers interpreted Eva's experience within the film's own terms of reference as a response to interpersonal and environmental aspects of the present day care home. They also generally recognised her present day experiences and actions as being interwoven with her earlier life experiences. Although they were often tentative about making explicit reference to historical events or locations, most students had made at least some specific links between events in Eva's past and present day reminders of them in the care home. In this sense the film could be considered successful in its original aim of challenging the biomedical standard paradigm by encouraging viewers to identify with Eva face to face through the medium of film

On the other hand, certain characteristics were still in evidence which I found hard to define, and which I had previously also attributed to the dominance of the biomedical discourse. There was a tendency, for example, to generalise in a sweeping way (*'Throughout the entire film no one takes the slightest notice of Eva'*), to be prescriptive about what Eva's family and the care staff should have done, and to discount alternative viewpoints or interpretations. In the final section of the assignment students were asked to make specific recommendations for improving Eva's quality of life, and these were often confined to general suggestions about staff training, or doing life history work, rather than specific recommendations based on what we are told in the film about Eva's life story and experiences. I had a sinking feeling; my action research experiment wasn't working.

One of the findings from the separate evaluation of *Ex Memoria* carried out for Wellcome Trust was that respondents to the questionnaire spontaneously commented on the film on three different levels: events shown in the film; how these resonated – in their view – with real life care practice, and aspects of the film 'as a film' (Capstick, 2007b). These different levels of response correspond interestingly with the distinction made between *syuzhet*, *fabula*, and *style* in formalist film theory, and there seemed to be some mileage in also applying this theory to the student assignments as

an initial means of identifying patterns of response in what participants had written. This stage in the data analysis marked a methodological shift from hypothesis testing ('Does film enhance students writing?') to a more emergent approach in which students' writing was used to generate theory about factors that may have influenced their responses to the film.

### **Formalist film theory and foregrounding**

Early Russian formalists such as Shklovsky and Jakobson who were concerned with the idea of art as estrangement, developed a distinction between fabula or 'story' and syuzhet ('narrative' or manner of telling). Translating this approach to film Bordwell (1985) suggests that the fabula is the storyline itself set within a chronological timeline, the syuzhet is the 'plot' presented in the order it is shown on screen, and style is the systematic use of cinematic devices. In other words, events portrayed on the screen, and the way they are presented, work together to allow the viewer to construct a fabula. For Bordwell, the fabula is 'an imaginary construct we create progressively and retroactively'; that is, both during watching a film and for some time afterwards (1985: 49). It is a non-linear process and the fabula is subject to repeated revision.

The fabula of *Sixth Sense* (dir. Night Shyamalan, 1999) for example, has to be completely refigured at the very end of the film when we come to realise that psychologist Malcolm Crowe, played by Bruce Willis, is a 'dead person'. Here the combination of syuzhet and style work throughout the film to convince us that Crowe is alive and visible to other characters. Following the final denouement, however, many viewers had to watch *Sixth Sense* again before being able to accept that Crowe's presence was never actually acknowledged by anyone other than his child patient, Cole, who 'sees dead people'.

Foregrounding is a term used within the formalist school to describe the ways in which texts achieve their effects by giving prominence to something by the use of innovative and unexpected devices. It is the means that are used to make objects unfamiliar in order that they can be re-perceived with fresh awareness. Although more

commonly applied to the analysis of literary text, foregrounding has also been applied in the context of visual arts and spectator response (eg Krampen 1996; Hakemulder 2007).

In film, as Van Peer and Hakemulder (2006: 551) point out

the term refers to drawing spectators' attention to some element ... by means of unusual filmic devices. Wollen (1982) uses the term to define counter-cinema (opposing mainstream cinema); for him it describes spectators' focus on processes of construction of meaning. Examples would be fixed positioning of the camera and the deformation of familiar objects through filters, mirrors and extreme close-ups.

Key terms in foregrounding theory include deviation and parallelism. The former is used to describe textual or filmic devices which use 'artistic licence' of various kinds, and the latter to refer to repetitions, reoccurrences and 'echoes' within the work. Examples of such devices can be found in *Ex Memoria*. The bird which appears on Eva's empty wheelchair may, for example, be considered an example of deviation, There are also numerous parallelisms, including Eva's two uses of lipstick, her two journeys along the care home corridor (the first from right to left and the second from left to right) and the reappearance of the actor who plays young Eva in the role of the care assistant, Becky. A more complex parallelism can be traced in the two scenes in which Eva is first kissed by her dark-haired grandson kneeling alongside her wheelchair, and then kisses the blond careworker who occupies a similar position in mirror-image (see illustrations on the following page).

I decided to apply this body of theory to the assignment data, as an initial way of discovering what - in their watching of the film - had been foregrounded for, or by, the participants. In order to do this, I started out by creating a kind of meta-text, independent of the script or film itself, which was the result of aggregating all 12 of the 500 word descriptive accounts in which students were asked to summarise what are *for them* the key events and interactions in each scene of the film. Each student's

Parallelism in *Ex Memoria*: Jacob and Eva/Eva and Martin



narrative summary of the film thus represents what has been foregrounded for that viewer within the given limit of 500 words. What has had little resonance, or failed to stand out, is less likely to be mentioned. Amalgamating the accounts in this way also meant that the most detailed or elaborate description of each of the elements identified by two or more viewers could be incorporated. The purpose of this first stage was thus to establish *how much* had been noticed by the group collectively, and in how much detail this had, optimally, been described. The amalgamated data represents the fullest obtainable syuzhet – a thick description of what the participants collectively had seen in the film.

### *Foregrounding method*

My first step was to reproduce electronically one of the 500 word summaries selected at random. I then worked through each of the remaining 11 accounts in turn amending this ‘base text’ whenever a participant mentioned something new, or made reference to something already included but with more information or narrative detail. For example I included a line mentioned in the form of reported speech when it first occurred. If it then occurred in a subsequent account in the form of direct speech I changed it accordingly, whether or not the direct speech was an accurate rendition of the line spoken in the film. If I then came across a mention in a later account that was in direct speech and more closely corresponded to the line as spoken in the film, I amended that item again.

Eg First occurrence: *Eva says they have the wrong one.*  
Amended 1 to: *Eva says ‘You have the wrong one, it isn’t me.’*  
Amended 2 to: *Eva says: ‘You’ve got the wrong one, the wrong one; it isn’t me.’*

If there was more than one version of an incident or line that seemed equally rich in content, I kept both until they were replaced by something with more detail

Eg First occurrence: *Gertrude is told to sit down and wait for tea.*  
Second occurrence: *Martin tells Gertrude that tea will be served later.*  
Eventually amended to: *Gertrude asks for a cup of tea and Martin tells her to go and sit down, repeating information about what time tea is served. This seems to displease her and she moves away muttering in German.*

The collective syuzhet of *Ex Memoria* created by this process is provided in Appendix 5. Two points need to be noted here. First, the amalgamated narrative account is considerably longer than 500 words, so the intention is not to present this as a ‘model answer’ to this part of the assignment. Individual students had to be much more selective about what they included. Second, my own preference for certain words and phrases over others will inevitably have been a factor in the creation of this meta-text, or collective syuzhet. My purpose here is, however, merely to provide the most elaborate version possible from this body of data in order to incorporate everything that had sufficient resonance to be foregrounded by at least one of the 12 participants. Identifying aspects of the syuzhet that were most frequently foregrounded for the group as a whole was the next stage of the process.

#### *Patterned regularities in the syuzhet*

My next step was to reduce each element of narrative in what I describe as the collective syuzhet, to a simple economical statement representing an action or interaction shown in the film, and noting *how many* participants had made reference to it, no matter how briefly. So for example, the collective narrative for Scene 2 begins, ‘We see an older woman in the foreground staring ahead. She says, “I think we should go home now”’. This was the most elaborate account of these few frames in the film that emerged from amalgamating all 12 individual accounts. In order to assess *how frequently* Eva’s desire to go home had been considered sufficiently important to be mentioned by individual students, this was reduced to ‘Eva wants to go home’, and a count was made of participants who had made any reference to it whatsoever. Eight participants had done so.

In total 93 such elements were identified (see Appendix 6). Some of these had been mentioned by only one viewer (eg ‘*Helena goes to enquire about Eva’s knees*’; ‘*Eva appears to flirt with Martin*’), while others were mentioned by the majority (‘*Eva talks about stealers/blacks/schwartzes*’; ‘*Jacob talks on his mobile phone*’). The most strongly foregrounded elements mentioned by all, or almost all participants proved to be Eva’s use of lipstick, the sound of gunfire in the first scene, Eva’s misidentification of her grandsons, and Martin’s intervention in Eva’s attempted ‘escape’. Before

discussing these elements in detail, I want to refer briefly to some of my observations about students' naming of characters in *Ex Memoria*.

### *Character naming in Ex Memoria*

Since students had been provided with names of the characters appearing in each scene of the film, it seemed worthwhile also to discover which of them had been most frequently mentioned by name. These characters were also likely to have been perceived as particularly central to the construction of a fabula. My analysis of character-naming in the film (see Appendix 7) shows that after Eva herself - who was named by all participants - Robbie, the younger of her two grandsons is the second most frequently named character (11 out of 12 participants), with Martin (mentioned by nine participants) and Jacob (mentioned by eight) following closely behind. Although there are more female characters in the film than male (11 as opposed to seven), it is, thus, the male characters who appear to have been foregrounded. Although these male characters do, by and large, have more central roles than many of the female ones, this seems unlikely to account fully for the bias towards naming males. For example, Jim – the male careworker involved in the bathroom scene - does not have a speaking role in the film. Jim is, however, still named more frequently than Delores – the female careworker in this scene – who appears twice and has several lines.

Eva's brother, Adek, was not included in the list of characters given to this group of students because he never appears on screen. Since this name was unlikely to be familiar to English-speaking students, this was an unfortunate oversight, and perhaps as a result, the majority of students (seven out of 12) do not mention Adek by name. Those who do have invariably misspelt the name, and whilst this is unimportant in itself, it may suggest that participants were reluctant to use a name they could not reproduce accurately. More significantly, uncertainty about Adek's identity, or the nature of his relationship with Eva, may also have led to a disinclination to mention him by name. There are indications in some of these assignments – as in other sources, such as online reviews of the film – that viewers have not always realised that the man who calls out to Eva at the beginning of the film, and Eva's lost brother, Adek, are intended to be one and the same person. A reviewer for *Culture Wars* (the

reviews website for the Institute of Ideas), for example, asserts that at the beginning of the film Eva is ‘awaiting her lover in the woods...She fusses over her appearance, anxious to please him. But he is late. Suddenly she hears him calling her, telling her to run, as shots in the village announce the arrival of the Gestapo’ (Marteau, 2006). In the scripted version of the film, this mystery lover does not exist, but – as will be discussed further below - he is an interestingly tenacious character in viewers’ construction of the fabula. It may be that uncertainty about Adek’s identity, and a consequent sense of puzzlement about the missing person/mystery lover account for at least some of the tendency to foreground male characters in the remainder of the film.

### **Foregrounded elements in the syuzhet of Ex Memoria**

The key findings during this stage of the process were that in participants’ narrative summaries of the film four elements of its syuzhet were mentioned with particular frequency. These are discussed below

#### *1) Eva’s use of lipstick*

This was mentioned by 10 out of 12 participants when it occurs in the first scene and by all participants on the second occasion when Eva applies lipstick on the corridor of the nursing home. As one reviewer put it

*There was application of lipstick **which stood out** and appeared twice during the film (emphasis added)*

In the first scene, it seems reasonable to assume that viewers are trying to orientate themselves to what they are being shown, not just in terms of the characters and events, but also the film’s genre. In this scene viewers appear to have made associations between the lipstick and aspects of Eva’s character and personality. She is described, for example, as: sexual, seductive, naïve, frivolous, self-indulgent, and ‘a private person’.

Several participants took the lipstick – and Eva’s apparent concern with her appearance – as an indication that she was waiting to meet someone in the wood. Her actions during this scene are interpreted as evidence that she is, for example

*Playing out and practicing her ...sexuality prior to meeting someone there*  
*Waiting for her date*  
*Wanting to look her best for someone*

Other viewers suggest – more obliquely - that

*Adek is on look-out*  
*It appears that someone is approaching*

There are also indications that some viewers suspect Eva may be guilty of leading Adek into danger, or that she protects herself at his expense.

*Her brother calls to her desperately, but she does not call back or go to him*

This helps to demonstrate how viewers are already, at this early stage in the film, beginning to work from the elements of syuzhet and style to develop a story (or fabula). The film itself provides little narrative information at this point but it seems that viewers draw on certain elements – pretty girl, sunny day, lipstick - in order to construct what they are about to see as a romance, and perhaps already as a mystery. Lipstick and cigarettes are frequent elements in film noir which, even in this naturalistic setting, work to mark Eva out as a proto-temptress. Since she evidently doesn’t want Adek to know she is smoking, we may be inclined to ask where she has been getting her cigarettes – particularly given their status as currency in wartime. For several participants it seems that a ‘second man in the woods’ is invoked in response to these perturbations. Whether consciously or not, connotations of this kind are, then, inevitably coloured by other films, and types of film, viewers have seen.

Eva’s second application of lipstick on the corridor of the care home is frequently taken as an indication that she believes she is about to meet someone connected in some way with the first scene

*Eva identifies this with something from her past, which prompts Eva to put on her lipstick*

*Lipstick...links both to her time of youth and attractiveness, but also to the time when...someone valuable was taken away*

It seems likely, then, that viewers form a connection between the application of lipstick and the disappearance of Adek. This may then intensify their response when Eva mistakes her grandson, Robbie, for Adek in the later scene set in the care home.

## *2) Gunfire in the first scene*

Eleven students refer directly to the sound of gunfire when Adek is captured in the woods during the first scene. The action in this scene takes place largely off camera, and a considerable amount of work has to be done by the viewer in order to understand what has, or may have, happened. Having known in advance of seeing the film that Eva's brother is rounded up and taken away at gunpoint in this scene, it is difficult for me to estimate how much of a sense of rupture might accompany this for first time viewers. The initial impression for many seems to be, however, that they are watching a romance in which a young girl is preening herself in a woodland glade in preparation for meeting her boyfriend. This is now disrupted by the sound of gunfire, orders barked out in German, and the cries of the captured man. The language used by participants often suggests a sense of dislocation at this point

*She hears a commotion; gunshots and her brother crying out her name*

*The peace is disturbed by shouting voices of German soldiers and the sound of gunshot*

*She witnesses the possible shooting of her brother by the SS*

Retroactive construction of narrative can be seen at work in some of these extracts, where information external to this scene is used to interpret the action. Eva's later

reference to Adek being 'lost' seems to have indicated to a number of viewers that he did not survive the war, although there is nothing in the film itself which actually corroborates this

*Presumably she never saw him again*

*Eva survived the war, but unfortunately Adek did not*

The concrete certainty with which some of these statements are expressed is striking. It is unclear, though, whether this is because viewers' identification with Eva leads them to feel they know what has happened, or whether it is because they genuinely believe they have been told that Adek died.

Following this aural intimation of disaster it seems that viewers' perception of the film's genre changes. This is particularly evident in comments on the use of sound in the film by the 10 student reviewers who were asked to focus specifically on style and filmmaking technique.

*The gun fire in the opening scene helps prepare us in some way for what's to come...it conjures up pictures of fear and flight*

Reviewers make frequent reference to sinister sounds that link this first scene to Eva's later experience of the care home ('echoing', 'whispering', 'sounds like somebody is whispering in the background' and TV noise that 'sounds like one of Hitler's rallies'). They also refer to 'harrowing' sights; 'eerie lighting on drab corridors, and 'cell-like' side rooms as Eva is wheeled along the corridor

*It made me think of a corridor leading to death (a lamb taken to the slaughter)*

*Individual people are kept in single 'cells' along a very long, stark corridor adding to the sense that Eva is in jail, or being kept against her will.*

*Complete despair to those who are trapped within these walls*

These comments taken from reviews of the film suggest that its style now begins to contribute to a growing sense of foreboding and a recognition of the links between Eva's past and present.

### *3) Eva's misidentification of her grandsons*

At different points in the film Eva greets both her grandsons fondly as though they are her lost brother, Adek. On the first occasion when the family have just arrived to visit, it is the younger grandson, Robbie (aged 12) who is mistaken for Adek, and all participants have made some reference to this. The second occasion when Eva addresses her older grandson Jacob (aged 27) as Adek in the bedroom was, however, mentioned by only four people. There is a second misidentification of Robbie which takes place in Eva's bedroom, where she wakes up after nodding off to sleep and greets Robbie (in the absence of his mother and older brother, and in decidedly un-grandmotherly tones) with the words, 'Such a handsome young man – be careful, or what will the ladies be thinking? Come...give me a nice kiss'. One participant interpreted this as 'flirting' on Eva's part, but other participants who make reference to Robbie's reaction to being asked to kiss his grandmother in this scene have interpreted it, somewhat implausibly, either as a second occurrence of Eva believing Robbie to be her brother, or a merely affectionate grandmother-to-grandson request.

*When she wakes, she again believes her grandsons to be her brother*

*She attempts to kiss her grandson but he refuses and runs away*

One participant misquotes the line as 'such a handsome *boy*... give me a *big* kiss' and suggests that Eva is being 'playful', thus softening the impact on a 12 year old boy of being asked to kiss his grandmother as though he is a secret lover. Whilst four viewers acknowledge that Robbie is frightened, uncomfortable or embarrassed at this point, others clearly feel that his retreat from the situation is inappropriate

*Robbie refuses to kiss Eva and runs off (withholding)*

If the elements of the first scene which stood out for participants have been foregrounded because of their role in retroactive construction of a fabula ('What is happening here?' 'What kind of film is this?'), something more complex seems to be happening here. Robbie is misrecognized on the second occasion as a character the film's syuzhet does not help us to identify. This 'handsome young man' cannot coherently be made to correspond either with Adek, or with the male authority figure for whom Eva mistakes Martin in a later scene. This is something that is consistently foregrounded for viewers, in the sense that they have registered the interaction taking place. They have, however, made implausible interpretations, given the actual words Eva speaks ('Such a handsome young man – be careful, or what will the ladies be thinking? Come...give me a nice kiss') and her coquettish tone of voice (see illustration on following page).

Viewers have, then, either overlooked the complexities of this scene, or they have used various forms of narrative smoothing in order to avoid dealing with its implications. As will be discussed further in Chapter 6, the double misidentification of Robbie does not easily yield itself up to interpretation. This is, moreover, the one point in the film at which Eva looks back at the viewer, not as a frightened girl or a sexually-compromised victim, but as a character in a position of power and knowledge. She looks back, in other words, from a position at which we cannot see her. She resists the forms of symbolization currently available for representing people who have been diagnosed with dementia. As with the care practitioner whose assignment I analysed in Chapter 2, Eva also has an excess which resists the 'call of the other'. As Lacan writes in Seminar XI, 'when I look at an object, the object is always already gazing at me, and from a point at which I cannot see it' (Lacan 1977: 109). This gaze – at what or whom we do not know – creates a kind of inchoate unease both in Robbie (the writer/director's alter ego) and in the viewer. To address Eva's gaze we have to ask what *she* sees; who she thinks *we* are.

#### 4) *Eva's 'escape' and Martin's intervention*

All participants made reference to the point in the final scene where Eva struggles out of her wheelchair and disappears from camera shot. All but one mention this in the

From *Ex Memoria*: Robbie and Eva: ‘Be careful, or what will the ladies be thinking.....?’



context of Eva having been left alone by the care staff, who are more intent on their own private lives

*The staff leave Eva in order to gossip*

*Two staff members stand talking about their private lives*

*She is abandoned by the lift*

The possibility that Eva's 'flight' is in part a response to her fear of the glass lift beside which she has been left – and which she is seen to cower away from - is less frequently mentioned and only two participants suggest that this may be linked with past experiences, or have wartime associations.

Martin's intervention is also mentioned by all but one participant, and for many viewers this was highlighted as the *only* example of positive interaction with Eva in the entire film, although Martin too was subjected to some criticism. Martin is most frequently mentioned here (by 11 participants) as a provider of 'comfort' and 'reassurance'. Several viewers refer to the sexual content of Eva's words and actions towards Martin at this point, and to Eva's apparent misidentification of Martin as a high ranking official

*Eva seems to think that the male nurse will help her with her papers for what is implied as sexual favours*

*Martin becomes uncomfortable when she begins to talk to him in a sexual way*

*Eva appears to flirt with the nurse obviously mistaking him for someone else*

It is noticeable, however, that these accounts take a passive view of Eva's sexuality. None of the participants mention that Eva moves Martin's hands towards her breasts, and only one quotes her as saying, 'You can do anything you like with me'. Eva's own demeanour at the end of the film would seem to suggest that she views Martin's agreement that 'everything is in order' as a conquest. The overt sexuality of her

approach to Martin and the suggestions of collaboration and manipulateness which underpin it are, however, played down by viewers in favour of a sanitized version which, ironically, detracts from Eva's individuality. The complexities of her character and the possibility that she may enjoy wielding sexual power over men, even at the same time as she fears their power are thus occluded.

### **The limitations of a formalist approach**

Foregrounding theory proved to be a very useful starting point in my initial organisation and categorisation of the data from student assignments. The connection between the narrative accounts of *Ex Memoria* written by students and the concept of *syuzhet*, as used by Bordwell, enabled me to identify patterns of response to the film which may not otherwise have emerged. As has already been suggested above, however, the reasons for a particular viewer's foregrounding of an element of the film cannot be considered intrinsic to the film itself, as formalist and structuralist approaches in film theory have tended to suggest.

As Van Peer and Hakemulder (2006) point out, the precise meaning of the term 'foregrounding' often has to be deduced from the context within which it is being used. Sometimes it refers to the reader or viewer's perception, sometimes to authorial intention, and sometimes to an effect on the viewer or reader. This uncertainty in itself points to a failure to engage with the possibility of extra-filmic connotations which are woven into the retroactive construction of a fabula. For students it seems likely that such connotations will be influenced by, for example, other films they have seen, experiences of real-life care practice, and relationships within their own families. Some elements may be subliminal and coloured by earlier or more deeply internalised discourses. As mentioned in Chapter 4, there are, for example, certain fairy tale elements in *Ex Memoria* which begins with a rather silly young girl having a nasty experience in a wood which is partly her own fault, and losing someone close to her as a result of her actions. There is something almost archetypal about a storyline that can be summarised as 'lipstick – gunfire – mistaken identity – escape/re-capture'. Since numerous interpretations of these elements can be advanced, however, it might be argued that they are not so much foregrounded, as 'overdetermined'. The manifest

image in a dream according to Freud (1900; trans Brill, 1913) is always overdetermined because it is underpinned by a multiplicity of latent meanings, rather than a single coherent message.

Foregrounding theory is generally uninterested in the social contexts in which films are produced or watched. Formalism, in other words, ignores ‘the multiplicity of social forces and practices at play, at work, in the reading of any text...The best any purely textual analysis can do is open up problematic areas of ...ideological space by activating the repressions, contradictions and latencies within it.’ (Lapsley and Westlake, 1988: 59). Students’ narrative synopses of *Ex Memoria* all tell the same story – one which is ‘given’ – but they tell it with different emphases and varying degrees of richness and complexity. Their connotative interpretations (or latent content) arise from their imaginative and creative engagement with the film in ways that read, and write, into its gaps, sometimes subverting the film’s conscious intentions, or uncovering unintended ambiguities.

When I first started to engage with this data, I framed these assignments as having been written simply in response to *Ex Memoria*. I did not initially consider what ought to have been obvious, that they had also been written in response to the content of the *Social Psychology* module, the Dementia Studies course as a whole, and the specific requirements of an assessed assignment. Eagleton (1983) notes that Bakhtin’s critique of formalism rests largely on the dialogic nature of language in a particular *context of production*. In other words, we always speak or write as an act of communication with someone else (an implied other), and what we say or write will depend upon the purpose of that communication. Students may thus use a variety of techniques and sources in order to second guess what an assessor may be looking for in their work. Those who are juggling academic study and a demanding work role may be particularly tempted to mirror back, in their assignments, a position or perspective they believe to be held by the assessor. Price (2003) discusses the ways in which post-registration nursing students on a distance learning course adopted distinct kinds of academic ‘voice’ in their relationships with nurse educators, and suggests that students’ main priority when adopting a particular voice is the management of anxieties related to assessment.

Whilst the strongly, and consistently, foregrounded elements discussed in this chapter are likely to have had considerable impact on each student's construction of a fabula, other factors are also likely to be significant here, not least the content of the *Social Psychology* module itself, and the way this may 'cue' participants to read the film in a particular way. Already, in these brief narrative accounts of the film, it appears that many of the connections, interpretations and resistances which appear are the result of influences beyond the film itself. In the next chapter I explore these themes in more detail in the context of the later sections of students' assignments where they have applied the theory from the *Social Psychology* module to the events shown in *Ex Memoria*. Here I argue that a symptomatic reading of these assignments reveals not only an absence of 'neuroathic ideology', as I had originally hoped, but also the presence of the psycho-social model itself *as* ideology.

## Chapter 6) Reading against the grain: the political unconscious of person-centred care

We shall not cease from exploration  
And the end of all our exploring  
Will be to arrive where we started  
And know the place for the first time (Eliot 1942: from *Little Gidding*)

### Introduction

In the previous chapter I explained how foregrounding techniques were used to analyse students' narrative accounts of the content of *Ex Memoria* as an initial means of discovering which aspects of the film had been perceived as most striking or salient for them. It seems that, as suggested in formalist film theory, the style of the film was influential in directing viewers towards a particular construction. Viewers were also likely to emphasise elements of the film which gave rise to unease or puzzlement, due either to the nature of the events represented (eg a shooting) or to ambiguities in the storyline itself (eg a misidentification). There is also, however, evidence to suggest that influences beyond the film itself have played a significant part in the construction of the fabula, which then becomes the raw material for analysis in the second section of the assignment. Often this is noticeable as much in what is not said, in what is overlooked or misrepresented, as in those elements that have been given prominence.

The longer and more analytic sections of these 12 assignments, have thus been approached from the perspective of what Ricoeur (1970) described as a 'hermeneutics of suspicion'. I have also drawn on Jameson's (1981) concept of the 'political unconscious' underpinning all texts. Interpretation, for Jameson, means the discovery of a latent meaning behind a manifest one, in order to 'rewrite the surface categories of a text in the stronger language of a more fundamental interpretative code' (Jameson 1981: 60). This practice of 'reading against the grain' requires a surface/depth model of interpretation which takes the text's meaning to be that which it *does not say*, but which - through attention to its gaps, silences, disruptions, and exclusions - reveals what are taken to be its absent causes and determining structures.

In these assignments, beneath or woven in with, the manifest content related to the events and dialogue of the film there are latent messages which are both surplus to the film itself and which, I will suggest, echo the orthodoxies of Kitwood's psycho-social approach. My aim here is not to direct critical attention toward the participants, their workplaces, or the organizations in which they are employed, but to identify aspects of their assignments which are symptomatic of Kitwood's model of person-centred dementia care. I suggest that they mirror back (often in a less sophisticated and therefore more blatant form) the ideological nature of the discourse of malignant social psychology.

### **Critical discourse analysis**

In Chapter 2 I drew on an approach to critical discourse analysis which assumes that the surface of a text is a means of concealing the ideological interests that are served by its deeper concealed meaning (Fairclough 2001). Ricoeur (1970: 33) suggests that the aim of this kind of reading practice is to reveal the political interests served by the text; 'the purpose of interpretation is to strip off the concealment, unmasking those interests'. My suggestion here is that whilst Kitwood's work may appear transparent in its critique of neuropathic ideology, it advances a concealed ideology of its own; a liberal humanist ideology which still bears traces of 19th century philanthropic notions of the deserving and undeserving poor, and the moral re-education of both the mentally ill and those who care for them. This ideology invariably psychologises the source of social ills by locating them in what Smail (1993) describes as the 'proximal' domain, where they appear in the guise of 'right' or 'wrong' acts carried out by individuals, rather than drawing attention to the role of 'distal' socio-economic powers in the genesis of personal distress. Liberal humanism is, as Eagleton (1983: 207) puts it, 'a suburban moral ideology, limited in practice to largely interpersonal matters [and] stronger on adultery than on armaments.'

If Kitwood's work does not entirely dismiss the significance of distal, socio-economic and historical forces in the experience of dementia, it directs attention away from them on the grounds that the best we can achieve within the proximal sphere of

influence, when providing care for people with dementia, is to make moment-by-moment individual moral decisions to act well or badly. At the same time, the need for political action to redistribute wealth in order to provide properly for the care of older people on the basis of need, and to improve the pay and conditions of care workers, is endlessly deferred. It is implicit in Kitwood's work on organizational defence that to suggest such things are important is to be in a state of denial, to seek excuses for the shortcomings of one's own care, to refuse to look into one's own heart and mind for the source of the problem.

In the following analysis of students' work based on *Ex Memoria* I suggest that a number of symptomatic points emerge, and that these cannot be explained solely by the style or content of the film itself. First, whilst there were indications of empathic identification with Eva, very often this was expressed in terms of her helplessness, passivity and dependence. Scenes which imply sexual interest or desire, potentially racist sentiments, or possible wartime collaboration on Eva's part, for example, were frequently either overlooked or rendered innocuous in the accounts participants gave of them. Second, other characters – the care staff, and particularly Eva's family – often attracted a kind of moral opprobrium which seemed disproportionate to their actions. This was particularly noticeable in the identification of types of personal detraction, Kitwood's indicators of a 'malignant social psychology'. A number of viewers generalise their identification of personal detractions suggesting, for example, that members of the care staff 'use infantilisation, banishment, and invalidation against Eva', but without linking this to any specific incident. Finally there is a tendency to disregard what Eva and, to a lesser degree, the other characters in the film actually say. These findings are discussed below with reference to film techniques, the impact of Kitwood's psycho-social model of dementia on viewers' responses, and Jacoby's theory of social amnesia (1975; 1996).

#### *Empathic identification with Eva: the past in the present*

A stated intention of the film is to make people think differently about dementia through the device of the face to face encounter with Eva. Reviewers commented on the different perspective that was offered by the camera staying locked on Eva

*The camera shots indicate how a person confined to a chair for long periods may only see a limited range of activities at a certain height*

*The focus on Eva, particularly her face, was compelling, made you...think about the different set of realities the staff and Eva were experiencing*

The film also suggests in numerous ways that Eva's wartime experiences are colouring her understanding of where she is now; that she associates the care home with things she believed were over, and with places that she had managed to avoid in the past by living on her wits. Almost all viewers make some mention of the traumatic nature of the events shown in the first scene and three make specific reference to post traumatic stress and the flashbacks which characterise it

*Eva is recalling a traumatic event from her native Poland*

*Symptoms of post-traumatic stress such as auditory and visual experiences can cause flashbacks for people like Eva who have lived through war experiences.*

A number of participants also identify specific 'reminders' of Eva's wartime experience in the present day care home.

*She perhaps believes the place to be a concentration camp and this is why she tries to 'escape'*

*Wartime songs and shouting may well be reminiscent of memories she has kept locked away*

*I wondered whether during the Nazi occupation of her country she had either used her sexuality or been sexually exploited in obtaining her freedom*

*The home makes her feel as she did in the war, so she tries to create change by drawing upon the skills she used then*

In addition, two students showed evidence of having done further research themselves to follow up on the historical leads

*In the Nazi death camps signs of age or physical or mental illness could be a death sentence....Ageing and loss of status can lead clients to a sense of helplessness..and can reawaken emotions and fears associated with their captivity experience (Brainin and Treicher, 1997)*

*Cooke and Matarasso (2005) note the 'lack of acknowledgement by health professionals of traumatic life events'.*

This aspect of the film was not, however, consistently picked up on by viewers. Two participants make no reference at all to historical events in their analysis of the film, while three more refer only briefly or vaguely to 'experiences' and 'roles adopted' during the war. Although this is a small study, there are some indications – as discussed further below – that viewers who made little or no reference to the impact of historical events on Eva's present day experience formed more negative impressions of Eva's family and the care staff, than those who had linked her responses and reactions with reactivated long term memories.

#### *Personality traits attributed to the older Eva*

There was a consistent tendency to attribute different personality traits to the older Eva from those associated with her younger self. This can be deduced from the descriptive language used in relation to Eva in the first scene ('frivolous', 'confident', 'sensual', 'seductive', 'proud', 'self-indulgent') and in later scenes. This appears to coincide with a tendency to represent the older Eva as a hapless victim of events, rather than someone who survived by cunning and stealth.

I found that particular adjectives or adjectival phrases had been used very frequently to describe Eva in the present day care home. These focused on her isolation, abandonment, helplessness and fear, whilst paying less attention to the retained wiliness she displays in resisting the way she is positioned by others. Words most frequently used to describe the present day Eva were 'frightened', 'distressed',

‘alone/lonely’, ‘worried’, ‘anxious’, ‘upset’, and ‘sad’. In all, 39 different adjectives are used to describe Eva in ways that position her passively, and these almost always carry negative connotations (eg uncertain, desperate, vulnerable, powerless, detached, ashamed, rejected, withdrawn, hopeless, disliked, unloved). Whilst Eva’s resistance – her struggles in the bathroom, her escape from the wheelchair - is no longer seen as ‘challenging behaviour’ to be managed by the care staff, few participants recognise it as having political context, as an expression of human rights either by a resident in a care home, or by a refugee. Eva is viewed predominantly as an object of pity.

Some words are used with striking frequency; the word ‘frightened’ and synonyms such as ‘afraid’ and ‘fearful’ occur over 40 times in this body of data. In the following extract the words ‘distress’ and ‘distressed’ are used four times in eight lines.

*They (staff) are oblivious to the distress they are causing Eva....in the corridor  
Eva immediately becomes more distressed...the carers make no attempts to listen  
to the distress in what Eva is saying... Martin acknowledges Eva’s distress.*

Sometimes this becomes repetitive and even tautologous

*When Eva is left in the corridor she looks frightened and afraid...left...in the  
corridor...Eva became worried and afraid.*

By contrast only nine adjectives are used which position Eva in the present day as an active agent, whether with positive or negative connotations, and these are used much more rarely (eg suspicious, flirtatious, determined, annoyed). On the corridor of the care home, for example, Eva has a brief interchange with another resident, Jenny, who is talking to herself in a circumlocutory fashion which can be characteristic of dementia. Eva tells Jenny emphatically to, ‘Shhh...Shut up!’ Participants have invariably interpreted this as a fearful or anxious response on Eva’s part. Whilst it is quite plausible that Eva’s response is based the idea that in wartime ‘careless talk cost lives’, the tone of voice in which Eva says this indicates – to me at least – irritation and contempt, rather than fear.

Nine out of 12 viewers have commented on the scene in which Eva alleges that ‘there are stealers here...the blacks, the schwartzes’, but none of the nine suggest that this might be a racist comment about the staff. Two have explicitly defended Eva against any charge of racism, locating the meaning of her words in the past.

*This is not an obvious racial comment but one which refers to the Waffen SS who took her brother away*

*Eva accuses the care staff of stealing. Her daughter fails to see that the real reasons for Eva’s accusations lie in the past.*

In the second of these examples it is interesting to note that the viewer has acknowledged Eva’s reference to the staff as ‘stealers’, whilst eliding the reference to ‘blacks’ altogether.

In the final version of the script, it is notable that adjectives used to describe Eva in stage directions are more frequently active/positive than they are passive/negative. They include, for example, ‘proud’, ‘animated’, ‘wily’, ‘conspiratorial’, ‘knowing’ and ‘canny’ (See Appendix 8). It seems, however, that for whatever reason these intended traits of Eva’s character have remained largely unrecognised by viewers.

#### *Attitudes of the care staff and family*

The care home shown in *Ex Memoria* was not intended to be one which offered a particularly poor standard of care. The intention was, rather, to give an impression of how standard care practice looks from the perspective of someone who is on the receiving end of it. The original portrayal of the family changed little during the script development process because the biographical and autobiographical aspects of the film were considered to be the director’s province. From general discussion it seemed that the family’s behaviour was intended to be variously humorous, ironic or poignant, rather than reprehensible to the extent that viewers have tended to suggest. On the other hand, it has to be acknowledged that there seems to be something deeply dysfunctional about the relationship between the family members. Helena usually refers to her mother, Eva, as ‘Granny’; as though speaking ‘through’ her to Robbie

and Jacob. Neither of Helena's sons speaks to their mother at any point in the film, and Helena herself never speaks directly to Jacob. It may well be that if viewers have picked up on these tensions, even at a subliminal level, it will have influenced their perceptions of Eva's family.

Negative attributions to, and generalisations about, the fictional staff in *Ex Memoria* appear if anything to be more prevalent than in the previous assignments for this module based on self-selected critical incidents. Reminiscent of the 'atrocious stories' that Dingwall (1977) suggests members of an occupational group tell in order to bind group identity by denigrating others, the tendency to attribute blame appears here to be exaggerated rather than reduced. Reynolds (2007) quotes Hall (1997) on the construction of professional identities through the creation of binary oppositions in which the qualities associated with the 'other' are always devalued (for example, the 'incompetent other'). It may also be that the fictional care staff are more distanced and therefore perceived as more thoroughly 'other' than participants' own colleagues or co-workers. In many cases, viewers have indicated – either implicitly or explicitly – that they would handle things differently from the care staff in the film.

Examples of extracts from student assignments which I would suggest are unwarranted based on the actual content of *Ex Memoria* include the following.

*There appears to be no acknowledgement of the fact that Eva has feelings, or concern for the fact that they may be the ones who are causing her emotional upset*

*Throughout the whole film Eva has been made to feel undervalued, useless, misunderstood*

*Transporting persons as lumps of dead matter without communication can offer no orientation or validation*

*It is evident that carers have no respect for Eva and certainly do not see her as being in any way equal to them*

*They had very little insight into the need for interaction with a person with dementia and it portrayed a care home whose staff had stigmatised the residents, finding their behaviour 'awkward' and 'difficult'*

Again, I would suggest that there is a tendency towards hyperbole and over-generalisation in many of these statements. This is particularly evident in the attribution of malign agency to staff. In these extracts members of staff in the film are held to be *causing* Eva's distress in a way that is deemed morally reprehensible, even when it is simultaneously acknowledged that they are unaware they are doing so.

There are many similar attributions of blame to Eva's family; for example

*Helena answers questions about the care home on Eva's behalf, without allowing her to reply*

In this scene the visitor directs his questions to Helena ('Excuse me, is this your mother?...'). Helena does initially reply on her mother's behalf, but then makes a rather inept and belated attempt to include her mother ('You're happy here aren't you, Granny'), at the same time presumably trying to preserve for her sons the illusion of a 'normal' family visit to a grandparent.

*Helena is more interested in doing tasks than in chatting to Eva*

*When Eva speaks of 'the robbers, the Schwartz's and the blacks, Helen ridicules her and makes no attempt to understand what the underlying meaning of her speech may be*

*Robbie and Jacob do not interact well with their grandmother and ignore what she is experiencing.*

*The younger child just stared and didn't speak – appearing not to show any respect*

It is particularly noticeable that participants indicate little sympathy towards Robbie, Eva's younger grandson. They have considered the impact of his actions on Eva, but express little recognition of his own anxiety, boredom, and embarrassment, or of his mother's tendency to push him into an emotional breach that she seems unable to enter herself. Whilst Kitwood's person-centred approach is not overtly intended to exclude anyone, the emphasis it places on the individual with dementia can lead to a culture in which blame for his or her ill-being is merely shifted onto other individuals who are easy targets, and endlessly recycled within the proximal zone of the family home or care setting.

*Identification of personal detractions: indicators of malignant social psychology*

One of the most significant findings from this body of data is the over-identification and exaggeration of personal detractions. A number of personal detractions were added to *Ex Memoria* during the script development stage. Most – other than in the bathroom scene - were intended to be 'mild' in nature. The very terms adopted by Kitwood to describe the different types of personal detraction tend, however, to demonize the person who 'commits' them. Whilst the malignancy of personal detraction is held by Kitwood to lie in the culture of the organisation, rather than in individual intent, the strong language of 'mockery', 'banishment' and 'treachery' suggests that such acts are knowingly perpetrated by malevolent individuals.

My own mapping exercise, prior to introducing the film into the curriculum, identified the following eight personal detractions

*Disruption* – Martin interrupts Gertrude's journey across the lounge to see Anja

*Intimidation* – Delores to Anja, 'We'll have to put you by yourself'

*Objectification* – Grace pushing Eva in the wheelchair without telling her where she is being taken

*Infantilisation* – Helena: 'Not been any trouble I hope?'

*Invalidation* – Helena: 'There are no stealers'

*Ignoring* – Eva's 'Who's there?' unanswered by Jacob, talking on his mobile phone

*Outpacing* – Helena - Talks too quickly for Eva to keep up at the end of the visit

*Imposition* – Jim and Delores override Eva's wishes in the bathroom

In some cases it is the sheer number of personal detractions participants have identified that seems excessive; as many as 14 different types have been noted by some participants. In other cases there is a distortion of what is actually shown in the film. A number of participants have suggested for example that in the scene set in the lounge of the care home, Delores ‘banishes’ Anja (*‘An example of banishment is when Anja is taken to her room’*), when what the film actually shows is Anja being told that she will be ‘put by herself’ if she can’t be quiet. In the reported version, however, this admonishment becomes an act.

This is also a good example of the concept of personal detraction foreclosing interpretation. The interpretation of what happens here is that *Delores* is guilty of ‘banishment’ (or as one participant put it *‘Delores demonstrated incompetent communication skills that were lacking in warmth and understanding’*). This does not take into account the possibility that Delores may be anxious because the manager is within earshot, and that she may be seen as incompetent if she can’t keep Anja quiet while a prospective client/customer is being shown round the home. Delores is a Filipina member of the care staff, possibly an economic migrant, and likely to be employed on minimum wage, or very little above it. Underpinning this scene are potential themes related to profit margins in independent sector care, and the exploitation of workers at the bottom of the employment hierarchy. Sassoon (2007) points out that a major independent sector care provider with 10,000 beds in 170 homes pays its staff the minimum wage to work a 48-hour week. Between 2002 and 2005 the company’s profits rose from £6.1 million to £43.6 million. At the time of writing the UK minimum hourly wage for employees over the age of 22 is £5.52).

In other examples, cause for concern arises from the character to whom the depersonalising action is attributed. Robbie, for example, is frequently charged with ‘withholding’ during the scene where he darts out of reach when Eva asks him to kiss her. Here it seems that the concept of personal detraction has been used to justify (or perhaps even to construct) the view that Robbie is blameworthy in this situation. As mentioned in chapter 5, Eva does not address Robbie either as her grandson or as her brother in this scene, but as an object of her sexual interest. His actions, when viewed

in this light, seem entirely understandable, but any sympathy viewers might have felt for him tends to be overcome by the pressure to ‘spot the personal detraction’.

A final finding related to personal detraction is that participants tend to ‘borrow’ from the strong language of malignant social psychology. The reference to ‘transporting persons as lumps of dead matter’ in the extract from an assignment quoted above (p 137), read oddly to me at first, until I realised that this participant was merely quoting from Kitwood’s own definition of the personal detraction termed ‘objectification’: that is ‘treating a person as if they were a lump of dead matter: to be pushed, lifted, filled, pumped or drained, without proper reference to the fact that they are sentient beings [sic]’ (Kitwood, 1997a: 47).

Whilst it is often unclear whether Kitwood holds individual members of staff or the organisational culture responsible for high levels of personal detraction, blame is attributed strongly to individuals in these viewers’ analyses. Whilst the assignment guidelines asked students to identify examples of both personal detraction *and* positive interaction, negative attributions dominate, and the ‘scattergun’ approach to identifying personal detractions adopted by a number of students suggests they may believe that the more they can identify the better.

#### *Inattention to ‘voice’*

Participants frequently criticised the fictional care staff for ignoring Eva, or not listening to her

*Carers make no attempt to listen to the distress in what Eva is saying*

*At no point did they listen to what she had to say*

Participants themselves, however, made noticeably little reference to Eva’s lines of dialogue. Where the words Eva speaks in the film *are* reproduced, this is often in the form of reported rather than direct speech, and such direct speech as there is has rarely been quoted verbatim.

Of the 14 separate occasions in the film where Eva speaks, only five were quoted verbatim and accurately by any student. Four additional lines of dialogue were mentioned by at least one student, but in reported speech only. Of the remaining five dialogue sequences three were reported inaccurately, and two were not referred to at all. While eight participants made reference to the first line Eva speaks in the nursing home ('I think we should go home now') only one quoted this accurately in direct speech. Although simplified forms of this line such as, 'I want to go home' or, 'It's time to go home now' may, on the face of things, seem reasonable substitutes they overlook the important point that Eva is already, in this scene, speaking *to* someone who isn't there. By oversimplifying her words, viewers thus tend to misrepresent her from the outset.

One of Eva's longest passages of speech in the film (beginning '*Of course, silly...I remember everything*' and ending '*...time to go home now*') was mentioned by only one participant using reported speech and incomplete wording. Other participants occasionally made reference Eva saying again, at this point in the film, that she wanted to go home, but without further contextualisation in terms of Jacob's failure to understand which home she is talking about. A revealing section of dialogue related to Eva's avoidance of the ghetto takes place between Eva and Martin near the end of the film.

Eva: *Yes, that's right, you'll help me won't you?*

Martin: *That's right*

Eva: *You'll help me with my papers – they're at home waiting for me. And I'll help you. You can do anything you want with me. Anything you want – right here – right now.*

Martin: *I...um...everything is in order*

Eva: *I.....thank you.*

There is undeniably some ambiguity in the scripted line relating to Eva's papers, and some viewers have assumed that it is the papers, rather than Eva's family, that are 'at home waiting' for her. This aside, it is notable that only four students make any explicit reference to this interchange between Eva and Martin, and only one quotes the words 'You can do anything you like with me' verbatim. Eva's demeanour at this

point in the film is that of a practiced seductress; her interchange with Martin is described in the script as ‘a ploy’. It appears, however, that there is a tendency to censor Eva’s direct (in both senses) speech in favour of a more euphemistic version in which she is merely seeking comfort and reassurance from Martin.

Lack of attention to what is said by Eva and other characters in the film led some participants to assume that Eva had been in the Warsaw ghetto; that she was transported to a concentration camp; and that she was subjected to sexual abuse or rape there. By contrast, the evidence in the film suggests that Eva relied on her feminine wiles and non-Jewish appearance to obtain papers under a false identity which allowed her freedom of movement, but resulted in constant anxiety every time her papers needed to be checked by someone in authority. Helena’s comment to the visitor, ‘*Mum made it through Warsaw - managed to avoid the ghetto somehow,*’ underpins this version of events, but this is another line that is not quoted directly by any of the participants.

### **Discussion: conformist psychology and person-centred dementia care**

It seems important to reiterate, at this point, that I do not intend my analysis to imply that students did not complete this assignment ‘properly’. On the contrary, they almost all followed the guidelines provided closely and conscientiously. In attempting to trace the source of the consistent ‘symptomatic’ tendencies discussed above it is possible, then, to advance a number of explanations. The first possibility is that the film itself has influenced viewers’ reactions. Much of the righteous indignation expressed on Eva’s behalf can, perhaps, be explained in terms of the film’s camerawork; the cinematic insistence on the Levinasian face-to-face encounter with Eva which forces attention on her in order to make someone who is usually socially invisible the centre of attention (see illustration on following page). As mentioned in chapter 4, this effect is further intensified by the lack of point of view shots. Not only do we never see things from Eva’s perspective, nor do we see them from the standpoint of any of the other characters. In the process, viewers perhaps become so over-sensitised to Eva’s experiences that they are less aware of the perspective of other characters.

From *Ex Memoria*: The Levinasian 'face-to-face'



As a reviewer comments

*We see very little of other people...around Eva because the film makes the viewer concentrate solely on Eva's face*

This filmic technique may well, then, have had the effect of putting Eva and her experiences under something of a magnifying glass. Whilst *Ex Memoria* may have provided a particularly fertile territory for the application of Kitwood's concept of malignant social psychology, I would argue, however, that the extent to which the film itself can be held to account for the characteristic tendencies of the assignments discussed above is limited. This is for three main reasons; first similar traits were already present in assignments based on self-selected incidents prior to the introduction of the film. It seems possible, moreover, that these characteristics have merely become more visible as a result of the use of film, rather than being the result of the film itself. It seems likely, for example, that instances of personal detraction have always been over-identified by students completing this module. In previous assignments based on self-selected incidents it would, however, have been impossible to check whether this was the case or not. Finally, to the extent that *Ex Memoria* may have contributed to these tendencies, this is only in its filmic reiteration of some aspects of the psycho-social model already present in the module content; for example, the dyadic relationship with Eva; the camera's positioning of her in a passive role and the, perhaps inevitable in film, privileging of the visual over speech.

*The theological origins of humanistic psychology*

In terms of its camerawork, at least, *Ex Memoria* may be considered to have features in common with Kitwood's person-centred approach; specifically in its creation of a dyadic but unequal relationship between carer and cared-for, observer and observed. The 'Levinasian' face-to-face encounter in *Ex Memoria* takes the film's message into the idealist domain of ethics and away from the historical and political themes related to the return of Eva's troubled past. 'Levinas' enterprise serves to remind us with extraordinary insistence' Badiou (2001: 22) says, 'that every effort to turn ethics into a principle of thought and action is essentially religious...ethics is a category of pious discourse' (Badiou 2001: 22). Clearly the film is also, however, capable of a deeper

materialist, socio-historical reading which offers a more complex view of Eva's character. Verbal clues to her story *are* provided if viewers are motivated to look for them and consider them significant. What seems likely is that a key obstacle in the path of this deeper reading has been the content of the *Social Psychology* module and its underpinning philosophy. Assessment-focused students are attempting to show that they can 'do' person-centred care, by constructing the fictional care home as a hotbed of 'malignant social psychology' and Eva as a cowed victim of its uncaring staff.

So, I would argue, it is not merely the film's *syuzhet* and style that contribute to participants' construction of a *fabula* but the lens of the psycho-social model through which the film is being viewed. Viewers, their minds 'filled with presuppositions' (Geertz 1983: 84) about ill-being related to malignant social psychology, reach the expected 'common sense' conclusions. Eva is thus characterised as a needy, blameless and homogenised 'person with dementia', typical of those presented in Kitwood's fictionalised case examples. The relationship of the more powerful other to the person with dementia is taken as read: the other has the power to bestow personhood or withhold it. The person with dementia brings nothing to the interaction and is merely 'vulnerable to the vicissitudes of others' (Nolan et al, 2002: 209). This notion of the dyadic relationship between carer and cared-for stands also as a model of society in which people's 'rights' are given to them as an act of philanthropy on condition that they accept their own subjectification; that they 'know their place'. History would suggest, to the contrary, that human rights are never guaranteed, but have always had to be prised from the hand of power.

As Baldwin et al (2007) have argued recently, close engagement with Kitwood's work suggests that his model of personhood in dementia is derived ultimately from theological rather than psycho-social concepts. His concept of personhood as a status granted by one person to another within a dyadic interpersonal exchange is explicitly drawn from the work of the Austrian theologian and philosopher Martin Buber (1922). Both Buber and Levinas saw the essence of human existence, or 'true meeting', as something to be found in the encounter between Self and Other. For both, moreover, the Other is fundamentally of value as a transcendental entity which bears the stamp of divine creation. That is to say, we meet God through our relationships with others. The extension of this concept into areas beyond theology is evidenced by the major

influence Buber's work had on the development of post-Freudian humanistic psychology in the US. What may appear to be a radical argument in theology – the idea that all human beings are a route to an encounter with the divine – leads in Jacoby's view to a psychology which is merely 'spiritualised'; which 'confuses psychic first aid with liberation' and in which 'the human community shrinks to the immediacy of the I/You encounter...abstracted from historical and social reality' (1975, 1996: 146-150). As with Kitwood's abstract 'person with dementia', conformist psychology is also, Jacoby argues, given to making pronouncements about abstract 'man' without ever arriving at an engagement with really existing people in their social, cultural and historical specificity.

### *The post-War reconstruction of psychoanalytic theory*

Central to the argument of Jacoby's text *Social Amnesia*, is the historical rift in the psychoanalytic movement which had already begun before Freud's death in 1939, and became increasingly apparent in the post-WWII period. Members of the Frankfurt School, including Marcuse, Adorno and Horkheimer remained faithful to Freud's view of psychoanalysis as a critical theory of society. Their theoretical work in the post-War period was, moreover, largely concerned to prevent any repetition of the Holocaust. Adherents of the American post-war humanistic movement, such as Adler, Erikson and Rogers, by contrast, put increasing emphasis on psychoanalysis as a form of therapy intended to bring about adaptation of the individual ego to the prevailing norms of society. In the spirit of the American dream, their focus was on progress toward a future society consisting of 'normal', healthy, well-adapted individuals.

One of the key themes of Jacoby's work on social amnesia (1975: 1996) is society's inability to learn from history. Jacoby (1996: 3-4) refers to the societal denial, or wilful repression, of things that are already known – the 'memory driven out of mind by the social and economic dynamic of this society...the impatience to hustle through the past as if it were the junkyard of wrecked ideas'. Jacoby views social amnesia as a 'general syndrome...Society [ie the industrialised countries of Western Europe and North America] has lost its memory... the inability or refusal to think *back*, takes its toll on the ability to think'. Although Jacoby sees social amnesia as a general trait in society, his text is largely concerned to provide what he terms 'a critique of

conformist psychology': predominantly the humanistic psychology which came increasingly to replace psychoanalytic theory in post-WWII America.

The module *The Social Psychology of Dementia Care*, within which *Ex Memoria* was incorporated, explicitly locates the theoretical background of the person-centred approach in humanistic psychology. One of the key terms introduced in the module is 'unconditional positive regard' (Rogers 1951). Emphasis on this concept as a central tenet of person-centred care may have led students to feel that in order to demonstrate their own person-centredness they should display unconditional positive regard towards Eva at all times, even if this involves writing about her in a way which pays little attention to her actions and words as they are represented in the film. As Masson (1990) points out, the requirement for unconditional positive regard is at odds with another claimed cornerstone of humanistic psychotherapy, congruence (or genuineness).

In fact the therapist is not a real person with the client, for if he were, he would have the same reactions he would have with people in real life which certainly do not include 'unconditional acceptance', lack of judging or real empathic understanding. No real person does any of the things Rogers prescribes in real life (Masson, 1990: 232).

Humanistic psychology thus offers a set of moral ideals, rather than insights into the actions and decisions of real people in real situations. Clinically, as Masson notes, humanistic psychotherapy is provided in sessions of less than an hour, perhaps once a week, by highly trained therapists. Kitwood promoted this as an approach that should be used by hard-pressed careworkers throughout the whole of the time they are on duty. If, at any point, a caregiver has 'the same reaction s/he would have with people in real life', this constitutes a personal detraction and evidence of a 'malignant social psychology' in the microcosm of the care setting.

Jacoby is protesting, in *Social Amnesia*, against the poststructuralist notion of the end of the 'grand narratives', and particularly the demise of Marxist and Freudian thought. He also draws attention, however, to the revisionism that was required in order for the original work of Marx and Freud to be rendered obsolete. Their ideas had first to be diluted, misrepresented and vulgarised by way of 'neo-' and 'post-' reconstructions.

Over time, Jacoby suggests, this enabled the original work to be forgotten in favour of social conformism and what he describes as the ‘monotonous rediscovery of commonsense’ (1975: 11). The extreme irony for Jacoby is that, in this process, Freud’s theory of repression was, itself, repressed. The relegation to the unconscious of memories which are too painful to deal with, as the result of a constant battle between the anarchic id and the controlling superego, was re-enacted at a societal level. Psychoanalytic theory was repressed in favour of humanistic ego-psychology and its one-dimensional view of the human psyche.

In support of his argument that the Frankfurt School represents the true line of descent, Jacoby quotes Freud as follows, ‘Not in any beyond, but here on earth most men live in a hell...My knowledge, my theories and my methods have the goal of making men conscious of this hell so that they can free themselves from it’ (Jacoby, 1975: 1996: 119). Humanistic psychology, by contrast, denied that traumatic experience was a cause of human suffering. For example, Adler (1927) perhaps the earliest of the Freud revisionists, asserted that ‘so-called trauma’ had nothing to do with human success or failure. Instead, he argued, we can choose to make out of our experiences, no matter how grim they may be, whatever suits our purposes.

Although Kitwood taught a final year undergraduate option module on the history of psychoanalytic theory for many years and was thoroughly familiar with these debates he did not, at any point, apply the psychodynamic concepts of unconscious mental life or repressed memory to people with dementia. In his discussion of the responses of care staff to people with dementia, moreover, Kitwood frequently employs the Adlerian concepts of ego defence and adjustment to suggest that those who care for people with dementia often enter into a kind of collusive avoidance because of their own unacknowledged fears and anxieties.

The highly defensive tactic is to turn those who have dementia into a different species, not persons in the full sense. The *principal problem*, then, is not that of changing people with dementia, or of ‘managing’ their behaviour; it is that of *moving beyond our own anxieties and defences, so that true meeting can occur, and life-giving relationships can grow* (1997a: 14, emphasis added).

For Jacoby, social amnesia leads inexorably to the decline of theory in favour of the kind of quick-fix pragmatism, concern with immediate reforms and gains, and ‘happy-go-lucky ethos’ that are evident in this extract from Kitwood.

In order to be accepted into the new US reformulation of psychoanalytic theory, European existentialism had, Jacoby says, to be

*...cleansed and sterilized of its European accents so as to be fit for human consumption... Whatever truth there is to the clichés that European existentialism was spurred by the death camps and resistance to fascism... is too much truth for its American representatives; they want an existentialism that poses no threats to their optimism and good cheer (1975: 52 emphasis added)*

Jacoby’s use of language is interesting here, in that it draws attention to the ongoing stigma that attached to those who had been persecuted and labelled as degenerate or unclean in some way. Frosh (2008) notes that although Freud believed the origins of psychoanalytic theory to lie firmly in Jewish history and culture, many of its later Jewish proponents, subjected to anti-Semitism or ‘culturally compromised’ in various ways, now attempted to assimilate not just themselves, but the theory itself. Indeed some, including Adler, converted to Christianity. The theoretical outcome, according to Jacoby, is a psychology which is uninterested in either its own or society’s history, and in which society is reduced to a series of dyadic interpersonal encounters isolated from any material, social or historical context.

Although the connections are very apparent, Kitwood’s work does not draw parallels between people with dementia and other marginalised and excluded groups.

Whiteford (2000) for example, refers to the experiences of prisoners and refugees as being one of occupational deprivation and social exclusion

lack of time spent engaged in meaningful occupation in the prison setting appeared detrimental to health and well-being... With few occupations except eating to provide structure and punctuate the day, and with little variation in time use patterns between days of the week and months of the year, they reported feeling ‘adrift’ in an undifferentiated sea of time (Whiteford, 2000: 203).

The experience of these prisoners, as described by Whiteford, is strikingly similar to that of many people with dementia in formal care settings. Whiteford also quotes Boua Xa Moua (1998) a Laotian refugee relocated to America

...whenever you want to go anywhere, all the time, you have to wait for someone, I mean if they don't come you can't go where you want...I would like to go back now. It's much nicer and peaceful back home. Here everything feels too lonely. Everything is too much. I always find myself lost in this world. (Boua Xa Moua, 1998: 101)

These words could easily be spoken by Eva in the care home, and by many people with dementia who are often subjected to frequent moves – from home to hospital, residential to nursing care - and then have to try to start again in a world where everything is strange. Whiteford recognises the importance of allowing people in marginalised and socially excluded groups to speak for themselves. By contrast, people with dementia are often 'spoken for' in Kitwood's work, through the medium of 'vignettes' (hypothetical case material) and fictionalised examples. His main text *Dementia Reconsidered* (1997) includes two lengthy passages in which he attempts to describe the contrasting experiences of 'unattended dementia' and 'person-centred care' from the viewpoint of the person with dementia. In unattended dementia, he suggests, in this brief extract

...you are left in chaos, carrying the terrible sense of a loss that can never be made good. Once you were a person who counted; now you are nothing and good for nothing. A sense of oppression hangs over you, intensifying at times into naked terror; its meaning is that you might be abandoned for ever, left to rot and disintegrate into unbeing. (Kitwood, 1997a: 77)

When person-centred care is provided, Kitwood suggests, the subjective experience of dementia is dramatically different

...you see that kind mother-person, already there, sitting beside you. Her hand is held out towards you, waiting for you to grasp it. As you talk together the fear evaporates like the morning mist, and you are again in the garden, relaxing in the golden warmth of the sun. You know it isn't heaven itself, but sometimes it feels as if it might be halfway there (Kitwood, 1997a: 85)

In Kitwood's view, the best-obtainable – halfway to heaven – condition for people is manifested through signs of well-being which include assertiveness; social sensitivity;

creative self-expression; helpfulness; affection; and self-respect . Assertiveness, it should be noted is defined in this context as ‘being able to express wishes in an *acceptable* way’ (Kitwood, 1992). A mainstream dictionary, by contrast, defines assertiveness as ‘insistence; confidence; ability to defend one’s rights and opinions, sometimes with unnecessary zeal’ (Concise English Dictionary, 1988: 56).

Harding and Palfrey (1997: 64) suggests that Kitwood’s signs of well-being are ‘remarkable for their neutrality or attractiveness’. People who exhibit such traits would seem indeed to have reached the ideal of humanistic psychotherapy in terms of their ego-adjustment. In the process however ageing and the experience of dementia are depoliticized. There is a danger here of reinforcing stereotypical views of the ‘well-adapted’, compliant older person as one who is without embodied passion, desire, or legitimate hostility in the face of authority. Anger, resistance, restlessness and sexual disinhibition are seen by Kitwood as signs of ill-being, rather than of legitimate self-expression.

Kitwood’s ‘new culture of dementia care’ may in fact have a very long history indeed. Foucault (1967) in his critique of the 19th century ‘liberation’ of the insane by the Quaker reformer Samuel Tuke, points out that as evidence of a ‘return to reason’, Tuke required social conformity, helpfulness, industriousness and docility on the part of his patients; traits which sound remarkably similar to those signs of enhanced well-being that Kitwood took as evidence of ‘re-mentia’. Tuke cited the behaviour of inmates at the tea-parties he held at his model asylum in York, The Retreat, as evidence for the effectiveness of his liberal humanist approach. The insane were, he claimed, ‘returned to reason’ by means of their ‘moral re-education’

The evening generally passes with the greatest harmony and enjoyment. It rarely happens that any unpleasant circumstance occurs; the patients control, to a wonderful degree, their different propensities, and the scene is at once curious and affectingly gratifying (Tuke 1813, quoted in Foucault 1967: 249)

This compares interestingly with a description of ‘extreme well-being’ in dementia from Kitwood (1992)

There has been a session of singing, with accompaniment from the piano. Now the pianist is tired. Mrs D stands up and sings an old Irish song in a trembling voice but almost perfectly in tune, and with great depth of feeling. At the end tears are running down her cheeks (Kitwood 1992: 141).

Single examples such as this one can obviously be taken out of context, but we would search Kitwood’s work in vain for any instance of well-being attributed to an Irish woman who stood up in a public gathering to berate the British monarchy, swear at the pianist for his conventional range of music, and demand a rousing chorus of rebel songs. This, I would suggest, provides a large part of the explanation for the somewhat conventionalised and conformist renditions of Eva’s history and character in students’ assignments based on *Ex Memoria*.

In the next chapter, I move on from discussion of my analysis of the data from these assignments to a consideration of social amnesia in the broader historical context of the lived experience of people who are now in the highest risk age groups for dementia, and its social and psychological impact.

## Chapter 7) Social amnesia, retrospective trauma and the ghettoization of dementia

EVA: Of course, silly...I remember *everything*...

(from the script of *Ex Memoria*)

The impact of the traumatic event lies precisely in its belatedness, in its refusal to be simply located, in its insistent appearance outside the boundaries of any single place or time.

(Caruth, 1995: 9)

The tradition of the oppressed teaches us that the 'state of emergency' in which we live is not the exception but the rule. We must attain to a conception of history that is in keeping with this insight....The current amazement that the things we are experiencing are 'still' possible in the twentieth century is not philosophical. This amazement is not the beginning of knowledge, unless it is the knowledge that the view of history which gives rise to it is untenable.

(Benjamin, 1940: 248-249)

### Introduction

At the end of the previous chapter, I outlined Jacoby's theory of the connection between social amnesia and conformist psychology (Jacoby 1975: 1996). During this study I have come to believe that the concept of social amnesia adds an important dimension to dementia studies for several reasons, which I will summarise here before developing my argument further. First, it requires a recognition that the person-centred approach to dementia care tends towards conformist rather than critical thinking. Although Kitwood's psychosocial model is undoubtedly a significant move away from the biomedical model of dementia, it cannot continue indefinitely to be regarded as radical or innovative. From the perspective of social amnesia, the 'disorder of forgetting' is located in society, rather than the individual brain. A historical dimension is added which opens up the possibility of new hermeneutic approaches such as the concept of retrospective trauma discussed later in this chapter. Jacoby also suggests that the erosion of links between past and present, the increasing

tendency to mistake novelty for progress, means that the lessons of the past are not learned; history repeats itself, albeit in changed circumstances.

This chapter also picks up on several themes introduced at the end of chapter 4, where I wrote about the turning point that I reached when trying to analyse the primary data for this study. In this chapter I want to pursue several of the lines of flight (Deleuze and Guattari, 1987) that opened up during the six months or so that I was struggling with my analysis of this data. At the point where the initial action research project became insufficient to *narrate* the action, I turned to an approach more allied to grounded theory. Glaser (1998) points out that in grounded theory everything is regarded as data, and literature is accessed as it becomes relevant; it is not given special treatment.

As often happens when we are intensely immersed in something, I found I kept coming across examples, similar to Eva's, of traumatic experience returning in the context of dementia. Many were anecdotal – picked up through personal correspondence, at conferences and in newspaper articles. These were 'lucky finds' – the kind of chance juxtapositions that Benjamin (1929) considered the source of 'profane illumination'. By following these threads, I came across other bodies of literature which have informed this chapter. These are of three main types: academic studies on historical trauma, largely related to Holocaust survival; practice literature on survivors who are now in care homes, and research studies on post traumatic stress disorder (PTSD) and dementia.

A number of themes that had originally been marginal now became insistently recurring ones: the centrality of wartime experience in the lives of people who now have dementia; the frequency with which dementia appears to lead to a reactivation of repressed, traumatic memories, and the analogies between the ghettos, the 'concentrationary universe'<sup>1</sup> and the situation of people with dementia today.

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<sup>1</sup> The term concentrationary universe or *univers concentrationnaire* is attributed to the communist member of the French resistance, David Rousset, who used it in his testimony of life in a concentration camp, *Les jours de notre mort* (1946). The term refers to a world beyond the bounds of normality where concentrationees are "set apart from the rest of the world by an experience impossible to communicate".

My focus in this chapter therefore shifts from close-up to wide screen; from Eva's story as a specific case, to the lived experience of those people born in the first half of the 20th century (and predominantly during the inter-war years) who now belong to the main 'at risk' generations for dementia. This is a vast subject area and one that I can only attempt to illustrate here by means of examples.

## **Historical trauma**

LaCapra (2001: ix) writes of trauma related to major historical events that

this problem has become crucial in modern thought in general, and is especially prominent in post-World War II thought bearing on the present and the foreseeable future. Trauma and its symptomatic aftermath pose particularly acute problems for historical representation and understanding.

Academic studies of historical trauma in recent years have tended to centre on the Holocaust as their subject area, and to take a specifically Jewish perspective on its survival and aftermath (eg Rothberg 2000; LaCapra, 2001). Holocaust studies is currently a growing area and one which has much to offer in understanding the social processes of remembering and forgetting, and the censoring of testimony which are also relevant to the study of dementia. I have thus drawn on heavily on these studies for theoretical insights.

At the same time, it seems important to note that such studies are, essentially, studies of the Shoah, rather than of the Holocaust as more broadly defined (see footnote p 7). Critical analysis of the Nazi campaign to exterminate European Jewry is vital for the understanding of everyone in the post-War world, and I would not want any part of the argument that follows to suggest that I think this is a subject that has been given too much attention. On the contrary, I have found it striking that the concept of historical trauma *has not* been employed to anything like the same extent in relation to those sub-groups of concentrationees who were also labelled as 'degenerate': communists, trade unionists, gypsies, gay men and the mentally ill or handicapped.

Moreover, the full extent of traumatic wartime experience among combatants, refugees, civilians and evacuees seems not to have been extensively theorised to date.

Beyond this again are the more private and individual experiences of domestic or institutional violence and abuse, which might also be considered 'historical' to some extent. Corporal punishment in schools was, for example, an everyday occurrence in the childhood of people who are now in their 80s and 90s. Over the following decades it then came, gradually and uneasily, to be seen first as a practice whose educational benefits were questionable, and then as possible assault. Corporal punishment in UK schools was not finally abolished until 1987, and then only after several rulings by the European Court of Human Rights. Society's ambivalence about the discipline of children still, however, seems to prevent full recognition of the impact of the violent physical assaults meted out in schools for so long and with public approval.

To map out the whole conceptual field of historical trauma in relation to the war years, it may be helpful to begin by thinking of a series of concentric circles, in which the Shoah lies at the centre, with the Holocaust, World War, and civilian life radiating outwards in successive circles. I will thus begin by outlining some real life examples which parallel Eva's story in *Ex Memoria*, before going on to consider the broader contexts of historical trauma.

#### *Jewish experience of the Shoah and late-life dementia*

The central significance of remembering in Judaic culture makes dementia a particularly poignant condition for observant Jews. As Rothberg (2000: 193) points out, a slogan often applied to the Nazi genocide by the Jewish diaspora is 'You must not forget anything'. This, together with the broader cultural imperative to 'Remember everything accurately' through holidays and festivals that are all connected in some way with memorialisation, perhaps gives point to Eva's statement in *Ex Memoria*, 'Of course, silly...I remember *everything*'. There is a double irony, here, however, in that Eva does, in fact, remember things her family never knew, have forgotten, or would prefer not to know.

Cook et al (2003) note that many aspects of the environment may act as reminders of traumatic experiences, including television news coverage of violent events, the sound of other people in distress, and loud noises. 'For women who have experienced

captivity or violent assault, the presence of unfamiliar men or physical contact by male health professionals may bring up unresolved trauma-related distress' (Cook et al, 2003: 1223). David (2003) similarly notes that aspects of dementia care provision may trigger memories of Holocaust experience for Jewish elders, including being asked to take a shower, medical procedures or dental treatment, the use of identification tags or badges, and harsh or unpleasant smells. An Australian TV documentary (ABC TV 22.10.06) reported that 50 percent of the 35000 Holocaust survivors now living in Australia are believed to have dementia. The documentary told the story of Tonia, a woman with dementia, who had survived a concentration camp and then experienced progressive moves from her own home to a hostel, to permanent nursing care, to a dementia unit, and finally to special care, with every move leading to parallel memory of wartime displacement and dispossession.

Wong (2003) relates the case of a woman with dementia in a Canadian home for Jewish elders whose year-old daughter starved to death in the Kaunas ghetto, following the German invasion of Lithuania in 1941. She herself was assigned to a forced labour gang. Apart from one brother, every member of her family died. At the age of 88 she was diagnosed with dementia. 'After all the losses she has suffered, the burning question for her is one of life or death. And so she asks, over and over again, if her brothers and sisters and cousins are alive' Wong (2003: 3). In this context repetitive questioning, can be seen to have a precise historical, as well as psychic, origin. It is not merely a request for attention or reassurance, but the return of repressed anxieties related to wartime deaths and disappearances, as the cognitive control which previously held them out of conscious awareness gives way.

This 'unlocking' of long-term memories in dementia can lead to painful events being spoken about for the first time, often in ways that are shocking to caregivers or other members of the family. Seidler (2007: 149), for example, recalls that for years his mother had told him that her sister died from an illness. Now, diagnosed with dementia, she was ready to acknowledge that her sister 'had been badly beaten up by Nazi guards on the street. She was never to recover...My mother could no longer hold the untruths that she had constructed for herself and the family, but somehow had to face the pain of what had happened'.

*Coming of age in the era of global warfare*

...coal and politics, invisible decades  
Of rain, domestic love and failing mills  
That ended in a war and then a war...

(O'Brien 1983. *The park by the railway*)

The direct death toll of World War II, whilst still impossible to calculate accurately, is currently believed to be in the region of 72 million people worldwide. Total casualties are estimated at 1,962 million. If we also factor in, as survivors of historical trauma, the civilian relatives of the dead and disabled, this takes us to around 10,000 million people. The current tendency to reduce War to Holocaust and Holocaust to Shoah, has perhaps then, much to do with the still unacknowledged damage to the collective psyche of all the nations involved. On the side of the Allied nations there seems still to be, in popular and cultural memory, a sense that WWII was something of a 'Boy's Own' adventure; a victorious battle between good and evil. We may know, roughly, the chronological order of events; but we don't want to muddy the black and white distinction between 'right' and 'wrong' sides by looking too closely at events that have been marginalised or conveniently forgotten. It is rather as though the shadows by which we recognise the past today are the wrong shape to fit what actually happened.

It was, no doubt, impossible for anyone living through events as cataclysmic as those of WWII to conceptualise their significance at the time. More than 60 years later, however, this still seems to be a process that society as a whole has not worked through. The post-Holocaust world summed up by Adorno (1973) in his phrase '*nach Auschwitz*' is not the world after a particular extermination camp, but the historical impasse that Auschwitz symbolises for the rest of the world. The world after Auschwitz is one in which all theorising about what it means to be human requires a radical reassessment, one that that by and large has still not happened.

Schefer (1995: 141-2) writes of growing up in wartime France as a form of 'mnemonic damage'

a primal consciousness of an era of planetary destruction which has lodged a soul within us like a bullet or piece of shrapnel that hit us and, by chance, reached a centre where it could live on after having done no more damage than destroy a town or kill someone other than us.

This ‘mnemonic damage’ seems among other things to have led to the societal repression of instances of extreme and widespread trauma during WWII which, whilst not falling within the definitions of either Holocaust or Shoah, involved similar extremities of experience. For example, 700,000 Russian civilians survived the siege of Leningrad, during which 1.2 million of their compatriots died from cold, starvation and disease in a period of only 18 months. If not all Holocaust survivors are Jewish, nor were all concentration camps presided over by Germans. Under the Nazi-Soviet pact, 1.5 million non-Jewish Poles were sent to gulags (forced labour camps) in the Soviet Union, something that has been almost erased from history following the Stalinist regime’s shift to the side of the Allies in 1941. Following the bombing of Pearl Harbour in 1942, more than 100,000 Japanese-Americans had their property seized and were interned in ten concentration camps on the US West Coast until the end of the war (Kashima, 1980). This has been a matter of official silence in the intervening years. Only ten years ago, Feeley pointed out that there were just two published texts on the subject (1998: 69). Kashima notes that for the detainees themselves in later life, ‘the camp experience simply didn’t exist – but was totally banished as it were to the darker recesses of their consciousness’ (1980: 114).

The ‘unspeakability’ of war-time trauma, for many, has not just been a result of the freezing of affect believed to accompany such experiences, and discussed further below, but also the societal taboo on disclosure of experiences which do not conform to the ‘institutional underpinnings of the social order’ and which thus ‘[feed] into overriding forms of collective fear and anxiety’ (Neal, 1998). The still prevailing myth is that WWII was a ‘clean’ war ‘where people died intact and quickly; where the injured overcame their disabilities; where cheerful, patriotic wives and sweethearts waited patiently and faithfully back home’ (Bender, 1997: 343). One result, as Bender points out is that subsequent generations have absorbed the ‘highly sanitised and stereotyped version of the War...regularly presented in various media – novels,

radio, and most especially the dominant forms of film and television' (1997: 345). The permitted, sanitised discourses of war have been perpetuated through filmic representations of various kinds: discourses of patriotic stoicism (Pathé newsreels), selfless heroism (*The Great Escape*) and, more recently, humour (*Dad's Army*; 'Allo 'Allo).

The reality, by comparison with this publicly sanctioned myth, is that there is no convenient 'episodic' start and end point for the wars of the 20th century, or for the traumatic experiences associated with them. Bender (1997) points out that those who were actively involved in WWII had often been brought up by parents and grandparents who were still grieving for relatives lost in the First World War. Bender suggests that 'the damage to the older generation caused by the First World War, and the limited communication during the Second, increased the psychological toxicity of the events being experienced' (1997: 344). Unlike Kitwood, who located 'malignant social psychology' within the interpersonal milieu, Bender here locates 'psychological toxicity' in national and social history.

The toxicity of the first half of the 20th century is, moreover, intensified even further when we consider that between the two World Wars came a depression which brought mass unemployment, poverty and ill-health. Board of Education studies for these years show that in some of the worst affected areas children were found wearing clothes 'that often fail to afford adequate protection and to maintain the self respect of the children...the meagre income upon which the families live cannot run to the purchase of both food and clothing' (Eichholz et al, 1928). For many families, it could not run to either. On Tyneside, as late as 1936, over 30% of schoolchildren were assessed as malnourished, a figure which rose to over 70% in some areas of the Welsh coalfields (British Association for Labour Legislation, 1938; Pearse et al, 1936). (See also Molly's story in Chapter 8).

The social movements and displacement of populations that took place during the war years also had their aftermath for later generations. Some stories, such as those of the *Kindertransport* and evacuation within mainland Britain are relatively well-known; others have received less attention. It is estimated, for example, that by the end of WWII, in spite of the extreme sanctions that were taken against collaborators, there

were 200,000 children in France who had German fathers (Gildea et al, 2007). In June 1940, the entire child population of Guernsey aged 3 to 14 years was evacuated within the space of a week, due to fears of a German invasion following the surrender of Paris. When these children returned home in 1945, having spent the intervening years in mainland children's homes or boarding schools, many of them had difficulty even in recognising their own parents, let alone readjusting to family life (Smith 2005, unpublished PhD thesis). These two small examples indicate the many ways in which the ripples from these mid-20th century events continue to spread outward into the future, whilst having barely ever been acknowledged at a societal level.

### **Dementia, retrospective trauma and Post Traumatic Stress Disorder (PTSD)**

Current estimates suggest that at least two-thirds of people with dementia are over 80 (Knapp et al 2007), and will thus have lived through the war years as children or young adults. When we consider the full range of situations which meet the standard definition of trauma, there is an increased likelihood that any older person with dementia may have been exposed to one or more of them. Hunt (1997) outlines five types of traumatic situation, and it has been suggested (Breslau et al, 1991; Norris, 1992) that between 40 and 70 percent of the population have experienced at least one of them.

1. Subjection to, or subjecting others to, bombing and other forms of attack or torture, in war, or within repressive political regimes
2. Acts of terrorism which aim to influence organisations or governments but which are directed against individuals or groups. These include hostage taking, and the explosion of bombs.
3. Personal attacks directed at individuals such as rape, and sexual or other forms of violence, within families and on the street.
4. 'Man-made' disasters [such as chemical explosions or ships sinking]
5. Natural disasters [such as earthquakes or floods]

(Hunt 1997: 4)

Central to my argument in this thesis, is that there is a point at which the past and present day experiences of people with dementia converge; that past experience is activated or reactivated because the person is reminded of the past by something in the present day. Miesen and Jones (1997: 152) note that in some people with dementia their experience of the onset of the condition

reactivates unresolved pain (stemming from past trauma), be this having survived the Japanese concentration camps; or having lost a future (Jewish) husband who was first hiding and later murdered; or having participated in the underground Resistance; or in hiding Jewish children during the war; or to have [sic] been ‘kidnapped’ as an adolescent girl to work hundreds of miles away from home in the war industry of the occupying army and never returning home; or...to have survived physical, sexual and emotional abuse within the family.

To take one example, *The Guardian* (9.6.07) carried a story about Wanda, a Polish Catholic living in Britain, who developed dementia in her 80s, and became convinced that the police would arrive at any time to deport her. At the age of 16 she had joined the Polish Resistance after her father was killed by a sniper. Her job then for several months – along with other children some of whom were as young as nine – was to carry messages through the sewers of Warsaw. Nicknamed Myszka (the Mouse) because of her smallness, she was eventually captured and sent to a number of concentration camps culminating in Bergen-Belsen.

After the liberation, Wanda lied about her age to avoid being taken to a refugee camp and was sent instead to a cousin in London. Here she married, and for many years seemed unaffected by the events she had experienced and witnessed. With the onset of dementia, however, she reverted to speaking only in Polish. She often mistook her husband for a camp guard, and believed that hostile, staring children came into her room. From the standpoint of the biomedical model of dementia, such phenomena are passed off merely as paranoid delusions resulting from neuropathology. From the viewpoint of the psychosocial model, Wanda might be seen as someone whose individual hardships had depleted her ability to cope with the additional challenges of memory impairment. From a socio-historical perspective - as Mackenzie (2007) has pointed out - Polish refugees escaped an occupying force which was blatant in its zeal for exterminating the entire population of Poland, only to be subjected to further discrimination and social exclusion on their arrival in this country. Present day media

reporting on asylum seekers frequently involves calls for their deportation, and it is more than likely that Wanda would have heard TV news reports about deportations or campaigns to deport people. It might be argued on this basis, that in perceiving history as having turned full circle, Wanda is less deceived than we are ourselves when we are persuaded to think of it in terms of unidirectional, linear progress.

*Nachträglichkeit: retrospective or diachronic trauma in dementia*

In response to stories like Wanda's, it is interesting to consider the phenomenon that Freud described as *nachträglichkeit*<sup>2</sup>, a retrospective or 'diachronic' trauma in which 'events of the past repeat themselves but are simultaneously restructured from the perspective of the present' (Rothberg 2000: 79). In critiques of Freud's work there is some debate between those who believe that retrospective trauma results from inability to understand the event at the time it first happened, and those who believe that it is the inability to *articulate* what has happened - its 'unspeakability' (Thoma and Cheshire, 1991). De Levita (1997: 97-98) points out that 'diachronic trauma is not a new trauma, but a traumatic reaction from an earlier date which at long last finds words to express itself – words which can convey the impact of something not previously experienced in this way'.

What seems centrally important, in Freud's conception of retrospective trauma, is that the initial experience need not at the time have been experienced as traumatic. The 'pathology' thus 'cannot be defined...by the event itself – which may or may not be catastrophic, and may not traumatize everyone equally' (Caruth 1995: 4). It is, rather, the later recognition of the 'real' nature of the event, by means of some form of repetition, or 'with hindsight' revelation, that brings past and present together in a new form of awareness.

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<sup>2</sup> Translated in the Standard Edition of Freud's work as 'deferred action', *nachtraglichkeit* is another German term that eludes exact translation; 'retrospective (or diachronic) trauma' seems closer to Freud's intention. In French it is translated as *après coup* or 'after shock'.

Coleman and Mills (1997) for example, report the case of a man with dementia, now living in a care home, who had been held in the Japanese prisoner of war camp at Changi, and was haunted by memories of the cruelty of his treatment there. 'As he told his stories of the camp, he occasionally screamed orders in Japanese. It was as if he relived those days, and heard once again the voices of those guards who had been in total control of his life. The progression of his illness appeared to have little effect on his memories' (1997: 171).

In dementia, I suggest, anything that has been experienced as traumatic in the past is likely to reappear in the form of retrospective trauma, and that even something non-traumatic, in the strict sense, can still be activated as trauma by association, because of its repetition 'out of time'. Perceptions of being back in a factory, or a barracks, or of having no food to give one's children, or needing to pay bills, can turn what may have previously appeared to be benign memories into malignant ones through a process of association. As discussed in chapter 3, such experiences also have much in common with Freud's notion of the uncanny; that is to say that, 'among the instances of frightening things there must be one class in which the frightening element can be shown to be something repressed which recurs. This class of frightening things would then constitute the uncanny; and it must be a matter of indifference whether what is uncanny was itself originally frightening or whether it carried some other affect' (Freud 1919 in Strachey 1953: 217).

#### *Post traumatic stress disorder (PTSD) and dementia: a review of research studies*

Post-traumatic stress disorder (PTSD) is the clinical term used today for symptoms of initial psychic numbing following a traumatic experience, followed by delayed intrusive recollection, and/or hyper-arousal. PTSD has only been recognised as a psychiatric disorder since 1980, but appears remarkably similar to the phenomenon Freud described as *nachträglichkeit*. As Caruth (1995: 5) notes, 'If PTSD must be understood as a pathological symptom, then it is not so much a symptom of the unconscious, as it is a symptom of history. The traumatized, we might say, carry an impossible history within them, or they become themselves the symptom of a history that they cannot entirely possess.'

Some form of the condition now known as PTSD has been recognised since at least the time of the American Civil War, when it was known as ‘soldier’s heart’ (Engel 2004). In the intervening years similar symptoms have variously been described as neurasthenia (or ‘shell shock’), combat fatigue, and combat stress. During World War II it was recognised that civilians, internees, and evacuees were at risk of developing similar symptoms in response to war-related traumatic events. PTSD is now also recognised to be a frequent consequence of rape, child sexual abuse (Cooper and Kristiansen 2004) and incest (Somer 2000). Often, however, recognition of psychological trauma related to war or natural disasters has been hampered by official denial of conditions that may be held to entitle large numbers of people to some form of compensation. A recent example is official denial of the existence of Gulf War Syndrome (Mather and Marsden 2004).

Kessler (1995) reported that 38.8% of males exposed to combat stress developed PTSD. Ursano and Benedeck’s (2003) report on a 40 year follow up of US servicemen who had been held in Pacific and Korean prisoner of war camps showed depressive symptoms and post-traumatic stress to be three to five times higher than in the general population. Some studies suggest that symptoms of PTSD that are present in the immediate aftermath of trauma diminish over time. For example, Kulka et al (1990) found that the prevalence of PTSD among Vietnam veterans was 30% in the year after the war and 15% 20 years later. It is, however, in the nature of PTSD that reminders of the original trauma are likely to trigger flashbacks, and a renewal of the original symptoms may occur many years after the original event.

As early as the 1970s a correlation between prisoner of war experience and the subsequent development of cognitive deficits was noted. This was attributed at the time to the physiological after effects of extreme weight loss (Thygesen et al 1970). Sutker et al (1990) found similar effects among prisoners of war from WWII and the Korean conflict. A number of more recent research studies suggest that the onset of dementia may unleash dormant PTSD (eg Mittal et al 2001; Van Achterberg et al 2001; Cook et al 2003). Studies have focused on Jewish Holocaust survivors (eg Grossman et al 2004; Yehuda et al 2004) and US and British veterans, particularly those who were prisoners of war (eg Johnston 2000; Orengo et al 2001).

In one of the earliest studies making a specific connection between PTSD and dementia, Johnston (2000) describes the cases of three World War II veterans who developed combat-related PTSD for the first time shortly *after* being diagnosed with dementia. Johnston comments that their ability to ‘function well’ in the immediate aftermath of war was probably due to the cognitive effort required to keep intrusive images under control. When their cognition began to deteriorate, Johnston suggests, these defences were lost and the images broke through. They began to have combat-related nightmares and to be hyper-reactive and anxious in any situation that involved war-associated stimuli. Other symptoms involved violent outbursts, tearfulness and a preoccupation with wartime experience that had not previously manifested itself.

Grossman et al (2004: 1) similarly report on two Holocaust survivors who appeared to ‘have adapted well, post-trauma’, but developed severe symptoms of PTSD following the onset of late life neurological illness. Yehuda et al (2004) found that Holocaust survivors diagnosed with PTSD showed marked deteriorations in memory with age. Verma et al (2001) report that former prisoners of war who had dementia and PTSD scored higher on assessment scales for ‘paranoia’ and lower on ‘verbal agitation’ than matched samples without combat-related trauma. It is always difficult to know whether findings such as these are artefacts of the rating scales used; however, one way of interpreting these findings is that the former PoWs showed more behavioural signs of fear and avoidance, whilst continuing to *talk less* about their anxieties.

In a significant paper, Cooper and Kristiansen (2004) suggest that symptoms of PTSD may often be overlooked in people with dementia, or, indeed, misdiagnosed *as* dementia. Their study involved 265 clinicians, half of whom were psychologists and half psychiatrists, responding to a paper-based case study. The findings indicated that in cases where the diagnostic criteria were ambiguous, clinicians were consistently more likely to diagnose dementia than PTSD. In conclusion, Cooper and Kristiansen (2004: 5) note that ‘clinicians need to recognize that aging may be a risk factor for onset of PTSD...stressful experiences that are often part of aging (eg loss of social supports, institutionalization) can result in a recapitulation of previous trauma and potentially lead to delayed onset PTSD or exacerbation of current PTSD symptoms’.

## **The ghettoisation of dementia: turning the screw of history**

I have argued in this chapter that all people who now have late-onset dementia lived through a period of history that much of society is now only able to admit into conscious awareness in a sanitised and mythologised form. I have also suggested that the concept of history as linear progress away from that period is a myth. Benjamin suggests that in order to see history stripped of the ideological myth of progress, we need to wake from a collective dream; from our usual somnolent acceptance of surface appearances (Cohen 1993: 5). Benjamin uses the concept of the ‘constellation’ to describe the bringing together in writing, of a montage of elements, so that the apparent continuum of history is disrupted. ‘It isn’t that the past casts its light on what is present, or that what is present casts its light on what is past; rather...the Then and the Now come together into a constellation like a flash of lightning’ (cited in Cohen, 1993: 10). For Benjamin a constellation undermines the ideology of progress, an ideology that in his own time failed to foresee or prevent the growth of Nazism<sup>3</sup>. My strong claim in this last part of the chapter is that there are many analogies between the anti-Semitism of the mid-20th century and society’s uneasy relationship with people who have dementia today; that dementia is being ghettoised. The montage of elements making up this constellation is discussed below.

Discrimination is almost invariably accompanied and fuelled by demographic panic, based on the idea that an undeserving or unproductive group of people are consuming more than their fair share of national resources. On a surface reading, policy documents on dementia invariably stress the need for research into prevention or cure, and the improvement of care services. Read against the grain, however, they often reveal an overriding concern with what has been heralded for many years now as the

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<sup>3</sup>Walter Benjamin (1892 – 1940) - German-Jewish critical theorist who went into exile in 1933 following Hitler’s rise to power. He later attempted to escape to the USA via neutral Spain, but after being detained at the Spanish border was believed to have taken his own life rather than be deported back to Germany. In 2003, newspaper reports suggested that Benjamin had been murdered by Stalinist agents determined to prevent his critique of orthodox Marxism being published (Zizek, 2006).

‘rising tide of dementia’ and its material implications for the mid-21st century economy.

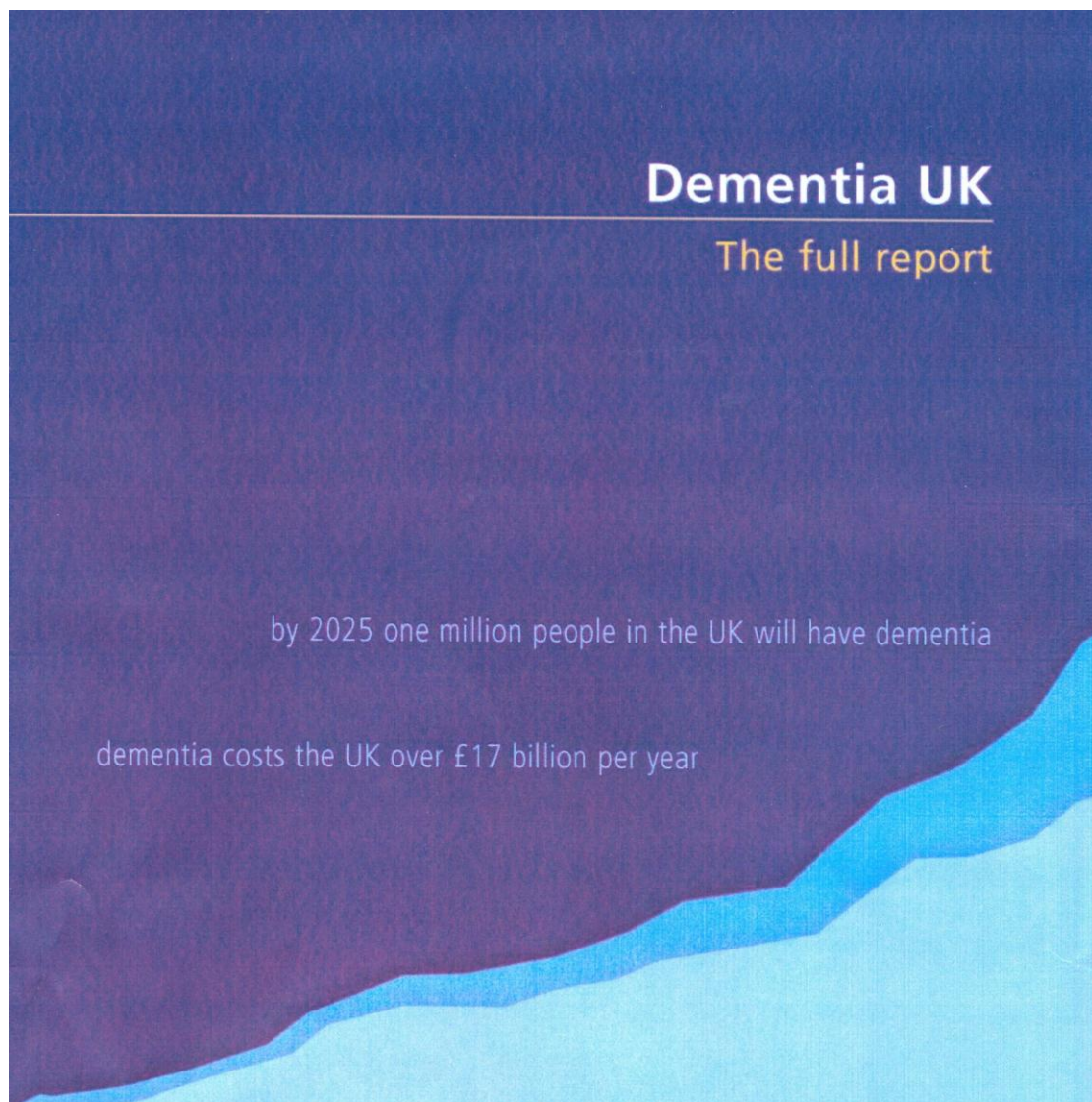
The metaphor of the ‘rising tide’, as applied to dementia, can be traced to the title of an article on the demographics of dementia by Ineichen (1987) published in the *British Journal of Psychiatry* (*Measuring the rising tide. How many dementia cases will there be by 2001?*). This title is almost certainly, however, a conscious or unconscious reference to the ‘scientific racist’ text, *The rising tide of color against white world supremacy* (Lothrop Stoddard, 1920). The metaphor of a tidal wave that will engulf society due to the over-representation of a particular group has no doubt passed into common parlance in such a way that it need not be used with any overtly discriminatory intention and I am not suggesting that Ineichen did so. The point remains, however, that the image of a society ‘swamped’ and overrun by non-productive older people who are about to bankrupt it has echoes of racist and fascist propaganda.

The recent Dementia UK report commissioned by the Alzheimer’s Society (Knapp et al 2007) carries on its front cover the following words, prominently displayed

by 2025 one million people in the UK will have dementia  
dementia costs the UK over £17 billion per year

This major report runs to 189 pages, but the two facts selected for emphasis are the number of people affected (too many) and the cost of their care (too much); there seems to me to be a strongly implied ‘already’ lurking beneath that second line. The blue front cover of the report bears an image that resembles surging waves, or perhaps steeply ascending lines on a graph (see illustration on the following page). Knapp et al (2007) estimate that around 700,000 people in the UK currently have dementia, but go on to suggest that prevalence may be up to three times higher than this figure, due to underreporting. Projections suggest that, due to the ageing of the population, prevalence could reach 1.7 million by 2050.

‘The rising tide of dementia’: Dementia UK report (2007)



As with all disease categorisation, however, it is who we decide should be inside the parameters that determines the size of the category. Projected prevalence rates for dementia in the mid-21st century may thus owe more to rhetoric than to established fact. The most widely used diagnostic screening test for dementia the Mini-Mental State Examination (Folstein et al, 1975) has been found to have an 86% false-positive rate in people over 75 (White et al 2002) and earlier diagnosis is leading to increasingly blurred boundaries between mild cognitive impairment (MCI) and dementia.

*Extending the disease category: stigma by association*

In Chapter 1, I discussed the extension of the original disease category ‘Alzheimer’s disease/pre-senile dementia’ to incorporate increasing numbers of people with late-onset dementia. The Alzheimer’s movement increasingly pursues its quest for research funding by extending this category to take in all cases of apparent memory impairment, however mild. Although mild cognitive impairment (MCI) is currently estimated to progress to ‘full blown’ dementia in only one in three cases (Fleischer et al, 2007) US studies are beginning to appear which conflate MCI and Alzheimer’s disease. In their otherwise valuable study of social disenfranchisement in people over 65, Beard and Fox (2008), for example, muddy the water considerably by treating people diagnosed with MCI and those with ‘early-stage dementia’ as a single population with ‘Alzheimer’s disease’. Beard and Fox go on to note, without conscious irony, that among the research participants they chose to amalgamate diagnostically in this way, ‘the lack of consensus on what comprises normal age-related memory loss was *a major obstacle in the incorporation of the disease identity*’ (2008: 1512 emphasis added).

The demand for earlier and earlier diagnosis of ‘Alzheimer’s’ thus appears, in many cases, to be leading to a tentative and provisional diagnosis - as ‘MCI’ - of what may well be part of the continuum of normal age-related memory impairment experienced to some extent by all older people. In the process, however, a climate of fear is created in which the most transient example of ‘memory lag’ provokes fears of terminal decline. Fear of not being able to remember may, indeed, become a self-

fulfilling prophecy, since anxiety has been reported as one of the most significant factors in predicting whether those diagnosed with MCI ultimately go on to develop dementia (Palmer et al, 2007). In an article on stigma and Alzheimer's disease, Scholl and Sabat (2008) report on a number of studies which suggest that people who have low confidence and self-esteem are likely to perform poorly on tests of recall, and also on tests used to screen for cognitive impairment such as the Mini-mental State Examination (Folstein et al 1975).

Agamben (1999) notes that in Nazi Germany, Aryans were first distinguished from non-Aryans, non-Aryans transformed into Jews, Jews into deportees, and deportees into prisoners. Only when no further degradation was possible and a condition of 'bare life' had been arrived at did this process of categorisation end. Similarly, it might now be argued that pseudoscientific means have been used to construct a category of 'others' in which the cognitively intact are first distinguished from the mildly cognitively impaired; the mildly cognitively impaired transformed into those who have dementia; those who have dementia transformed into those with 'Alzheimer's', those with Alzheimer's into the terminally ill, and the terminally ill into the 'already dead'. At the end of both processes, what is left is the *Muselman*, the 'living dead'. *Muselman*, a term used in the death camps to refer to those who, having lost the will to live, were considered no longer human but merely as animated skeletons, has much in common with the imagery used in relation to people with dementia today ('the death that leaves the body behind').

The endless extension of this category of the 'living dead' can be illustrated by the case of the author Terry Pratchett, aged 59, who was recently widely reported in the media to have been diagnosed with Alzheimer's disease. Pratchett has, in fact, been diagnosed with posterior cortical atrophy, a primarily visual disturbance that causes problems with reading and depth perception. Whilst posterior cortical atrophy can, over time, lead to some symptoms that are clinically similar to those of dementia (eg misrecognition of faces), it would not even be accurate to say that Pratchett has been diagnosed with dementia, let alone that he 'has' Alzheimer's disease. This did not, however, prevent *The Times* (17.3.08) using his story to head up an article on the campaign for increased research funding for Alzheimer's disease, with the title 'A Living Death'.

In recent years vast sums of biomedical research funding have been dedicated to the pursuit of genes for Alzheimer's disease. These research projects are justified to the lay population by suggestions that once such genes are identified they can then be eliminated. Here there is a direct line of descent between the pre-WWII German and post-war eugenics and genomics projects. Hitler was fascinated by theories of eugenics, developed from Enlightenment philosophies of progress, which appeared to offer the promise of human perfectibility. Franz Kallman, who argued in pre-War Germany for the sterilization of the relatives of people diagnosed with schizophrenia, continued to advocate this programme with enthusiasm following his arrival in the USA in 1936 as a refugee from Nazism. In 1938 he wrote that schizophrenics were

a source of maladjusted crooks, asocial eccentrics and the lowest type of criminal offenders. Even the faithful believer in ...liberty would be much happier without these...I am reluctant to admit the necessity of different eugenic programmes for democratic and fascistic communities...but there are neither biological nor sociological differences between a democratic and a totalitarian schizophrenic. (quoted in Rose et al 1984: 208)

Kallman went on to become president of the American Society for Human Genetics, and US sterilisation programmes for the mentally ill and 'morally depraved' continued in some US states until the 1970s.

My argument here might well be contested on the basis that, although some of the outcomes appear similar, there is really no comparison between the ideological genocide carried out in the mid-20th century and the current treatment of older people diagnosed with dementia. There is, of course, no intentional programme to eliminate people with dementia. There is, however, within the medical-industrial complex the same driving force towards the scientific perfectibility of human beings; the same motifs of hygiene, efficiency and progress persist. In pursuit of this perfection, older people with erratic memories are, for example, subjected to experimental drug trials that have no benefit for themselves, in service of the greater good: the 'eradication of Alzheimer's'.

### *The concentrationary universe*

The quality of life enjoyed by people diagnosed with late-onset dementia varies considerably, but it is characterised in general by high levels of segregation and social invisibility. There is considerable debate about whether people with dementia should be cared for in their own homes or in formal care environments; residential and nursing homes. Within formal care services there is further debate about whether people with dementia should be in mixed care settings (with older people without dementia) or in specialist units, and in specialist units there is debate about whether people with early onset dementia (under 65) should live in the same units as those with late-onset dementia. Typically, a person with dementia once admitted to formal care, will be moved several times, and (as in Tonia's case earlier in this Chapter) these moves will often be to successively more controlling or medicalized environments.

MacDonald and Cooper (2007) report that currently around 50 per cent of all people with dementia are in care homes and that present provision will need to double over the next 30 years in order even to maintain the status quo. The authors suggest that we are on the cusp of a national crisis of care provision. Ballard et al (2008) report that, within care homes, people with dementia are often inappropriately sedated so that they can be dealt with by untrained staff. Neuroleptic drugs, initially developed to treat psychoses in younger adults, are prescribed to 45% of older people in care homes and were found by Ballard et al (2008) to lead to significant deterioration in verbal fluency and cognition. People prescribed such drugs were twice as likely to die during the course of this five-year study as those who were not.

Rothberg (2000) suggests that it is the very interpenetration of the everyday and the extreme that defines the concentrationary universe. What Rothberg means by this is that although a concentration camp may, in one sense, be thought of as a parallel universe in which the unthinkable happens, it is also run along lines that we already recognise from everyday life, and is thus part of a continuum with the everyday. Arguably, even the atrocities of the Holocaust would not have been possible had we not already had prisons, asylums, workhouses and factories. Similarly, everyday aspects of a care home can be recognised as part of a continuum with traumatic past

events. Primo Levi commented that ‘the Lagers [a general term for camps of various kinds - labour, concentration, extermination] constituted an extensive and complex system which profoundly compenetrated the daily life of the country’ (Levi, 1989: 15 cited in Rothberg). In a similar way, the various kinds of care setting where older people live out their final years are present in every community, although the worlds within them are generally kept out of mind, and out of public view, enabling the population as a whole to carry on as though nothing is happening. Within care homes it is not unusual for people to be deprived of personal possessions and dignity. One student reviewer who felt that *Ex Memoria* painted too positive a picture of life in a care home had this to say about his own workplace, ‘You do not often see jewellery worn, other than rings. Glasses and dentures are often missing; usually slippers not shoes are worn’.

Passive euthanasia - the hastening of death by sedation, withdrawal of food and hydration - is already common in dementia. Opinion is divided as to whether euthanasia – either active or passive - is to be avoided in any circumstances in dementia (eg van Delden, 2004), or whether this is a humane and painless way of allowing those with no remaining quality of life to die (eg Terman, 2007). As mentioned in Chapter 3, there are currently hundreds of thousands of Internet pages related to euthanasia and dementia. Whilst many of these provide balanced and reasonable arguments about the relative benefits and disadvantages of advance directives, and ‘do not resuscitate’ orders, others take a more robust approach to the withdrawal of food and hydration from people with severe dementia who are considered to be unable to state their own wishes. Here too there are frequent references to the economic burden of care and the projected increase in numbers of people with dementia.

Adorno (1970) in a radio broadcast entitled *Education after Auschwitz*, suggested that we need to build awareness of the links between civilization and barbarism for the very reason that ‘the fundamental structure of society and its members, which brought it [Auschwitz] on, are today the same’ (cited in Rothberg 2000: 49). Adorno insists that Auschwitz was *not* a single aberration that can be dismissed in the post-War world as something never to be repeated; rather it was a logical conclusion of the Enlightenment notion of human perfectibility and progress through science. He saw

an urgent need to educate the post-War generations to anticipate and prevent the continuation of these myths (Adorno 1977) which are so evident today in society's response to the cognitive changes of ageing.

As Funkenstein (1993: 29) says of the need to bear witness to the atrocities of the Holocaust, 'We can be deprived of our identity against our will. It is our duty to understand...how it can happen and to rescue as many life stories – identities or, if you wish, narratives – as we can out of the ashes'. This will be the subject of my final chapter.

## Chapter 8) Art, history, narrative: dementia studies and social justice

When I grow sick or mad  
Mock me not nor chain me  
When I reach for the wind  
Cast me not down  
Though my face is a burned book  
And a wasted town. (from *War Poet*. Keyes 1942)

The orientation on the past tends towards an orientation on the future.  
The *recherche du temps perdu* becomes the vehicle of future liberation  
(Marcuse 1955: 34)

### Introduction

This thesis falls, conceptually if not entirely structurally, into two halves. In the first, the original ‘compliant’ action research study, I considered the potential for art, particularly the visual medium of film, to challenge and humanise the predominantly biomedical construction of dementia which still predominates today: Kitwood’s ‘standard paradigm’. In the second, increasingly rhizomatic and ‘subversive’, thesis the interface between art and history came to be an increasingly important theme, and I developed a second line of argument about the need for a socio-historical perspective to challenge some of the more conformist tendencies of Kitwood’s alternative psychosocial model.

As I have acknowledged earlier, Kitwood’s multifactorial model of dementia (1993; 1997a) was a necessary move away from ‘neuropathic ideology’, recognising as it does that dementia is the result of an interplay between many factors. My argument in this thesis is that that some of these factors have received much less consideration than others, and that as a result the debate, such as it is, has remained largely one

between medical science and psychology. Key among the still largely unexplored avenues is the period of history during which those who now have dementia grew up. A socio-historical perspective on dementia has the potential to open up a more interdisciplinary approach because it brings into the arena many other fields of social inquiry including the arts, humanities, social sciences and critical theory. In addition to the possibility of historically-related trauma which has been my main subject here, a fully developed historicist take on dementia would also require, for example, a more fully developed exploration of the effects of standards of living and social welfare in the early 20th century on the subsequent health of different populations. It might also involve further critical analysis of changing social constructions of dementia during the lifetimes of those now diagnosed with the condition, since this will inevitably influence their own construction of what it is they are experiencing.

I have suggested here that once an older person's short term memory starts to fail, and the ability to censor long-term memory is simultaneously weakened, dormant post-traumatic stress may often be unleashed. This is not, I would reiterate, a causal argument which attempts to explain why people develop dementia. My suggestion is that the nature of dementia makes the repression of traumatic memories increasingly difficult and a 'return of the repressed' more likely. Thus many of what are considered within the biomedical standard paradigm to be 'behavioural problems' of dementia, stemming from pathological changes in brain tissue, may better be understood as symptoms of post traumatic stress. I have further suggested that such stress is frequently triggered or exacerbated by the associations that a person with cognitive impairments makes between institutional care and traumatic or unpleasant experiences earlier in life. Post-traumatic stress disorder seems to correspond closely with Freud's concept of retrospective (or diachronic) trauma, although this has not been widely recognised in the field of psychiatry (Mather and Marsden 2004).

The possibility of post-traumatic stress seems worth considering in all cases where the words or actions of people with dementia cause concern to caregivers, or are difficult to interpret. The tendency, however, even in more enlightened care environments at present is to adopt, in keeping with Kitwood's psycho-social model, a proximal and synchronic approach to understanding the causes of ill-being in people with dementia. This tendency towards the dyadic and interpersonal is further exacerbated by the

social amnesia which has obliterated or conventionalised collective memory of past events and social conditions, which often become increasingly salient for people with short term memory difficulties.

In Western societies where people are now living longer than ever before, the results of advanced brain ageing should perhaps be viewed as inevitable, and part of a continuum with ‘normal ageing’, rather than as a disease. This is certainly an argument that Whitehouse (2007) puts forward in favour of abandoning the search for a ‘cure’ for old age. Like any other human organ or organ system, however, some people’s brains and nervous systems will age less well than others and the reasons for this cannot, to my mind, reasonably be divorced from standards of social welfare during their lifetime. Whilst it seems likely that dementia is a final common end-point for many underlying causes, the widespread malnutrition of the ‘hungry thirties’ will, for example, have had major implications for the subsequent general health of those affected. Associations between height, childhood nutrition and later development of dementia have recently been reported by Schnaider Beerli et al (2005) and Huang et al (2008). Dementia studies now needs a more robust engagement with questions of social justice that have been sidelined by the discourses of person-centred care and the new culture.

This study has moved a long way, along rhizomatic trajectories, from its starting point. In this final chapter I do not want simply to ‘conclude’; to close down what has been opened up in the process. Instead I wish to discuss what I think it is possible to do with these findings in the context of practitioner education, but also what it is not possible to do given the current professional and policy agendas impacting upon dementia care education. As Brown and Jones (2001: 184) put it, ‘Here there is no sense of an endpoint having been reached. More new opportunities are opened up for inspecting how the present and future might be understood in relation to alternative constructions of the past’. The constructions of the past I wish to consider here are predominantly those of people with dementia themselves.

## **The art/history/narrative nexus and dementia care education**

As suggested at the end of Chapter 7, the recovery of narratives of historical trauma is perhaps the only way we now have left of countering social amnesia related to the ‘war years’. Treating the narrative biographies of people with dementia as historical testimony is also an important aspect of any project to develop a model of dementia that is based on a concept of human rights, rather than philanthropically-met needs. There has been a long history of silencing people with dementia on the basis that they are ‘unreliable narrators’ or ‘confabulators’. From the perspective of psychoanalytic or deconstructive literary criticism, however, such objections can have little currency today when it is recognised that all our narratives are ‘multiple, multivoiced, discontinuous and fragmented’ (Sermijn et al 2008: 636). The voices of people with dementia can thus no longer be discounted on these grounds.

Beneath these surface arguments for excluding the voices of people with dementia, I suggest, lies a different unconscious fear. People with dementia lose the ability to censor their own traumatic memories, and thus to conform to the ‘stiff upper lip’ stoicism that has characterised survivorhood in the post-War period, and has made the appearance of an ‘efficiently functioning’ society possible. People with dementia thus become the voices of an unwritten history; they can only be listened to, or at any rate believed, if we are prepared to face the ‘unspeakable’ that is society’s unconscious. On the ‘reverse side of what is written’ as official history, as Marcherey (1978: 94) says, lies the collective, societal repression that is ‘history itself’.

All of this implies that, at least in principle, a more interdisciplinary approach to teaching dementia studies is required, one that draws not only on the arts, but also on sources that have the potential to counter social amnesia through a more unflinching engagement with 20th century history, particularly in its less palatable aspects. As I will go on to discuss in the later sections of this chapter, there are significant obstacles to such an approach being implemented in the foreseeable future. I will nevertheless start by outlining some educational strategies and approaches that are being, or might be, adopted.

### *Fictions, histories, and life history work*

Practitioners can, first of all, be encouraged in a variety of ways to develop their awareness of people diagnosed with dementia as historical beings, in the context of the interface between personal history and historical events. Following its pilot use as part of this study, for example, *Ex Memoria* is now delivered regularly as part of a different core Level 2 module in the Dementia Studies programme. The assignment associated with it has, however, been framed more specifically in the context of life history work with people who have dementia. In previous life history assignments it has been relatively rare, in my experience, for students to make reference to war-time, or other traumatic events in their clients' past. Having watched *Ex Memoria*, 11 of the most recent group of 19 students, subsequently made reference to war-related or other historical trauma, when they wrote up the life history of a person with dementia in their own workplace. To give just a few examples: one student wrote about a man whose mother and brother were taken to Treblinka and never returned; another about Mrs R who had an embarkation leave wedding, and whose husband then died of malaria in Africa when she was pregnant with their second child, and a third about Mr A who had to move house several times as a result of the wartime bombing of Bristol and was later sent to Korea on National Service.

It would thus appear that the film has sensitised students to the historical events people with dementia may have lived through or taken part in. As a result their accounts map more closely onto the actual history of the 20th century than does Kitwood's ahistorical developmental model. It is still often the case, however, that when students come to write a real life history, they pay relatively little attention to the words of the person diagnosed with dementia, and they often rely uncritically on information that is already on record, or that can be garnered from other members of the family. In one account, for example, it is implied that the coincidence of having been born and married in the same years as the Queen of England has been the defining experience of a woman's life. This owes little to her own narrative, but seems to conform to the kind of retrospective conventionalisation that often shapes family history. On those occasions when it is clear that a student has drawn directly on the narrative of the person whose life history they are writing, this often puts a different slant on the events recorded. One man talks, for example, of how, 'the war

smashed everything' for him; another supplements the bald facts of his wartime service in Germany and Poland (already in his records) by describing how the bridges he was involved in building were often destroyed as soon as they were completed.

In the context of the arts and health agenda, it thus seems important to move beyond using sources that are simply related to the condition with which student-practitioners are concerned – in this case, novels and films involving characters with dementia. Accurate fictionalised or testimonial accounts of historical events also have considerable potential for supplementing students' understanding and building awareness of the interplay between personal biography and public history. Such sources often give a different perspective on events that have been mythologised or sanitised in popular sources and official literature. They can, as Bickford (2008: 138) suggests, resist the homogenization of history in favour of 'a call to solidarity that is not reliant on bonding through shared experience, but instead is based in shared resistance and shared commitment to social justice'. For example, the sense of anger and dislocation experienced by many returning British servicemen after WWII has been novelised effectively by Melvyn Bragg in *The Soldier's Return* (1999), and by Martyn Waites, in *The White Room* (2005).

Part of Ian McEwan's novel *Atonement* (2001), itself based on a contemporary memoir, describes the retreat of the British Expeditionary Force from Northern France in 1940. The Dunkirk evacuation is largely remembered today for the 'miracle of the little boats'; the fleet of non-military vessels that arrived to ferry British servicemen back across the channel. What we are shown in the novel, by contrast, is the military debacle that even Churchill, at the time, acknowledged Dunkirk to be. The following extract is also a good example of the interpenetration of the extreme and the everyday, the banal and the terrible, which Rothberg (2000) identifies as definitive of historical trauma

They passed men who could barely walk for their blisters. Some were barefoot. A soldier with a bloody chest wound reclined in an ancient pram pushed by his mates. A sergeant was leading a carthorse over the back of which was draped an officer, unconscious or dead, his feet and wrists secured by ropes. Some troops were on bicycles, most walked in twos and threes. A dispatch rider from the Northern Light Infantry came by on a Norton. His bloodied legs dangled uselessly, and his pillion passenger, who had heavily bandaged arms, was

working the foot pedals...[Turner saw]...a long black barge slipping under the bridge in the direction of Furnes in Belgium. The boatman sat at his tiller smoking a pipe, looking stolidly ahead. Behind him, ten miles away, Dunkirk burned. Ahead, in the prow, two boys were bending over an upturned bike, mending a puncture perhaps. (McEwan 2001: 240-44)

Late life trauma and memory disturbance related to wartime experience are the themes of a number of recent novels including *Those Who Save Us* (Blum 2004), *A Short History of Tractors in Ukrainian* (Lewycka 2005) and *The Madonnas of Leningrad* (Dean 2006). Interestingly, as with the memoir on which *Ex Memoria* is based, all three are written by women, from the perspective of a daughter whose parent now appears to be experiencing some form of retrospective trauma. Whatever their literary merits, this again raises the questions of *whose* perspective we are being given, whose *voice* we are hearing, and *why*. For the purposes of art or entertainment, it may matter relatively little if the words of a character with dementia fail entirely to convince (as in *Ex Memoria*), or if he or she is given inner monologues which seem to belong more properly to the author (as in *The Madonnas of Leningrad*). In educational contexts I would argue, however, there needs to be significant justification for using such material in preference to the words of people with dementia themselves. Whilst literary fiction, film, poetry and drama all have a significant role to play, and certainly a much greater one than has traditionally been the case in health and social care education, there cannot ultimately be any substitute for first person narrative.

### *Recovering censored testimonies*

Recent years have seen the beginnings of a 'narrative turn' in dementia studies, but as Cayton (2004) and Williams and Keady (2006) have pointed out the polyvocality of people diagnosed with dementia can easily be overlooked in favour of a reductive project to 'hear the voice of people with dementia'. As demonstrated by the material from Brown and Clegg (eds 2007) discussed below, the voices of people with dementia are neither singular nor unanimous. Indeed, Bakhtin's concept of *heteroglossia*, seems to be a particularly apt one in this context, given its connotations of 'speaking in (many) tongues' (Bakhtin 1981). In addition, I would argue, there is a

need to move away from the current narrow focus on narrative disclosure as either a form of therapy for the person diagnosed with dementia, or a service-driven requirement for ‘user involvement’. What is also needed is a wider recognition of such narrative both as art and as socio-historical testimony.

Fine and Weis (1998: 27) write of the need to theorise and contextualise differently ‘voices that have been historically smothered’ and to ‘relentlessly create textual room for counter-hegemonic narratives’. Many people who now have a diagnosis of dementia will have experienced this smothering of their voices twice; once in the context of historical trauma, and again in the context of their current diagnosis. Like others of their generation, their experiences of historical trauma have been repressed, or suppressed, by society. It has frequently been noted that those who survived concentration camps or captivity as prisoners of war, were unable or reluctant to talk about their experiences. Strous et al (2005: 2288) note, for example that

many Holocaust survivors do not voluntarily disclose their experiences. In addition, some commentators have suggested that the Holocaust, taught as history, has been ignored by many persons in the mental health community...personal histories often omit features of traumatic experiences

Seidler (2007: 143) notes, similarly, that the Holocaust was ‘an event that could not easily be spoken about...even though it was experienced through a sense of overwhelming loss.’ Not only did speaking about traumatic memories mean that the speaker him- or herself was forced to remember them, often it appeared that no kind of catharsis or support was available, because other people simply did not believe: ‘You are met with the incredulity of listeners. The incommensurability of wartime atrocities, spoken of in the safety of an ordinary front room can seem like delirium or exaggeration’ (Appignanesi L, 2000: 129). Not only were such disclosures unwelcome, this would suggest, they were greeted from the outset as ‘false memories’ self-aggrandisement, or some form of neurotic over-reaction.

Heller (cited in Sutton 1997: 155) noted the same tendency in his study of the experiences of ageing veterans

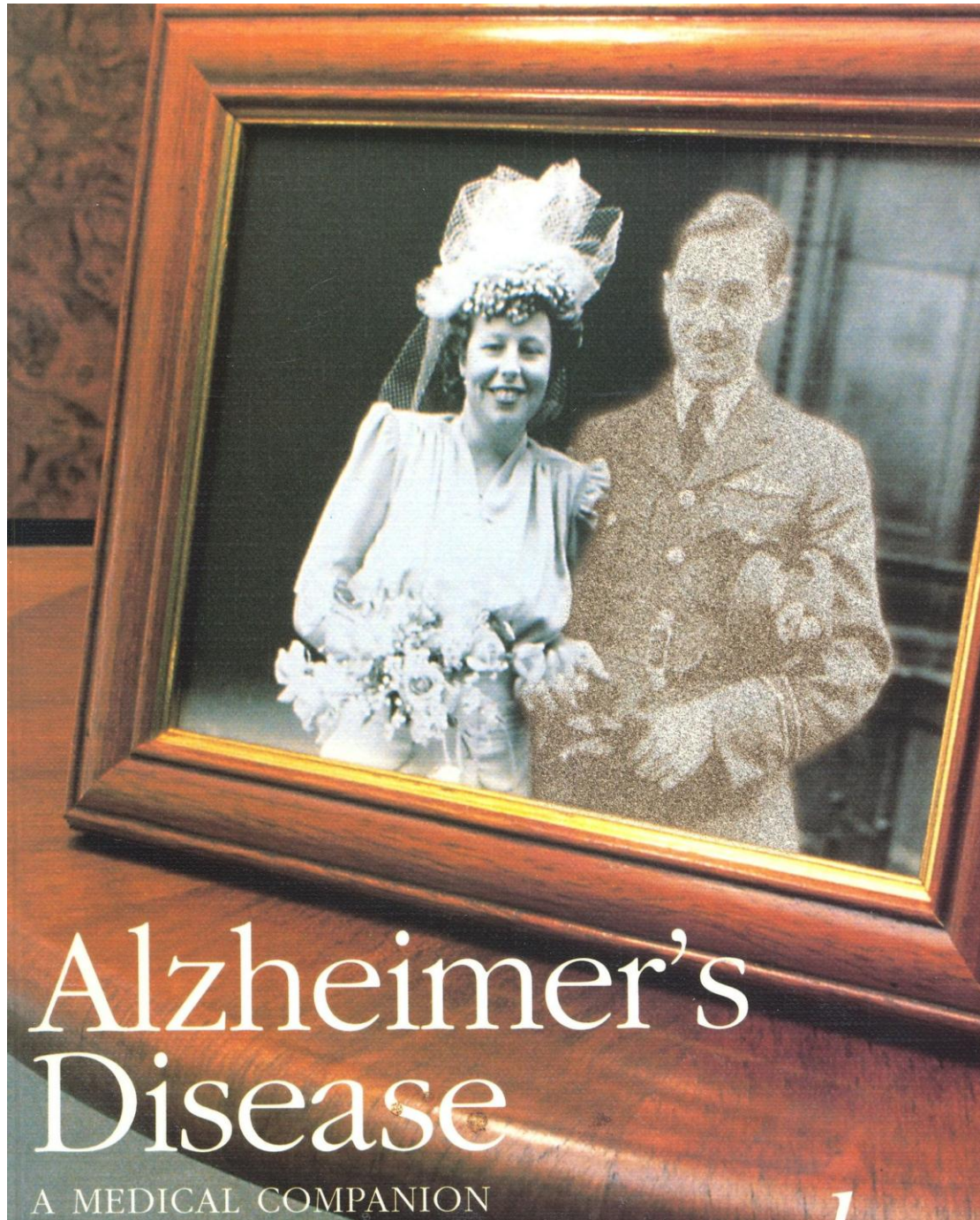
When they try and speak of it the memories overwhelm them and they fall silent. The British servicemen who saw Auschwitz from the inside, as prisoners of war, can never forget its horror. Nor is it possible for them to understand why, when they came home as young soldiers almost fifty years ago, no-one wanted to hear the story of what they had witnessed. Even today survivors share the feeling that still no-one is listening.

Ironically, the internalised shame and fear of not being believed, or of once again being identified as defective or weak, has contributed to an extreme fear of dementia among some communities. Mackenzie (2006: 235) points out that ‘variations in the ways stigma is operationalised in different cultures are rooted in particular historical events, spiritual beliefs and traditions that have influenced the process of conformity in each culture’. In older Polish people, for example, Mackenzie suggests, there has been a tendency to try to keep dementia within the family in order to avoid the renewed stigma of a condition that would have made the person a target for extermination under the Nazi occupation. Teaching resources thus need to reflect, from a historical perspective, the ethnic and cultural diversity of populations of older people, and the different ways in which dementia is constructed among varying communities.

#### *From confabulation to fabulation*

The second form of historical smothering of the voices of people with dementia results from the widespread perception that, as a result of their current diagnosis, their words and actions now have little importance or meaning. It has frequently been assumed that due to their cognitive impairments and associated fragmentation of speech or unorthodox modes of expression it is not possible to ascertain the views of people with dementia. This is, however, a convenient assumption; one that has often been used to exclude people with dementia from decision-making or self advocacy. Downs (1997; 2000) for example points out that, where such assumptions are present, attempts to elicit the views of people with dementia are rarely made, and any

‘Disappearance of former serviceman with dementia’: cover of a medical textbook.



questions that *are* asked may be inappropriate. Baldwin (2006) describes this, tellingly, as the ‘narrative dispossession’ of people with dementia.

‘Confabulation’ in dementia has been divided into two types: momentary/provoked and fantastic/spontaneous (Orulv and Hyden 2006). The first refers to a tendency to ‘invent’ answers to routine questions that the person with dementia cannot answer due to gaps in short term memory. The second is the apparent ‘invention’ of life history events (particularly ‘grandiose’ ones) that did not actually happen. In neither case is confabulation considered to be deliberate lying. It is, however, often described as ‘false memory’, a problematic construct in the context of dementia for a number of reasons. The first is that the ‘grandiose claim’ may actually be true, but merely seem implausible to listeners. As Clegg (Brown and Clegg eds 2007: 9) notes in relation to his own biographical work with people with dementia, ‘If someone says they dodged crocodiles while they swam in the Tigris, or that they dated the Acid Bath Murderer you would have thought most people would find some way of digging deeper, but they don’t’. In many cases, this resistance to ‘digging deeper’ is because the person is simply not believed. The two people who had recounted these memories to Clegg both, however, go on to give accounts of the experience that seem too detailed and precisely contextualised simply to have been fantasised.

In other cases, the story may be an invention, but still be a symbolic representation of something that has ‘truth value’ even though made up of elements that are ‘storied’ to a greater or lesser degree. Often it seems to be the case that what are classed as ‘false memories’ are not in fact false at all, but merely stem from the belief that something that actually happened in the past is still happening, or is about to happen again. As discussed in chapter 7 this phenomenon is perhaps often better to be understood as a return of the repressed, than as a ‘false memory’. Finally, it must be said, people with dementia should also be recognised as capable of telling deliberate lies. To suggest otherwise is to deprive them of a form of agency that has served other groups of marginalised and oppressed people as one of their few resources. Benjamin suggests that among the greatest weapons the oppressed have at their disposal are not only courage and fortitude, but also humour and cunning (1999: 246).

People with dementia may then be regarded, artistically, as fabulators, rather than pathologically as confabulators. In literary criticism the term ‘fabulation’ was used initially by Scholes (1979) to describe a genre of fiction which, in common with postmodernist texts, tends to decentre the notion of genre itself. Fabulation involves disruptions of temporal order and the compenetration of the everyday and the bizarre, the tragic and the comedic, the terrifying and the mundane. It may be argued, then, that the fabulations of people with dementia, whose narratives are often fragmentary allusive and characterised by neologisms, can best be explored by working along what Parker (2005) has described as ‘the line of the Symbolic’; by being open to their potential to disrupt and disorganize conventional ways of seeing. This is how I have approached the narrative biographies of people with dementia contained in Clegg and Brown’s (2007) anthology *Ancient Mysteries* discussed in the following section.

This existing body of biographical material has considerable potential for being used educationally, particularly in situations where practitioner-students lack the confidence, skill or time to obtain first-person life history narrative from people with dementia, or indeed to believe that it is possible to do so. It also offers a wealth of examples of the courage, fortitude, humour and cunning of people diagnosed with dementia.

### **Ancient Mysteries: In their own words....**

How slowly they return

Like princes into the halls they once owned (Douglas, 1943)

*Ancient Mysteries* consists of 28 stories told by people with dementia to David Clegg (Brown and Clegg eds 2007). These testimonies have been allowed to stand alone as personal and social history narrated by people who now happen to have dementia. Here there are no claims to the ‘bestowing of personhood’, but through a painstaking process of listening to what is already there Clegg has pieced together stories that would otherwise never have been heard. Not only were a number of contributors believed to be more or less mute before the project began, some of the stories include the last words they ever spoke.

These stories range in length from 27 pages to two lines. Among them are a diverse array of characters, including the ‘Belle of Bangalore’, Lulu’s dressmaker, Sybil Thorndike’s maid, acquaintances of Doris Day and Amy Johnson, a Bletchley Park code-breaker, and a 102-year old cowboy. There are also people whose lives have been blighted by war and poverty, by the early death of parents, and by sadistic teachers. The broad sweep of 20th century social history unfolds alongside the quirky and mundane. Ellen ends her story with the recollection that she’ll have to go now because she’s left a pan on the stove. Elizabeth refers to her diagnosis as ‘Outsider’s disease’, and Sheila recalls the disappointment of a reunion with her newly-wed soldier husband due to the bromide the army had put in his tea.

The lines from Douglas (1943) quoted at the beginning of this section seem particularly relevant in the context of narrative dispossession. Douglas, a poet of the Second World War, is speaking of the difficulty the dispossessed have in reclaiming what should be theirs. For many of the contributors to *Ancient Mysteries*, the preservation of historical memories and their re-emergence in the process of telling is a strong theme. ‘Such a long time ago it seems; like I’d forgotten it for centuries’ (Sid); ‘these things keep coming back at midnight – nothing in the day’ (Jean); ‘I wonder why it is I can remember these things? I’m wondering now if I’m the only person who remembers....’ (Catherine).

The stories in *Ancient Mysteries* contain many examples of both extreme and everyday historical trauma, illustrated here by extracts from the stories of Molly, Maria, Sid, Daisy and Catherine.

#### *Molly’s story: everyday trauma*

Molly tells what appears at first to be the story of a conventional happy childhood in the 1930s until we realise that, within her family, TB, diabetes, epilepsy and rickets carried off one member after another. In Fig 3, I have summarised some of the main events of Molly’s childhood, as narrated to Clegg. This gives added point to the section of chapter 7 where I discussed the impact of the depression on children growing up in the 1920s and 30s. It is evident from Molly’s story that in spite of all her losses and deprivations she considers herself to have had a happy childhood. At

the same time it does not seem an exaggeration to consider many of her childhood experiences as examples of 'everyday' trauma.

*Fig 3 Molly's story: a working class childhood in the 1930s*

Molly and her twin brother Jack were the youngest in a family of six remaining children. Three others had died before Molly was born. At the age of three (her earliest memory) she was taken to hospital with scarlet fever. Her father used to beat her with a belt across her back, but she 'wouldn't cry for him'. In 1931/2 her father was put on the dole and was never able to get a proper job after that. The family was means tested. All the children were ill 'because they never got the right vitamins and minerals'. Molly says she spent most of her childhood in hospital and convalescent homes. One sister was epileptic, and a brother had rickets. Another brother died aged 11, of diabetes and malnutrition, a few weeks before WWII broke out. The oldest child, Owen, had TB and was sent to Ireland to live with an aunt. Molly's mother also had TB and was in a sanatorium for about eighteen months. She died at home at Christmas, having 'lost her life's blood', when Molly was still less than eight years old. 'I remember her in the house...her body in the coffin'. Molly adds that she believes that her father always blamed her for her mother's death.

(from Brown and Clegg eds 2007: 23-28)

Molly then goes on to talk of events that would meet the criteria for extreme trauma, or post-traumatic stress disorder (PTSD). She tells how, during the war, her best friend was killed, probably by a bomb (Molly describes it as a 'land mine'), moments after they had parted outside a cinema, '...it dropped close by and blew her head off her shoulders...blew it clean off' (Brown and Clegg eds 2007: 30).

*Narratives of extremity: Maria, Daisy, Sid and Catherine*

Although many of the stories in *Ancient Mysteries* are dominated by memories of war it is noticeable that the strands related to historical events, and those of the everyday are closely interwoven. Maria, for example, talks of the little piece of family land in Italy with chickens and rabbits, and 'some fresh eggs for myself...' before revealing that her accordion-playing uncle was hanged there by fascists (Brown and Clegg eds 2007: 63). Sheila confesses that during the incendiary bombing of London she remembers 'crouching in the corridor praying that if only the bombs would stop I would never do anything dishonest or bad again' (Brown and Clegg eds: 83). Sid

notes his own luck in getting through the war ‘without a scratch’ and being back in time for the street parties, but then notes ‘they were all right until you started to look round...then you found the realisation of it...people you’d known for years...all dead...all dead...I lost all my school friends.’ (Brown and Clegg eds 2007: 103)

Daisy’s account of the London Blitz is clearly one of extreme trauma

Once the siren went you were on edge all night...the worst night everyone cried...the top of the road was bombed...a big bombing session...you can’t describe the noise...I used to put pillows over my ears but you could still hear it...the sound of people screaming and crying...people running up the road...little children all covered with blood...babies burnt black...you can’t describe it...the smell...terrible (Brown and Clegg eds 2007: 125).

Catherine’s story is, however, a particularly significant one for my purposes here, since it appears to demonstrate not merely the return of memories of extreme historical trauma, but also an allusive mode of expression that is filled with ‘dream-like’, or surrealist, imagery

...it worked out that eventually I was going to be murdered...by this new umbrella or something it was...I was drowning three times an hour back then...looking back it was the most important thing I ever did...I can’t forget it...that the wind and rain always settled on me...but when it comes to agony the Germans thought they had something special...why they did it nobody ever knows until this day (Brown and Clegg eds 2007: 145).

Catherine’s narrative, five pages in total, suggests that she is a Russian Jew whose family suffered at the hands of both fascist and Stalinist regimes, before coming to London as refugees, where they were again subjected to anti-Semitism. Her reference here to ‘drowning three times an hour’ and, elsewhere in her story, to a bath of cold water ‘where they put me to rest for no reason at all...until I die’, sound eerily reminiscent of experiments on hypothermia carried out on concentration camp prisoners, which involved plunging them repeatedly into freezing water (David 2003). ‘The Germans told everybody that this is the last measure’, Catherine says, ‘they put me in a...what do you call it? It looked like a bath...that was the whole point...’ (Brown and Clegg eds 2007: 143).

Once the association has been made, it seems increasingly likely that Catherine is referring here to the ‘final solution’, and to Nazi experimentation. The fragmented nature of her speech makes it comparatively unlikely, however, that her words would be interpreted in this way by care practitioners. There is, for example, the substitution of ‘last measure’ for ‘final solution’. Catherine also continues from the last quote given above to say that the ‘bath’ was ‘a pram...they put me in a pram...a new pram with a wonderful big canopy’ and that the pram then ‘caught fire...while I was in it’. So here we have an apparent chain of associations, where attention often has to be paid to connections and repetitions, rather than literal meanings.

Clegg reports that Catherine laughed frequently as she told her story, and she also appears to identify at points with the aggressors; as in her comment above about ‘the most important thing I ever did’. In another part of her story she remarks that the Germans ‘said I was taking their bread...They gave me a silver umbrella...I don’t know why I was given it...somebody must have liked me...but who liked Jews?’ This is followed a little later by, ‘they still tried to murder me...the Hitler people...with a huge umbrella...it was their new invention...and it was only me that it came for’. This feeling of having been singled out for some special fate is reported to be common among concentration camp inmates who were chosen to take part in experiments because they were stronger or healthier than their peers (Bettelheim 1960). It is, however, unclear what Catherine is referring to when she talks of a ‘(huge) silver umbrella’. A characteristic ‘standard paradigm’ response is to pass this off as dysphasia (word finding problems) particularly, perhaps, since Catherine isn’t speaking in her first language. This ‘umbrella’ seems, however, to have the quality of a dream image whose latent meaning is perhaps different from its manifest content; a symbol that stands in metaphorical relationship to the repressed material that is striving to return (Freud 1900).

Like those of many people with dementia, Catherine’s narrative is characterised throughout by strikingly creative images, apparent non sequiturs, and circumlocution. In this it also has much in common with the work of modernist and surrealist writers. Indeed, Brown (2007: 9) in his introduction to *Ancient Mysteries* notes that, ‘Some [stories] are complete and can stand alongside any memoirs written in a more conventional manner, while others are breathtaking contortions of language

approaching the verbal inventiveness of Surrealist sound poetry, or the other-worldliness of sound collage, or the cut-up experiments of William Burroughs and others'. There is thus a great deal of interest to be found in narratives such as Catherine's, both as history and as art, but they inevitably resist any form of determinate interpretation or closure. We may never know the 'facts' of Catherine's lived experience, but her story nevertheless has huge potential for opening up issues related to historical trauma, the nature of interpretation, and social justice.

The work I have undertaken during this study has already informed my own professional practice in many ways and will continue to do so for as long as I remain employed in this field. Given the historicist slant of my thesis, however, it seems misguided to introduce a note of false optimism at this late stage by implying that I think my argument or its implications for educational practice will be taken up with enthusiasm elsewhere or, still less, that it will influence policy or practice. As Brown and Jones (2001) write, an inevitable failure of research which is intended to be 'in the interests' of any particular group of people, is that an approach which may be held to work in a particular local context does not thereby come to inform national policy. Many of the current trends in the field of dementia care, and in Higher Education, work against anything I have suggested here being adopted on a broader scale, and perhaps even within my own immediate work area. In the next section I will link these professional and policy constraints back once more to the concept of social amnesia.

### **The 'monotonous rediscovery of common sense'**

Dementia care in general is still dominated by a 'training culture' and, as Downie and McNaughton (2000) among others have pointed out, training is a technical-rational approach to preparing practitioners; one that involves a focussing in and narrowing down on particular tasks. Education, on the other hand, involves both a broadening out, and a recognition that there are many different ways of approaching the same situation or phenomenon. Policy sources repeatedly refer to the need for increased 'training' for care staff. The National Services Framework for Older People (DoH 2001) identified workforce development as a priority area seven years ago. The

recent dementia UK report (Knapp et al 2007: 82) recommends again that ‘Dementia care training should be made a core and substantial part of the training curriculum for nurses and social care staff. National Minimum Standards must be developed to include dementia specific requirements on dementia care training’. The soon to be published results of the consultation on the first National Dementia Strategy are certain to reiterate this message.

There is, however, little if any evidence ‘on the ground’ of serious commitment, or funding to make even basic programmes of training a possibility for all direct careworkers; indeed many of their supervisors and line managers will not have had specialised preparation for this area of work. On the BSc course at Bradford in recent years we have had numerous instances of students having to leave without completing their course because of the withdrawal of employer funding, or their inability to self-fund due to low rates of pay. The current reality, in spite of the repeated calls at policy level for ‘more training’, is that the vast majority of direct dementia care continues to be provided by people who have received no specific training or education in this field. Mozley et al (2004) for example, found in a care home study that only 8 percent of direct care staff had received any in-service training on the psychological needs of residents with dementia.

This repeated cycle of demographic panics, followed by expensive consultation processes and remarkably similar policy statements which are then not acted upon, seems to be precisely what Jacoby was referring to when he wrote about the ‘monotonous rediscovery of common sense’ (Jacoby 1975; 1996). Indeed the concept of ‘training’ itself can be considered a ‘common sense’ one derived, as it is, from what Freire (1972) described as the ‘banking model’ of education; the idea that if some information is put into people they will perform more effectively in the service of their superiors. Within this common sense approach, for example, nurses, who have been required since the early 1990s to have a Higher Education qualification in order to practice, are still to be ‘trained’ rather than educated when it comes to dementia care (Knapp et al 2007: 82). These aspirations, even were they to be met, are low level ones, and reflect the prevailing view of dementia care as an area of work requiring little skill, creativity or initiative.

The financial crisis in the NHS has led to major cuts in commissioning by strategic Health Alliances (SHAs) of places on nursing and other health care courses, leading to ‘knock on effect’ job losses in HE health studies departments. These are not all new developments, of course, but part of the political and economic background against which the Dementia Studies programme was first developed. Kitwood himself seems to have half-anticipated that this might happen. In commenting on the prospects of the development of his new culture of dementia care, he wrote

There are many obstacles in the way, and the forces of reaction are strong. It is conceivable that most of the advances that have been made in recent years might be obliterated, and that the state of affairs in 2010 might be as bad as it was in 1970, except that it would be varnished by eloquent mission statements, and masked by fine buildings and glossy brochures. (Kitwood 1997a: 133)

Although Kitwood suggests that professional hierarchies of power and commercial interests are among the ‘forces of reaction’ he refers to here, ultimately he comes back to the concluding point, something of a mantra in his writing, that the dismantling of individual psychological ego defences is the route to making the new culture of care a reality. One of my unhappy conclusions at the end of this study is that Kitwood’s psychosocial model of dementia has itself been a barrier to the development of new perspectives. Whilst he makes reference in passing to the impossibility of long term culture change within a capitalist economy, he does not at any point suggest that what is needed is a political campaign to agitate for the human rights of people with dementia.

### **Conclusion: ‘everything that concerns people...’**

Who are the keepers of collective memories? In the final analysis, we all are. The intersection of personal biography with historical events is crucial to the many aspects of knowing who we are and what we are to become.

(Neal, 1998: 213)

If I have achieved nothing else in this thesis, I hope to have shown that dementia, as Gramsci (1971) famously said of history itself, is about ‘everything that concerns people’; that it is an interdisciplinary field rather than one to be pushed to the

academic margins, the equivalent of the locked ‘back-wards’ and out of sight care homes where people with dementia have so often been confined. The social ghettoisation of dementia discussed in Chapter 7 appears still, however, to be accompanied by a degree of academic disdain. Despite its evident potential for study from the perspectives of currently ‘hot topics’ such as trauma, history, memory, and narrative, dementia has, until recently, been subjected to relatively little serious critical theorising. Whilst there are some welcome signs that this is beginning to change, as Johnson (2007: 96) suggests, cultural studies is also affected by social amnesia; ‘Cultural studies and that style of sociology often called ‘social theory’ have shared a fascination with the new and also, all too often, a rather short historical memory. We all want to say something new about something new’.

In its humanistic faith in the potential for transformation through interpersonal relationships and its optimism about progress towards the ‘new culture’, Kitwood’s model of dementia did not locate dementia in the context of 20th century history and its associated denials and impasses. Instead he presented a model of dementia care based on individual morality, which as Eagleton suggests can never, of itself, lead to political change

What it means to be a better person...must be concrete and practical – that is to say, concerned with people’s political situations as a whole – rather than narrowly abstract, concerned only with the immediate personal relationships which can be abstracted from this concrete whole. It must be a question of political and not only ‘moral’ argument...Political argument is not an alternative to moral preoccupations: it is those preoccupations taken seriously in their full implications (Eagleton 1983: 208).

The problem today lies less in Kitwood’s original formulation of his psychosocial model (perhaps a necessary transitional stage between biomedical and socio-historical perspectives) than in its continued dominance. One of the dangers of the conformist, psycho-social approach is its implied message that the accumulation of small acts of kindness will one day change the world; that social justice can somehow be achieved without social or political change, without awakening from the ‘dream history’ of the 20th century. Benjamin’s concept of profane illumination was precisely aimed at such awakening; his ultimate concern as Lukacher (1986: 277) says, is with ‘the

ability of language to uncover fundamental historical concealments...to give voice to the dead and the oppressed, whose experience has always been elided from traditional historical understanding'. This also needs to become an aim of dementia studies.

‘So we beat on, boats against the current, borne back ceaselessly into the past.’

(Scott Fitzgerald 1925/1993: 115)

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## Appendices

**Appendix 1: About  
the film, Ex Memoria  
(information for participants)**

## **About the film, Ex Memoria**

Ex Memoria is a short fiction film (approximately 12 minutes long) which attempts to capture some of the experiences of a woman with dementia who is living in a care home. The film was made with funding from Wellcome Trust's SCIART funding stream and is the product of a collaboration between writer/director Josh Appignanesi, producer Mia Bays, and Errollyn Bruce and Andrea Capstick of Bradford Dementia Group. SCIART projects are intended to use arts media to increase popular understanding of medical/scientific issues.

The film focuses on the central character – Eva – a woman in her late 70s, who is was born in Poland, and her interactions with staff, other residents and visitors. Ex Memoria is filmed in a way that attempts to highlight Eva's view of events. It challenges us to think about what she is experiencing, and invites us to consider what it is like to be an older person with dementia trying to make sense of past and present.

All the speaking roles in the film are played by actors. The film is divided into a number of scenes, as follows. In order to help with your viewing of the film the characters in each scene have been identified below in the order in which they speak.

### **Scene 1: A wood: Poland 1940**

Young Eva

### **Scene 2: The lounge of a care home: the present day**

Mrs Eva Lypsysc

Grace – first member of staff

Gertrude – resident with Zimmer frame

Martin – second member of staff

Anja – resident in armchair

Delores – third member of staff

The home manager

Man visiting

### **Scene 3: The corridor**

Eva

Jenny – resident in side room

Hanna – resident on corridor

Helena – Eva's daughter

Grace – member of staff

Jacob – Eva's older grandson

Robbie – her younger grandson

Boris – resident at piano

Home manager

Man visiting

**Scene 4: Eva's room**

Eva

Helena – Eva's daughter

Jacob – older grandson

Robbie – younger grandson

Becky – young care assistant

**Scene 5: The bathroom**

Eva

Jim – member of staff

Delores – member of staff

**Scene 6: The corridor/lift**

Eva

Grace – first member of staff

Trinh – second member of staff

Martin – third member of staff

## **Appendix 2: Information letter and consent form**

Dear

Study title: Using film in dementia care education

As you know, your final report assignment for the module The Social Psychology of Dementia Care, which you are currently undertaking as part of the Dementia Studies programme, is based on your viewing of a short film – *Ex Memoria*. I am currently undertaking research on the use of film in dementia care education and would like to ask for your assistance with this project. I hope to find out how different audiences respond to and interpret *Ex Memoria*, and whether the introduction into course curricula of this and similar films is likely to be helpful in improving awareness and understanding of dementia. To help with this, I would like to carry out an analysis of your assignment after you have submitted it.

Your participation is entirely voluntary. If you agree to take part your assignment will be marked and returned to you in the normal way before I carry out my analysis. This will have no effects whatsoever on the mark you receive for the assignment, nor will you be identified when the study is written up or in any subsequent publications. Individual quotes from your assignment may be used, but they will not be attributed to an individual. All requirements of the Data Protection Act will be met when storing data related to the study.

If you do not wish to participate in the study, your assignment for the module will still be based on the film, but I will not retain a copy of your report for analysis. If you agree to take part, and then change your mind you can withdraw at any time without having to give a reason. Please complete the attached consent form and return this to me using the reply paid label enclosed. Your early response would be very much appreciated.

If you have any questions please feel free to contact me.

Andrea Capstick,  
Lecturer in Dementia Studies

Tel. 01274-235192 (UB ext 5192)  
Email [a.j.capstick@bradford.ac.uk](mailto:a.j.capstick@bradford.ac.uk)  
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**Contact person: Andrea Capstick, Lecturer in Dementia Studies**

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**Tel 01274-235192**

**Fax 01274-236395**

**Short title of project: Using film in dementia care education**

Please delete as necessary:

Have you read the information sheet provided? Yes/No

Have you had the opportunity to ask questions and discuss the study with Andrea Capstick? Yes/No

Have you received satisfactory answers to any questions? Yes/No

Do you understand that you are free to withdraw from the study at any time and without having to give a reason? Yes/No

Do you understand that you will not be identified by name in any documents or articles based on this study? Yes/No

Do you agree to take part in this study? Yes/No

Signature of participant.....

Date.....

I confirm that the purpose and nature of the study and the risks involved have been fully explained.

Signature of investigator.....

Date.....

### **Appendix 3: Certificate of research participation**

## *Certificate of Research Participation*

This is to certify that during the academic year 2005/06

X X

contributed as a research participant to the following project

***Ex Memoria: an exploratory case study of  
the use of fiction film in dementia care  
education***

**Awarded with thanks**

*Andrea Capstick*

Principal Investigator, Lecturer in Dementia Studies  
Bradford Dementia Group

## **Appendix 4: Information sheet for student reviewers**

## **Ex Memoria: Guidelines on completing your review (artistic technique and imagery).**

In order to complete this review you will need to:

- 1) Read through the information sheet 'About the film, Ex Memoria' and the handout 'How film can help us notice more'.
- 2) Watch the dvd of Ex Memoria. I'd like you to watch it at least twice, and you may want to watch it several times. If you want to watch the film with others and discuss it with them before writing your review, that's fine.

**NB. Sound is important in this film. Experiment with the volume before you start, set it rather higher than usual, and make sure that you and anyone else watching can hear clearly.**

3) Write your review which can be as long or as short as you wish, commenting in particular on anything you think works well or badly in the film in terms of the artistic techniques and imagery used (eg lighting, sound, camerawork, symbolic images etc). How you write the review is entirely up to you but you may, for example, want to comment on

- points already mentioned in the handout 'How film can help us notice more'
- other similar features of the film that you have noticed yourself
- how you think the artistic techniques used in the film relate to what you can work out about Eva's life history
- how the film compares with any other representations of people with dementia you have seen in fiction film

It's important for my research that you give unbiased responses, so please feel free to say so if there are things in the film that you think don't work, that you found difficult to understand, or that could have been done better. Remember that this isn't a coursework assignment and you are not being assessed on what you write!

4) Fill in the cover sheet with your details so that we can send you your certificate of research participation, and return it along with your review in the reply paid envelope provided, if possible by 15 September 2006. If you say that you wish to remain anonymous on the cover sheet, identifying details will be removed from your review by administrative staff before it is passed to me.

## Appendix 5: Collective syuzhet of Ex Memoria

### Scene 1: A wood: Poland, 1940

We first see Eva as a young and attractive woman in wartime Poland. She looks smart and proud of her appearance. She is strolling through a wood, not far from home, having just left her brother Adex (sic). She calls out to him in Polish, looks to see if he can see her and – reassured that he can't – experiments with a cigarette. She reaches for her handbag, opens her compact and looks in the mirror. She checks her make-up, puts on lipstick, and blows herself a kiss. She walks sexually and seductively. It appears that she is waiting to meet someone.

It is very quiet. Suddenly birds fly past. Within a few seconds the peace is disturbed by the shouting of German soldiers and the sound of gunshots, followed by a struggle. It appears that Eva's brother has been captured, and she hears him call out her name. She replies in a terrified voice and covers her mouth. We hear a vehicle driving away, then once again it turns to eerie silence.

### Scene 2: The lounge of a care home: the present day

We see an older woman in the foreground staring ahead. She says, 'I think we should go home now'. No-one responds and she looks sad and worried. The nursing home looks comfortable, but the lounge is a thoroughfare – a public arena where visitors are shown round and residents are ignored. The residents are of different nationalities.

Staff enter the lounge. Gertrude is obviously feeling anxious and, when asked by Grace, does not know where she is going. Gertrude asks for a cup of tea and Martin tells her to go and sit down, repeating information about what time tea is served. This seems to displease her and she moves away muttering in German.

Another resident Anja is evidently distressed and whimpering. Delores responds in a negative way by explaining she will take Anja out of the lounge for disturbing the others. Eva looks distressed by Anja's treatment.

The manager enters the room showing a male visitor around. She explains that residents are 'free to do as they please'; however, she appears nervous, especially

about Anja, whom she ignores. Eva hears the manager's voice and appears to be trying to make sense of what is said. No one responds to Eva or notices her non-verbal communication. At the end of the scene, Grace approaches Eva from behind and she is wheeled out of the room, but not informed of the reason, or where she is going. Eva looks worried and frightened.

### Scene 3: The corridor

Eva is wheeled down a long, dark corridor. The environment is very institutional. Noises echoing around the corridor appear to cause Eva uncertainty – a man can be heard shouting in the background. The doors are open; residents have neither privacy nor interaction. Eva has to sit in the corridor waiting when Grace leaves her without explanation to deal with something else. During this time another resident, Jenny, begins to talk very loudly. This appears to annoy Eva who whispers to her to 'Shut up!' Eva and Grace continue their journey through the corridor in silence. When they pass Hanna, Hanna tells Eva that she loves her.

Eva looks worried. She is seen applying lipstick as she goes along. She is delivered to a room where her daughter, Helena, and two grandsons, Robbie and Jacob, are waiting with flowers to greet her. Helena initially ignores Eva, asking Grace if her mother has been any trouble. Eva smiles at the boys and the flowers. She is pleased to see Robbie and calls him Adeck (sic). Helena corrects Eva, who says that Robbie reminds her of her brother. Helena agrees about the family resemblance.

Boris's piano playing disrupted by Jacob who 'bangs on the keys'. Helena is asked by the male visitor what she thinks of the home and speaks for Eva by saying 'You're happy here aren't you?' Helena also mentions Eva's escape from Poland during the war. Robbie jerks Eva violently backwards and forwards in her chair, frightening her.

### Scene 4: Eva's room

Helena looks disgusted at something she picks off Eva's clothing. Eva appears suspicious of the care staff and she confides in Helena that 'There are stealers here'. When Helena asks who, Eva replies, 'the blacks, schwartzes'. Helena dismisses Eva's

fears as nonsense; she sighs and walks away. The family seem to bustle around but do not spend much time communicating with Eva.

Robert, Eva's youngest grandson is encouraged to tell Eva about his holidays, while Helena goes to enquire about her mother's knees. Robbie declines, ignoring his mother's request and pretending to be a robot. Eva drops off to sleep. When she wakes, she begins to flirt with Robbie, saying, 'Such a handsome young man – give me a big kiss'. Robbie is embarrassed and darts away from Eva, who laughs politely.

Jacob is talking on his mobile phone with his ear plugs in. Eva becomes disturbed by the sexual nature of his conversation. She looks worried and afraid. She can't see who is there or who Jacob is talking to. Jacob appears unaware of her distress. Eva is faced away and pushed further into the room while he finishes his conversation. Jacob bends down to Eva; she mistakes him for her brother. Jacob corrects her. Eva tells Jacob, 'When they come to get us....time to go home'. She then starts talking in Polish. Jacob shows kindness but says he doesn't understand. He is interrupted by the return of his mother, preparing to leave.

Helena informs her mother that she has spoken to Matron and the doctor will visit her during the week. The family say their goodbyes which seem rushed and without meaning. Eva is left alone and deep in thought. Becky the young care assistant comes in and starts to arrange the flowers. She seems wary of Eva, and does not speak to her.

#### Scene 5: The bathroom

Two staff members, Jim and Delores, wearing gloves and aprons, are trying to sit Eva on the toilet and she appears to be very upset. Eva is physically attempting to hold her skirt down and Jim and Delores are tugging at her clothes, ordering her to go to the toilet. Initially Eva is giggling, but she begins to protest saying, 'Not here, not here'. The staff persist, 'You know you've done this before'. Eva continues to protest by saying 'No'.

## Scene 6: The corridor/lift

Eva is now being taken by Grace through another unfriendly corridor. She is hyperventilating, her posture is hunched, and she appears to be rocking in the wheelchair. She pulls her clothing tight around her neck and upper body. She seems worried by the noisy electric lift and other equipment.

Eva is left to sit by the lift while Grace and Trinh gossip about problems in their private lives within her earshot. She sees an empty hoist being wheeled out of the lift. After Eva has seen the lift going up she looks round at the staff, waits until the staff are not looking, and seizes the opportunity to escape. The staff do not see Eva move from the wheelchair. Moments later Grace shouts when she realises Eva has gone. Whilst they are looking for her a small bird flies in and sits on Eva's wheelchair. From the shouting and sounds of a struggle it is evident that the staff have found Eva and she is prevented from leaving.

Martin takes Eva's empty wheelchair. We then see Eva being dumped back in the chair. She appears anxious, telling staff 'You've got the wrong one, the wrong one, it isn't me!' Martin helps to get Eva back into her chair, and tells Grace and Trinh that he will deal with this. Martin kneels down, and places his hands on Eva's. He maintains eye contact; his approach is calm and sensitive. He tries to comfort and reassure Eva by telling her 'Everything is going to be fine'. Eva misinterprets this, and appears to flirt with Martin, obviously mistaking him for someone else. Eva seems to think that he will help her with her papers. In a desperate attempt to escape confinement she offers sexual favours in exchange for her freedom, saying 'You can do anything you want with me...right now'.

Martin makes no attempt to challenge Eva's confused speech. He is uncomfortable and embarrassed, but tells her that 'Everything is in order'. This appears to comfort her and she thanks him. Martin then says that he will make a 'nice cup of tea' and leaves Eva once more alone on the corridor. Eva looks as though a weight has been lifted from her shoulders. We see the same wood as at the beginning.

**Appendix 6: Individual elements of syuzhet identified by participants**

<u>Scene 1, A wood - Poland 1940</u>	<u>No of participants who mention</u>
It is wartime	5
Eva is attractive/smart	4
Eva calls out to her brother/Adek	4
Eva smokes a cigarette	6
Opens handbag/compact/mirror	3
Eva puts on lipstick	10*
Eva's walk	4
Eva waiting to meet someone	4
Silence/quiet/peace	3
Birds fly past	2
Voices/shouting	9
Gunshots	11*
German soldiers	5
Capture of Adek	6
Eva's reaction to Adek's capture	8
Vehicle driving away	5
 <u>Scene 2 – lounge of a care home, present day</u>	
Eva wants to go home	8
Gertrude prevented from walking	8
Martin promises tea later	9
Gertrude speaks in German	3
Anja's distress	6
Threats to remove Anja	6
Eva's response to Anja's treatment	2
Manager showing male visitor round	7
Eva trying to understand what manager is saying	1
Eva wheeled out of lounge	9
Eva not informed of purpose/destination	7

### Scene 3 – The corridor

Grace leaves Eva without explanation	2
Eva's response to Jenny's talking	8
Hanna says 'I love you'	2
Eva's second use of lipstick	12*
Eva's family waiting	6
Flowers for Eva	3
Helena's query to Grace	6
Eva mistakes Robbie for Adek <sup>1</sup>	10*
Helena corrects Eva	4
Helena agrees with Eva about family resemblance	2
Boris's piano playing disrupted by Jacob	5
Helena responds to male visitor on Eva's behalf	7
Helena claims that Eva is happy in the home	4
Helena refers to Eva's escape from Poland	2
Robbie pushes Eva in wheelchair	6

### Scene 3 – Eva's bedroom

Helena picks something off Eva's clothing	4
Eva – the stealers/blacks/schwartzes	9
Helena's dismissal of Eva's fears	6
Robbie told to talk to Eva about holidays	1
Robbie pretending to be a robot	2
Helena goes to enquire about Eva's knees	1
Eva falls asleep/wakes up	3
Eva flirts with Robbie/asks him to give her a kiss	4
Robbie is embarrassed and runs away	6
Jacob on mobile phone	8
Sexual nature of telephone conversation	2
Eva moved in wheelchair by Jacob	1
Eva doesn't know who Jacob is talking to	2
Jacob mistaken for Adek	4
Jacob corrects Eva	2

Eva explains the need to go home to Jacob	3
Jacob doesn't understand	3
Helena informs Eva about doctor's planned visit	3
Family kiss Eva goodbye	4
Eva left alone	3
Becky comes in/arranges flowers	3
Becky does not speak to Eva	4

#### Scene 4 – The bathroom

Jim and Delores wearing gloves and aprons	1
Trying to put Eva on the toilet	6
Jim and Delores tugging at Eva's clothes	7
Eva attempting to hold her skirt down	3
Eva's protests 'not here, not here'; 'No.....'	7
Jim and Delores persist	7

#### Scene 5 – The corridor/lift

Eva's signs of distress	8
Eva's reaction to the lift	6
Eva left alone while staff gossip	11*
Eva gets out of her wheelchair	12*
Staff don't notice that Eva has gone	2
Grace notices and shouts	4
Bird on wheelchair	3
Martin brings the empty wheelchair	1
Staff get Eva back into the wheelchair	9
Martin says he will deal with this	3
'You have the wrong one; it isn't me'	6
Martin attempts to comfort Eva	11*
Eva appears to flirt with Martin	1
Eva's misidentification of Martin	2
Eva's concern to get her papers dealt with	4

Eva offers herself in exchange for freedom/papers	7
Martin is uncomfortable/embarrassed	5
Martin offers reassurance	11*
Eva thanks him	2
Martin goes to make a cup of tea	5
Martin leaves Eva alone in the corridor	5
Eva smiles/looks happy/relieved	3
Wood/s	2

NB 1) \* = Most strongly foregrounded elements

## **Appendix 7: Participant foregrounding of characters in Ex Memoria**

## Foregrounding of characters in Ex Memoria

Number of participants who mentioned each character by name/title

Eva	12*
Adek	5
Grace	5
Martin	9*
Gertrude	7
Anja	7
Delores	5
Manager	6
Man visiting	5
Jenny	3
Hanna	1
Helena	7
Robbie	11*
Jacob	8*
Boris	4
Jim	6
Trinh	3
Becky	2

NB 1) \* = most strongly foregrounded characters

2) The manager and man visiting are not given names in the film, but appear on the cast list with these titles

3) One participant confuses Grace with Dolores; one confuses Hanna with Jenny; one participant names Trinh as 'Trish'.

**Appendix 8: Adjectives used to describe Eva  
in the script of Ex Memoria**

## **Adjectives used to describe Eva in the script of Ex Memoria**

In order of occurrence

### **Passive/negative**

Expressionless  
'Buttoned-up' (unclear)  
Worried x 3  
Suspicious x 2  
Confused x 2  
Fed up  
Anxious  
Disengaged  
Scared  
Alarmed x 2  
Terrified x 2

### **Active/positive**

Proud  
Aware  
Expectant  
Animated  
Wily  
Conspiratorial  
Wry  
Knowing  
Pert x 2  
Wary  
Determined  
Quick  
Wide-eyed  
Canny\*  
Lascivious  
Calm  
Rapturous  
Joyful

NB \* Eva's interchange with Martin is described as 'a ploy' on her part.