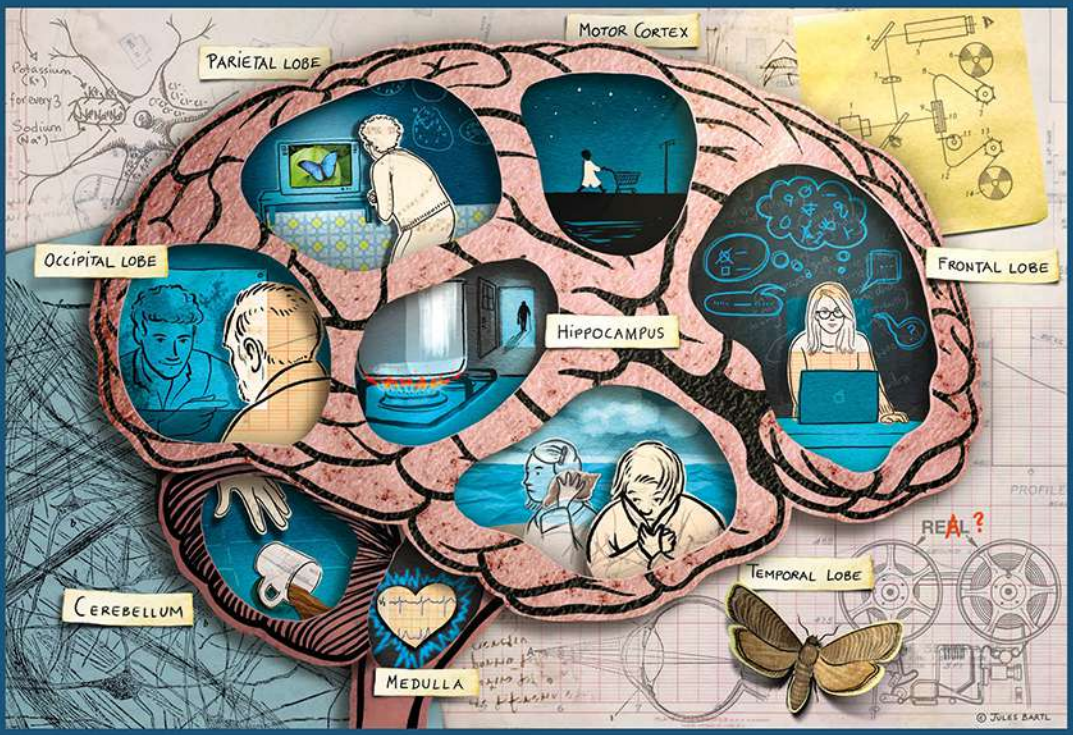


DEMENTIA ON SCREEN

Global Perspectives

MICHAEL CHANAN

BLOOMSBURY

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In memory of my brother Noel, who was unable to read it.

Last scene of all,
That ends this strange eventful history,
Is second childishness and mere oblivion,
Sans teeth, sans eyes, sans taste, sans everything

Shakespeare, As You Like It

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It is customary to affirm that the only person responsible for the opinions expressed is the author. Here I add that this applies especially to the accounts of the films, which are entirely my own, and doubtless betray my own likes and dislikes.

Chapter 1

OUT OF SIGHT

Prelude: Discovery—First Theme: Cinema—Second Theme: Symptoms—Development: Costs—First Variation: Symptomology—Second Variation: Memory—Third Variation: Disconnect—Fugue: Time—Adagietto: Aesthetics—Scherzo: Medicalization—Finale: Liabilities—Coda

Prelude: Discovery

This is a book about the stories that films tell about dementia. The subject is not, for the author, simply an academic one. I began watching films about dementia because an older brother of mine fell victim to what turned out to be Alzheimer's, though when I started this study he had yet to receive a formal diagnosis. Since diagnosis is the gateway to the care system, he was therefore in both personal and official limbo, and my first concern in turning to films, both fiction and documentary, was to be able to gauge and if possible comprehend my brother's deteriorating state of mind by comparison with these palpable representations of an impossible object – a subject who is becoming absent to themself. My knowledge of Alzheimer's until then was informal, and came mainly from visiting a cousin, now in her nineties, who fell victim to the disease not long before my brother. I approach the topic, however, as both a documentary filmmaker, a métier I share with my afflicted brother, and as a film scholar alert to the history and theory of screen representation, which the films discussed in these pages put to the test.

It creeps up slowly. Before the emergence of modern psychiatry it used to be attributed to old age and senility, the condition Jaques in Shakespeare's *As You Like It* called 'second childishness and mere oblivion'. In the nineteenth century it came to be called 'senile dementia' and now it's just called dementia, the Latin word for 'loss of mind'. De-mented, but not in the same way as the forms of mental breakdown that are treated in psychiatric hospitals. These may occur at any age and may sometimes be alleviated or at least held at bay by drugs, although this kind of biological psychiatry risks the reduction of diverse forms of mental distress to neurochemical imbalance without acknowledging trauma, social context or existential meaning. Dementia, primarily a disease of old age, is progressive and has no cure, although scientists have been busy looking for one for decades. Few people in Shakespeare's time would have lived long enough to

end up this way. Today, thanks ironically to modern medicine and people living longer, it's a major cause of death worldwide, especially in countries where the population is ageing fastest. In the UK, it's the leading cause – 11% of all deaths according to the Alzheimer's Society. This is compounded by the population explosion which followed the Second World War, known by demographers as the Great Acceleration, in which the global population, after growing slowly over the previous few centuries, exploded from 2.5 billion in 1950 to 8 billion in 2023. The more people living longer, the more dementia. There are also a small number of cases when it strikes at a younger age, classified as early onset, and it was one of these that led to the discovery in 1906 by a German psychiatrist and neuropathologist, Alois Alzheimer, who observed abnormal clumps of protein in examining a patient's brain after her death, of the disease that now bears his name. Today, Alzheimer's is the primary, though not the only form of dementia.

Those are the statistics that turn up from a simple web search, which like all statistics need to be interrogated (as I shall do), but what they mean is not only that the longer someone lives the more likely they are to be afflicted with dementia, but also that an even greater number of people will become intimately involved in caring for them, whether paid and unpaid, at home or in an institution, accompanying their deterioration and eventual inevitable demise. At the same time, the pressure on the social care system is exacerbated by the fact that birth rates have been falling and there are fewer offspring to care for them.

Ludwig Wittgenstein held the view that death is not an event in life.[1] He should have said, in your own life, because it is in other people's. Death has always been a constant presence in every culture, and some would argue that culture is defined by the all too human consciousness of death. But this consciousness has a history, and in modern societies, the improvement of medicine has not only increased life expectancy but also made the direct experience of death of the past, of people of all ages, much less common. As a result, there's a difference between the deaths we nowadays learn about in the news, innumerable victims of wars, earthquakes, floods, political violence and murders, which affect us at a distance, and those that come closer as we grow older, of people we know in the flesh: your intimates, relatives, friends, people you've worked with, some of them older, some younger, some after falling ill, some suddenly. The last of these are particularly distressing (I think of a dear friend who died on her own doorstep quite suddenly) but Alzheimer's and other dementias are terrifying, both to suffer and to witness. The fears provoked are both physical and mental. On the one hand, the dread of physical frailty and dependence, on the other, the loss of mental faculties, the slow death before death, in which the mind is extinguished before the body.

Dementia seems to bring back the idea promulgated by Descartes in the seventeenth century of a separation between mind and body, even though science now teaches the opposite, that the two are deeply entangled, and you can't have one without the other. Descartes' famous formula, 'I think therefore I am', induces him to regard thinking as entirely distinct from the body. The neurologist Antonio Damasio calls it Descartes' error, on the grounds that it denies the organic relation between the brain and the body that houses it.[2] However, science is paradoxical, and at the same time, some scientists would have us believe we can create artificial

minds in the circuits of electronic machinery. Both constructs are problematic. What concerns us here is neither neuroscience nor electronics but lived experience and its portrayal, the subjectivity of consciousness that neuroscience is unable to explain and is lacking in computers but which comes alive on the screen, where what we see are not scientific theories but representations of human beings, real people or actors, struggling with the intrusion of the disease.

While we can't avoid the science that defines dementia, there are reasons why we shouldn't take it entirely on trust. For one thing, it turns out to have inconsistencies that appear as soon as you scratch the surface, as we'll learn. For another, biomedical approaches to the brain are conducive to what is known in cognitive science as mechanomorphosis, the projection of mechanical models onto the working of the mind. It was ever thus. The ancients, who on the one hand intuitively thought of consciousness as the pneuma, the vital spirit, literally 'breath' or 'wind', and on the other, knew something of hydraulics, conceived of the brain as a system of humours and pressures. At the birth of the modern era, Descartes, in separating mind and body on the basis of nothing that would count as scientific evidence, considered the latter as a self-regulating clock in which the brain that housed the former was animated by the entry of the immortal soul through the pineal gland. (The pineal gland is now known to regulate the sleep–wake cycle, seasonal biological rhythms, sexual development, and various other functions.) Newton and later thinkers projected a similar intuition into the notion of god as the supreme watchmaker. In the mid-nineteenth century, the brain was likened to a telegraph system. The early computer age turned this into the analogy of information processing and the vocabulary of memory 'storage', 'encoding' and 'retrieval'. AI brings new metaphors in talk about 'neural circuits' modelled on discoveries about the brain which teach themselves how to mine data for patterns.

In short, each era's dominant technology becomes a new metaphor for the mind, but even now, when the latest technology enables scientists to examine the internal structure of cells and neurons in ever greater detail, the fundamental mystery of consciousness remains unexplained. The stuff in our heads, the fabric of memory, intelligence and imagination, remains resistant to mechanical explanations because it can't be reduced to cause-and-effect. It was Freud's genius to provide a radically alternative psychodynamic theory of mind, which was rejected by scientific positivism as unverifiable, anecdotal, lacking in rigour, and incompatible with experiment, predictability and empirical quantification, but this is what happens when you consider not the type but the individual, not the theoretical evidence but the private world of consciousness. The recognition of Alzheimer's disease occurred in the moment of this scission. When Emil Kraepelin adopted the eponym four years after Alzheimer reported his discovery, one of his reasons, according to a trio of recent authors, was the wish to show, contra Freud, that some mental disorders were organically based.[3] This became the dominant scientific paradigm, and mechano- (or techno-) morphic models have continued to guide the questions neuroscientists ask and how biomedical investigations are framed to the exclusion of the existential dimension of living subjects, which escapes mechanical models of cognition but becomes accessible through symbolic representation. For example, through literature, or the subject of this inquiry, the cinema screen.

Kraepelin was the preeminent authority in the field of psychiatry at the time and his approval of Alzheimer's findings has acquired almost legendary status in the literature, which isolates it from its historical context. The account given in a new book by a neuroscientist, Michael Hornberger, destroys any idea that Alzheimer's discovery was a eureka moment, the product of individual perspicacity or luck.[4] On the contrary, like so many scientific discoveries, it came about through advances in technology. In this case, a series of improvements in the field of microscopy in the late nineteenth century, the fruit of the industrial development of precision instruments, including higher resolution lenses and the development of staining techniques allowing detailed investigation of previously invisible cellular structures. The same technology enabled Santiago Ramón y Cajal to discover the structure of the neuron. These developments began a radical transformation in the understanding of the brain, but not of consciousness. There is a gap between physical description and subjective experience, which is exposed on the film screen.

It was Alzheimer's interest in microscopy that took him to Frankfurt where he met Mrs Deter, the patient whose brain he later put under the microscope, but he was far from the only one pursuing this avenue. Hornberger mentions the names of several other researchers in Paris, Vienna and Tokyo who had already published observations of plaques, and especially the work of a now forgotten Dr Oskar Fischer who published several cases of 'senile dementia' in 1907 featuring the same plaques and fibrils in the brain that Alzheimer had observed. None of them understood the significance of these novel observations because they didn't know what these features consisted of. When Alzheimer presented his findings at a conference in 1906, says Hornberger, he 'concluded his presentation by saying that he found this to be a "curious" disease process, of which there had been an increasing number of cases in the preceding few years'. Even Kraepelin, four years later, said that 'the clinical interpretation of this Alzheimer's disease is … still unclear'. But there was little by way of further research to clarify matters until the application of electron microscopy in the 1960s, a technology originally developed in the 1930s in Germany but only disseminated and improved after the war (like magnetic tape recording: both technologies were treated as strategic, developed under wraps, and after the war similarly transformed the sector they affected). Electron microscopy allowed the examination of the plaques and tangles at much higher resolution than previously possible. The plaques were first identified as containing amyloid in 1927, but the exact composition wasn't determined until the mid-1980s, around the same time that tau was identified as the main component of the fibrils.

The argument between medicine and therapy plays out over the question of insanity. Dementia is not a psychiatric condition. It might seem that psychoanalysis, which is preeminently about memory and its recovery through language, would hardly be applicable to the treatment of a disease in which memory is not repressed but lost. Nevertheless it offers a framework for understanding the disease in psychosomatic terms, not in the sense of 'all in the mind' but the interaction between the psyche and the soma, which in psychoanalysis are linked from birth. At the opposite end of life, in the early stages of dementia, the psyche begins to feel threatened and responds with alterations in behaviour and mood. The ego feels

under attack and fights back against the loss of its integrity by means of defence mechanisms like denial, projection, splitting and paranoia. Gradually, these defence mechanisms fail and the individual becomes more distressed and agitated, prone to outbursts of aggression and hostility alternating with withdrawal, despair and loneliness. What traits emerge depend on personality, which is partly shaped by attachments formed in infancy that now reappear, transformed with growing incapacity and regression to dependency. The subject may follow their carer around, like a dog follows its human, or may greet the daughter who cares for them as their mother. Scenes of both turn up in films, both fiction and documentary. Biomedicine views them as symptoms; psychoanalysis, seen not as a therapy but as a model of the psyche, offers us a way to comprehend the sufferer's inner turmoil; the film screen invites us to empathize with both the sufferer and their caregiver.

What remains when language and active memory atrophy are feelings and emotions, which the brain processes separately from thinking. According to the neuropsychologist Oliver Turnbull, it is not an accident that we speak of 'gut feeling' and 'intuition'.[5] The emotion centres of the brain are buried deep in the oldest (in scientific language, phylogenetically ancient) parts of its structure, sometimes described as the 'reptilian brain', and they remain anatomically separate from the cortex and other parts of the brain, like the hippocampus, involved in the formation of autobiographical memory, although still linked to them. Emotional memory thus remains active even when cognition has failed, and according to Turnbull, so does the kind of basic emotional learning that operates in human relationships when we quickly assess whether someone we don't know is friendly and trustworthy or not. We are genetically equipped to do so, and newborns rapidly learn to recognize faces and read their expression. Turnbull points to care home residents with late-stage dementia who form relationships with both staff and fellow residents whom they didn't previously know and whose names they can't remember. Or sometimes they take a distinct dislike to someone, and when things go badly, this is attributed to the disease. Emotional behaviour finds little place in the dominant biomedical models of dementia, except when it becomes disruptive and is suppressed by administering tranquillizers. When the progress of the disease brings new emotions of fear and terror as consciousness fragments, all the biomedical model can do is treat them as symptoms to be dampened by medication. Turnbull brings scientific evidence to echo the call from critical gerontologists for a more humane care regime. One of the questions on my mind as I review these films is therefore whether the film simply reflects the biomedical model or in any way contests and challenges it. The cinema of dementia, as I shall show, confronts the dilemma of the gulf between the depiction of the disease through the prism of medical research and portraying the subjective experience of sufferers and those around them. This echoes the explanatory gap in neuroscience, known as the 'hard problem' of consciousness – the mystery of how subjective experience arises from the electro-chemical processes in the brain.[6]

*

It is cultural creation in which subjectivity is given substance, and central to the transmission of culture is the way figurative art generates body images which reflect the human body back to us, both as ideal and individually, from classical Greek sculpture to the Renaissance to the rise of portraiture and beyond, to its fragmentation by Cubism. The configuration of face-and-body is a biological constant but attitudes towards it, and the discourses which form around it, shift through time. A cultural revolution began in the second quarter of the nineteenth century when photography was invented, inaugurating a new age of self-consciousness and narcissism, which at the end of the century entered a new register when cinematography projected moving bodies on a screen. Body images of all kinds, still and moving, now assault us at every turn, and old age comes off poorly. It isn't just a question of ageism. Questions of gender representation are also involved. Women are made aware of ageing much earlier than men – the cosmetics industry depends on it. On the other hand, certain groups of people – the disabled and those considered senile – remained invisible until only recently, as if their bodies were too unseemly, and no one thought much about their state of mind. Now the disabled and neurodivergent have become more visible, both in the street and on the screen, they have begun to speak for themselves and books have been written about how they're represented. The senile, however, remain disadvantaged, normally hidden from view and voiceless, especially when they have dementia.

Now classified as a disease, the condition was known to the ancients. Pythagoras, Hippocrates, Plato and Aristotle all recognized cognitive decline in old age, a stage in which, said Pythagoras, 'the system returns to the imbecility of the first epoch of infancy' at which 'very fortunately, few of the human species arrives'.[7] The term 'dementia' was first used by the Roman physician Celsus in the first century CE, who distinguished four types: frenzy, melancholy, deceptive images, and mental aberrations.[8] A century later, Aretacus of Cappadocia spoke of 'senile dementia', and in the fourth century, Oribasius, physician to Emperor Julianus, wrote about brain atrophy causing loss of intellectual capacity and paralysis. But this was esoteric knowledge, and since the condition was rare, it remained indistinguishable in general awareness from other forms of mental disorder or insanity until very recent times, well after the emergence of psychiatry in the nineteenth century, which adopted the term 'senile dementia'. The connotations of the designation, as the poet Lesley Saunders writes, were almost wholly negative, and the concept came to be applied 'quite indeterminately to refer to … a range of psychoses, other psycho-social disorders, brain diseases, neuro-developmental illness as well as mental deterioration associated with old age. In some cultures, the connotations are even more negative, related to a sense of "curse" or "evil"'.[9]

What Alzheimer identified are biomarkers (biological indications) of disease in the form of abnormal clumps of amyloid between nerve cells which impede their communication, and tangles of tau inside nerve cells which kills them, but his findings remained enigmatic until the advancement of biomedical research that began in the 1960s, when leading figures in the field began to argue against the catch-all terms 'senile' and 'senility', in favour of a language that distinguished the pathological conditions of the disease from the normal process of ageing. They believed that without a clear distinction between normal ageing and

dementia, the subject was surrounded by stigma, those afflicted were to be hidden away like the mad old aunt who lives in the attic; the intention was to remove the stigma, but it wasn't so simple. Although it isn't the only incurable disease, the stigma remained, embedded as much in the new terminology as the old, because it didn't alter the facts on the ground – the condition is bewildering, progressively worsening, and there was no medical treatment; there still isn't, at least none that makes any real difference. While cancer began yielding to medical advances, to be diagnosed with dementia is a sentence of death foretold, with the immediate effect of disqualifying the afflicted from full social participation and robbing them of agency in their own life, in ways more radical than the physically disabled. This expulsion is experienced from different positions by sufferers and those who care for them, but both are subjected to a disgrace not alleviated by advances in medical research. Civil society gave birth to advocacy groups, with the double purpose of challenging the prejudicial terms in which dementia continued to be seen more widely, while at the same time supporting biomedical research. This twofold aim is a trap. There is a mismatch between research and care, the medical and the social. In due course this gave rise to a critique of the medical terminology and its aporias, as well as the forms of treatment it promoted, calling instead for attention to the lived experience as opposed to the symptoms.

This is not a problem restricted to dementia. As long ago as 1977, the US medical psychiatrist George Engel criticized the dominant biomedical model of disease, with its basis in molecular biology, which reduces complex phenomena to primary causes, for excluding the social, psychological and behavioural dimensions of illness.[10] The biomedical model embraces both reductionism and mind–body dualism, the doctrine that separates the mental from the somatic which 'fostered the notion of the body as a machine, of disease as the consequence of breakdown of the machine, and of the doctor's task as repair of the machine'. In the real world, the boundaries between health and disease, between well and sick, are far from clear, but diffused by psychological and social considerations, and this requires what Engel calls a biopsychosocial model, which encompasses the medical framework, the patient and the social context in which they live with its many determinants, including the social system devised to deal with the disruptive effects of illness, that is, the physician and the health care system. He warns, however, that 'The power of vested interests, social, political, and economic, are formidable deterrents to any effective assault on biomedical dogmatism', and this indeed is what has impeded the adoption of a biopsychosocial model of dementia.

This critique also affects the endeavour of writing about the representation of dementia on screen. It is one thing to deal with words like 'senile' and 'demented' by placing them in their historical context, and important not to use Alzheimer's as a catch-all term for all types of dementia (several having now been distinguished). Revisionist terms, however, can also be problematic. A recommended phrase like 'living with dementia' is ambiguous, since it may refer to either the person with dementia or their caregiver. Nor is 'cognitive impairment' always a satisfactory term, not only because it echoes medical terminology, but because the subject's problems aren't just cognitive. My solution is to be guided by ordinary language, in Wittgenstein's sense of the appropriate language game to use in the circumstances,[11]

and to speak of the sufferer or describe them as afflicted because that's how we naturally speak about disease, and the English language offers no other single words to do so (nor am I clever enough to find a suitable neologism). The critical thing when writing about films is that the identity ascribed to the person with dementia shifts according to how they're seen – they remain themselves to their close family, even as they become estranged; to the doctor and the nurse they're a patient – and the terminology used in the analysis of the film needs to fit what's on the screen. Formal language refers to this as the way the scene is focalized, the perspective through which a film's narrative is filtered – whose point of view, knowledge, or perceptual experience the audience shares at any given moment. (I'll come to the forms of focalization below.)

The problem is philosophically perplexing. While I draw on Wittgenstein's philosophy of language, this is not a subject that can be fully encompassed in ordinary language, for several reasons. First, because film analysis has its own technical language, much of which has passed into everyday speech but in doing so often becomes loose and imprecise. Second, our conception of dementia is informed by biomedical knowledge, which is scientific and technical, and we shall have to grapple with it. Additionally, because of what the scientific discourse excludes: the existential quandaries it creates around how we think of mind, memory, consciousness and self. These are perennial philosophical questions which cinema, however, is well able to evoke.

First Theme: Cinema

Here I present what I think of as the scenario for this book.

Unlike madness and psychiatric disorder, which made their first appearance on the screen back in the days of silent cinema, dementia remained off screen until its first tentative appearance in characters who display symptoms that remain unidentified, and even then, only rarely, until it emerged into public discourse as a disease rather than an extreme form of old age. The first films in which it plays a central role and is named are two US television movies made in 1970; the next don't appear until the 1980s. In factual television, it was framed at this time as a public health issue, but it also appeared in a handful of television movies in the USA and in Australia, in the surprising form of a sitcom. A few outliers followed in the 1990s, from countries including the USA, Italy, Japan and Hong Kong, increasing in number as the decade drew to an end, before the new millennium suddenly brought a spurt of films from different countries within the space of a couple of years, which has continued in waves and cycles ever since.

It is tempting to see this as the emergence of a new genre, which might be called the Alzheimer's drama, except that it doesn't quite fit, because the films are too varied. What we see is an extended family of films about dementia belonging to different genres – biopic, domestic drama, love story, tragedy, thriller, even comedy – which vary their scenarios and recombine their tropes in the various ways we shall examine. Here Wittgenstein is distinctly helpful. This is close to the way he

characterizes different types of games, which share their features in the same way as the overlapping and criss-crossing resemblances between members of a family, among whom no individual feature is essential, except the one that classifies the game by the means used to play it, like a ball, or a pack of cards, or a board with pieces. But in each category, every game has its own rules. In this case, the essential feature is that someone in the film has some form of dementia, whether identified as such or not, but otherwise, any two films can be quite dissimilar. We are not looking at a single identifiable genre, like the Western, say, with codified narrative and visual conventions. Indeed, a good number of dementia films are hybrids, in the same way as romcoms or sci-fi horror. *Robot and Frank* (Jake Schreier, 2012), for example, is a hybrid of three genres, domestic comedy, sci-fi and thriller.

Perhaps we should speak of the variety of dementia films as a quasi-genre, loosely connected by theme, style, or approach, but this is too loose. It doesn't indicate how they work. Nor is it a metagenre, because this is too narrow. Metagenre in film theory refers to films that are self-aware, and by means of some kind of self-reflexivity, prompt the viewer to recognize that what they're watching is an artistic fabrication. The paradigms are Federico Fellini's *8½* and Jean-Luc Godard's *Contempt* (both 1963) or François Truffaut's *Day for Night* (1973), which foreground the filmmaking process and the role of the director within the narrative. This happens in a few documentaries about dementia, but only occasionally. Another, less familiar term suggests itself, the idea of a paragenre, which attaches to the dementia film like a doppelgänger, or a shadowy and elusive archetype. The paragenre is undefined, like a spectre which can't be pinned down. Where the metagenre transcends genre, the paragenre serves as an infinitely adaptable schema or blueprint for films that share a preoccupation with the disease but comprise a multiplicity of varying scenarios in the guise of different genres, hybrids included, in which dementia is focalized quite differently. The paragenre validates this manifold.

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The first important television documentaries appeared in the 1990s, and evolved to cover a more or less standard set of topics and approaches, depending on the length of the film and the slot it occupies, from formulaic short reportage to extended expositions in a variety of styles, or what the film scholar Bill Nichols called the modes of documentary,[12] expository, poetic, observational and so forth, which I shall examine in Chapter 2. But documentary is an impure art inclined to stylistic bricolage and most documentaries are hybrids in which these modes are generally employed alongside each other in various combinations and various interests. The imperative for factual accuracy and its elucidation must be judged in terms of the supposed sensibilities of the targeted audience, or the commissioning editor, or the sponsor. None of these agents, however, sets the menu of topics and approaches to dementia from which each film chooses its particular focus. This derives from the growing attention of the medical and scientific communities to the disease, the ideological influence of the dissemination of the biomedical agenda in the public sphere, and the advocacy of civil society organizations; politicians, with one or two exceptions, almost never.

When this agenda arrives in fiction cinema, the films that result are constrained to follow certain typical plot lines corresponding to the clinical progress of the disease, and always end up the same way – there are no happy endings. Even if the end is left open and the final stages aren't shown, what one film critic called the 'exit strategy' is crucial (and this will be reflected in my accounts of the films). Is the denouement realistic, or symbolic, or escapist? The scenario, where the film begins, is also variable, and in part this reflects where the film comes from. Films from the Global North tend to crystallize around the biomedical agenda and the tragic impairment of the individual self, and might be called the medicalized Alzheimer's drama. Those from countries in the Global South tend to work differently. Here medicalization is underdeveloped, diagnosis, if it occurs, is not supported by social care, and non-Western cultures are less individualistic; the result is what might be called the socialized dementia narrative. To be clear, there are not many of them. There are some very large film industries in the South, because there are some very large countries. India produces double the number of films every year (around 1,500) as China, where the rate is roughly the same as the USA, and there are only a handful of dementia films from these countries. Others come from countries like South Korea, Iran, Chile and Mexico, with established film industries, but most countries in the South are too small and underdeveloped to sustain domestic film industries of their own, and not all of those that do have touched the subject.

Two notes of caution about these terms. One is simple. There are several forms of dementia which are all called Alzheimer's in common usage, and not all dementia films are specific, especially those from the Global South. The second is more complex and requires a short digression. When the term 'underdevelopment' first gained currency after the Second World War, it was introduced by mainstream economists to refer to countries previously regarded as 'backward' or 'poor', which were characterized, among other things, by high rates of poverty, illiteracy, disease and mortality. Viewing these countries from the perspective of those that are 'developed' and 'rich' carries the implication that these industrialized nations are the model that underdeveloped nations should aspire to follow, indeed that they are bound to do so. By the 1960s, this linear and purely economistic logic was being challenged, primarily by economists of the left in Latin America schooled in Marxism, who argued that underdevelopment wasn't simply a stage of development but rather a historical process created by colonial exploitation and maintained through unequal economic relationships. Twenty years later came another shift as cultural critics entered the field and introduced the term 'postcolonial' to examine the legacy of colonialism after independence. In this perspective the word 'underdevelopment' became suspect, because it was held to inscribe the power of the Western academy to define and categorize the non-Western world, claiming universal authority while devaluing non-Western knowledge systems, social structures and cultural practices. There is some truth in this, but there is still no better term to describe the underlying process of economic exploitation. Was it a coincidence that the terms Global North and South first entered the vocabulary of international diplomacy around this time? They may be euphemisms, but they

can still serve as appropriate descriptors on condition that we recognize that they're not strictly geographical (some of the countries of the Global North are in the polar south) but geopolitical. What they indicate are relations of power: the economic, social, cultural, political and ideological consequences of what a less diplomatic vocabulary identifies as the exploitation by the core countries of capitalism of the countries of the economic periphery. (I shall say more about this when I look at the films in Chapter 6.)

Each of these domains – economic, social, cultural, political and ideological – is a field of contestation, and what concerns me here is the way they play out in the cinema, where the economics of production is constraining but the scope of representation is not. Aesthetics are moulded by the enfolding culture, which retains its own power of imagination, and significant differences between films from North and South arise directly from the differences in these domains. However, the account I present is historical, and must therefore begin with the emergence of the dementia film in the Global North. Moreover, this history is dynamic, and its waves and cycles reveal changing attitudes and schools of thought about dementia, its clinical definition, treatment and care. While I discuss documentary and fiction separately, the book is organized to pursue this evolution, and presents a diachronic account, rather than proposing, for example, a synchronic taxonomy, which I argue is theoretically unsustainable because, considered in terms of genre, the basis of the dementia film is inherently unstable. Consequently, films will fall into groups according to their position within the cycle they belong to. These groups are formed by different criteria. Sometimes they comprise a moment of aesthetic innovation which introduces new cinematic paradigms, and sometimes they correspond to themes that present themselves as sites of fresh thinking beyond cinema, like a series of documentaries about music therapy, or the problematic of the care home. These themes are explored in both documentary and fiction, but the way they're treated is characteristically different.

Music is indicative. Only occasionally the primary theme in fiction, it can also take the form, if I may put it this way, of a counterpoint or second theme to the main axis of the drama. But most often it's non-diegetic, and then it plays the role of what Derrida calls a supplement,[13] an added element which is nonetheless integral to the whole, like the contents page of a book, a newspaper which is not complete without its supplement, or in this case, soundtrack music. Music, however, is often equivocal. A taken-for-granted part of the whole, it shifts between a something extra which is included, so to speak, for free, and a substitute, which provides something that is missing, such as supposedly telling us what a character is feeling, or imbuing the *mise en scène* with a certain mood. The problem is that it can be as untrustworthy as an unreliable narrator. On the other hand, its ambiguity can be used to great advantage.

One last rider. This ground plan means that some films are treated in greater detail than others, depending on factors like the complexity of the plot or the subtlety of its focalization. This is largely a reflection of the degree to which the film in question is more or less insightful as a representation of the enigmas of the disease. Some films are patently misconceived and it's easy to see why. But this is

not a matter of objectivity, and I don't wish to pretend that the aesthetic judgement it involves is disinterested, impersonal or in any way pure. On the contrary, it's always enmeshed in the viewer's aesthetic taste and dispositions, and the reader will become aware of my own. Moreover, questions of ethics also come into it, and so does the politics of representation. There is no point in hiding or denying this. All these factors are pertinent to understanding the dialectics of the cinema of dementia.

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The putative full trajectory of the medicalized Alzheimer's drama runs from first symptoms, enacted in critical moments of bizarre behaviour and lapses of memory, leading to diagnosis – the pivotal episode that signals medicalization. The symptoms, occurring at different stages throughout the narrative in no necessary order, include failure of habitual skills, spatial disorientation, loss of coherent speech, estrangement from both self and others, loss of physical functions, ending in mental obliteration, vegetation and eventual death. Precursors apart, the genre is exemplified by *Iris* (Richard Eyre, UK, 2001), a biopic of the writer Iris Murdoch which already displays its essential characteristics, and is quickly followed, the same year or the next, by films from Sweden, France, Spain, Argentina and Japan, though not all conform to the medicalized model. The dementia film is a chimerical genre that takes on different guises, but this is the way genre cinema works. Genres are promiscuous, and they interbreed. The French film is a romantic comedy, the Swedish film is a farce, the Argentinian film a social comedy, the Spanish film doesn't even name the protagonist's dementia but treats it as a metaphor for historical amnesia.

Since the path of dementia is different for every sufferer, the episodes have no given order and the story can be told in many different ways, but the model Alzheimer's drama in the Global North has several propensities. One is the instinct to accentuate the drama by focusing the story on someone with an exceptional mind, like a writer or composer, as if dementia isn't horrible for everyone. Another is the tendency to revolve around the sufferer's relationship to their immediate carer, frequently their spouse, as both become isolated and withdrawn from the world in a dyadic relationship played out in a domestic setting, held together by bonds of love that are severely tested as the disease progresses. Alternatively, the family may be dysfunctional, or the setting may be a care home.

A third propensity is the pull towards a realistic portrayal, which poses a very particular problem: how to represent the discomposed subjectivity of the person at the centre of the story, whose behaviour can no longer be judged according to normal standards? This is a central question we shall come back to, but it's not just a matter of how to dramatize it, or of acting, which is crucial, but the politics of realism. As the African-American scholar Rebecca Wanzo asks, realistic for whom?[14] African Americans, she says, are twice as likely to develop dementia as white Americans, but sufferers in films are disproportionately white and highly educated. Given the susceptibility of genre cinema to court the mainstream audience, this is hardly surprising, but what it pictures is a world of social privilege

that, among other things, is usually able to ignore the financial costs of care that confront everyone else.

The subject matter is hardly attractive to Hollywood, with its aversion to stories that forbid a happy ending, and that approach disability through narratives that depict a heroic overcoming of adversity. The dementia film is typically an independent production that emanates from around the world, including countries in the Global South where not only is medicalization underdeveloped and social care extremely restricted, where it exists at all, but dementia is seen in the context of non-Westernized social and cultural values. These films tend to stretch the dementia drama in different directions, which turns the emergent genre form cultivated in the Global North inside out. We shall explore these differences, which are rooted in the geopolitics of medicine, but to speak of Western values in this context is to raise a warning flag of many colours, which mixes economic, cultural and ideological hues in the promotion of values that the hegemonic culture claims are universal, which might be true of the findings of biomedical science, but in cultural and ideological terms are not universal at all.

Both fiction and documentary suffer from certain liabilities. Common to both is the complaint made by a trio of authors that the popularization inherent in the medium is rarely innocent or unproblematic.[15] They contend that all mainstream films need to be approached carefully, using what the philosopher Paul Ricœur termed 'a hermeneutics of suspicion', that is, the premise that the surface meaning of a text can conceal underlying ideological interests. They grant that 'artistic license is unavoidable' and that they are 'not so much concerned with the aesthetics of these representations as their ethics: the question of whether they do justice to the broader constituency of men and women living with dementia'. What they mean by justice is framed in terms drawn from another philosopher, Miranda Fricker, who has spoken of the misrepresentation of disadvantaged social groups as 'epistemic injustice', which comes in two forms that mirror each other. Testimonial injustice is the assumption that the person with dementia is an unreliable narrator of their own experience, unable to give a meaningful account of themselves. Hermeneutic injustice is a wilful failure to understand what the subject is saying or communicating, a tendentious refusal of interpretation. Together or separately the image they produce on screen of a subject with dementia is that of someone of less than sound mind, and this becomes the dominant stereotype in genre-bound cinema, which habitually deals in stereotypes that reduce entire social groups or types – cowboys and Indians, cops and robbers, madonnas or whores – to a few easily recognizable characteristics. In this case 'It's Alzheimer's; it's worse than death. The brain dies and the body carries on without it.' This is true enough, but the argument is weakened by its abstract nature. For example, the authors' neglect of aesthetics results in vagueness about the difference between mainstream cinema and what they refer to as 'arthouse or independent film'. Not that there's a clear distinction to be made, except at opposite ends of what in aesthetic terms is a continuum, like the obvious contrast we shall discover between the more or less contemporaneous mainstream *The Iron Lady* (Phyllida Lloyd, 2011) and a year later, the esoteric arthouse treatment of *Amour* ('Love', Michael Haneke, 2012).

This is also to say that the tropes that attach to the person with dementia in all these films are of the same type, insofar as they correspond to the experiential and clinical properties of the disease, but how they're treated can be very different, and this is what we need to untangle.

We shall discover that, over a quarter of a century, the dementia film has been engaged in an evolving dialogue with itself and with the world it translates onto the screen, which is subject to the conflicting pressures of various forces. Of these, biomedical, social and cultural factors are readily indexed in the film, directly or indirectly, economic factors are referenced only rarely, and political and ideological influences remain pretty much invisible. But they still have a role to play – that of the elephant in the room, or in formal terms, as a structuring absence, which underlies and gives negative shape to what appears around it on the screen, making certain things invisible and unthinkable. The audience's understanding of what they see is negatively moulded by what they don't, the gaps and silences, what is left unsaid, omitted, not even implied, whether the exclusion is intentional, the working out of the film's dramatic logic, or the result of the filmmakers' ideological assumptions. Whichever it is, and to put it simply, if the film is about a successful author, or musician or member of the professional classes, there is no need to inquire how they pay for the required care. The Marxist economist Leo Huberman once remarked how early cinema never showed anyone paying for anything, people would ride around in taxis and never pay the driver. Why pay any attention to something so mundane unless it has narrative significance? The omission has persisted. But in the dementia film it does, and mishandling money comes up as a symptomatic trope of the presentation of the disease. However, the economics of care is neglected.

In formal terms, if the film is a text, the structuring absence is not a subtext but a countertext, a negative space of disavowal that makes it impossible to perceive or even think of the absent elephant, which can only be revealed through the attention of critical analysis to what is outside the frame as well as what's in it, especially since these absences are not just found on the screen – they are also detectable in the discourses of dementia in the public sphere which the films draw on and reflect.

These considerations apply to both fiction and documentary, but there are also differences that the aforementioned authors neglect, despite their valuation of ethics as a question of just representation. They have little to say, for example, about the ethics that apply to the subjects in the documentary and the question of consent, nor about the obligation to treat them responsibly and respectfully both on and off camera. (This also applies to actors, with the difference that their on-screen persona is not the same as off-screen.) The difficulty is that when the documentary camera invades their space, it feels all too easily like an intruder, alternately voyeuristic and prying. This is about the politics of representation. The problem is precisely about not stereotyping the characters, not treating them as some kind of representative average person, because there is no such thing, and to suppose so is already to depersonalize them, an act of epistemic injustice (which is nonetheless committed by many a documentary). It's a delicate problem

because in documentary, to the degree that it's taken as a representation of the real world, the particular is liable to be read as a representative of the universal, and that opens the door to the stereotype, which the unwary documentarist working in an institutional setting falls into all too easily. The effect is paradoxical, the opposite of the way the natural history documentary positions animals, exploiting the astonishment of closely watching their behaviour to give them an inner life. Here the sufferer's inner life becomes inaccessible, and they end up either talking nonsense, or behaving like a zombie, or, at best, joining in sessions of music therapy like marionettes. To break with this ideological construct calls for a sense of critical realism, rooted in social and existential reality, that is, in spheres that are understood to be socially and subjectively constructed, including by the filmmaker themself. We shall find – and this is not an accident – that a favoured form for the independent documentary about dementia is the self-conscious first-person film about someone close to the filmmaker, whose individuality is fully alive in their relationship. Fiction has more latitude, because despite the pull of the stereotype, its foundation is precisely the individuation of character. Not only is the viewer alerted to tell-tale symptoms but the fiction film is able, through its own narrative devices, to enter the subject's disordered head and evoke their world. Some do, many don't.

What is perhaps at stake here is the difference between what the camera shows and what we read into it. The former is what semiotics calls the profilmic scene, the image as it appears to the camera, which in fiction cinema, according to Walter Benjamin, is 'the height of artifice' in which 'the sight of immediate reality has become an orchid in the land of technology'.[16] Think of this as soft realism, the naturalistic verisimilitude of surface appearance, as opposed to the deep realism (or the lack of it) which evokes what cannot be observed directly, because it consists not in people and things but in their relationship with the socio-economic forces and structures lying behind them. Soft realism is perceptual – in the dementia film, for example, it includes the supposedly accurate depiction of symptoms and behaviours, medical interventions and so forth – but this is also highly conventionalized. It operates through the grammar of what the film theorist Noel Burch called the 'institutional mode of representation' (IMR), in which continuity editing aims at the illusion of a seamless, full reality, with nothing lying outside it.[17] Deep realism, on the other hand, is cognitive and semantic, and delves behind appearance, either directly and indirectly, to invoke underlying social, economic and existential truths to which the film gives depth through the dramatic, symbolic and metaphorical resources of fictional narrative. As we shall see, both may be inflected in different directions. Many films, especially those from the Global North, remain satisfied with soft realism, plausible narratives, and medical diagnosis as the governing framework for understanding the subject's behaviour. Some use non-naturalistic techniques like disorienting camerawork or fragmented narrative to convey the subjective experience of dementia; some dispense with medicalization. Most focus on personal stories, which tends to narrow the thrust to the dyadic entanglement of the sufferer and their carer, to the exclusion of the wider social context. Some swap a loving family for a dysfunctional one, or

the domestic setting for the care home. A few adopt a historical stance, notably films from Spain and Chile, where, due to their particular national histories, dementia is liable to be seen as a metaphor for the historical amnesia of societies traumatized by fascist dictatorship. A few break with the IMR entirely, replacing it with the esoteric experimentalism of the art house.

The paradox of the medicalized Alzheimer's drama is that it cannot be judged primarily by medical criteria, even when the film follows them closely. There's a slim body of academic writing in specialist journals that approach the representation of dementia on screen from a clinical perspective, and find certain films wanting because one way or another they falsify the clinical picture. Sometimes it's true that a film strikes a false note which impugns it, and to be sure there are many dementia dramas that condense the time span of the disease into a more compact narrative (and I shall mention examples of both), but the problem with these accounts is (again) their lack of aesthetic sensibility. Apparently oblivious to the work of film theorists and historians on the language of cinema, they are liable to strike a false note by evaluating the wrong thing and thus missing the point. A prime example is a collective article in the journal *Aging & Mental Health* from 2013 called 'Dementia in the movies: the clinical picture', which analyses a selection of twenty-three movies since 2000 according to four criteria.[18] These authors' first mistake is to exclude films which possibly portray dementia but it isn't explicit, thus excluding a good number of highly significant films, including several from the Global South. Their criteria are films where (i) the person with dementia (PWD) is the leading character during the whole movie; (ii) the PWD is the leading character with dementia in parts of the movie; (iii) they're a relevant supporting character; and (iv) where they have only a minor role. This is nonsense. The criterion of screentime is not without significance but simply counting the frames is irrelevant to the role of the PWD within the drama, in which, diagnosed or not, they can be dominant without being present on screen much of the time, or only in the background, as we'll find in *High Hopes* (Mike Leigh, UK, 1988), *El hijo de la novia* ('The Son of the Bride', Juan Jose Campanella, Argentina, 2001) *The Savages* (Tamara Jenkins, US, 2007) and *A Separation* (Asghar Farhadi, Iran, 2011). What are such films about if not the existential impact of dementia on sufferers and their families that clinical detachment all too easily ignores?

Second Theme: Symptoms

The growing prevalence of dementia has the consequence that, as you grow older, it encroaches ever closer on your social circle. For myself, the first time was already many years ago, a respected older academic colleague, with whom I'd enjoyed memorable conversations. Then after a gap, another, who was a little younger than me, and hale and hearty when I last saw him. Over the following years, I heard from friends about parents who had fallen victim to the disease. Finally it arrived in my family at the same time as the coronavirus pandemic. My cousin S., who by

lovely coincidence shared her birthday with my eldest brother – born in the same year but on opposite sides of the Atlantic – had lived alone since her mother died, in the same flat in London the family moved into in the 1950s. I was very fond of her, visited her often and spoke on the phone in between. Now, under lockdown, these phone calls became very strange. She began talking about unlikely goings-on involving neighbours – she lived in a very respectable block of flats and her neighbours were friendly – which didn't make sense and sounded distinctly paranoid, a trait she'd never displayed. I was extremely worried, unable to make the trip to see her, until A., a distant cousin on the other side of her family got in touch and told me she'd been taken to hospital in a state, and was being tested for Alzheimer's. I only learned much later what had happened. Isolated by lockdown, S. had taken to wandering the corridors and knocking on doors in evident distress, even in the middle of the night, when you weren't supposed to do that at any hour, and was then found collapsed in the lift, at which point the caretaker contacted A., who quickly went round and called an ambulance. A., who is a psychologist by profession, immediately realized S. was in crisis and needed to be sectioned. On the way to the hospital, S., who is fiercely independent, became very aggressive, and then, when they arrived, because this was in the middle of lockdown, A. was unable to accompany her inside and had to leave her there. A traumatic experience for both of them. One saving grace: not long before, S. had given A. power of attorney, so she was able to take control of the situation, and after S. had spent several weeks in a dementia ward, arranged for her to return home with a carer round the clock. In recounting this, I am well aware that the story would be very different for someone without the private resources to pay for live-in care. Now she has friends who visit and take her out, and has outlived my eldest brother who died three months after their ninetieth birthday, peacefully and not unexpectedly, at home, surrounded by his family.

Then the same thing happened with my second brother N., whom I hadn't seen since before lockdown – he lived alone in the West Country, a widower with no children. We spoke at intervals on the phone. Now these too became strange conversations suggesting incongruous behaviour, which showed up in several ways. From one call to the next, he forgot what he'd told me previously. He began having memory lapses which went beyond the 'senior moments' that everyone experiences. He grew frustrated when he couldn't find the word he was looking for. A couple of times he launched into an unnecessary argument. Then he started talking about losing things, or rather about people entering the house and stealing things – the same paranoia as S. He developed a phobia towards using his computer, although he was previously a swish film editor who began using computer editing when it was first introduced at the start of the 1990s, but now, when he phoned to ask for help with some computer problem (before he gave up completely), I couldn't understand his attempt to explain what was going wrong. He has a few friends he spoke to on the phone but was ever more isolated, withdrawn, depressed and confused. I've read that it's common for someone entering dementia to be unable to recognize what's happening to them and refuse help. What if, like N., they're not so much unaware as in denial, and although declaring their confusion, simply

refuse to go and get tested? He had a private help who visited him most days. His GP confirmed that he has 'significant cognitive impairment affecting his memory' and 'some paranoid thoughts', but 'has been refusing further investigations' into his 'presumed dementia'. This is not an official diagnosis but as I go on to discover, a form of coded medical language with its own history. The immediate concern is that it means he wasn't yet registered with the social services where he was living, and this is a problem which is likely to come back to bite.

Between N. and me is my third brother G., who lives not far from me and whom I see regularly. What happens next falls mainly on his shoulders, and marks the difference between the slow atrophy of long-term memory and the more rapid loss of short-term memory. The former is private to the individual, the latter has practical consequences not only for the sufferer but also for those close to them. Since N. always used to be very efficient at running his affairs, G. already had power of attorney. This was fortunate, because N.'s most problematic memory lapse was not so easy to deal with. He decided he was fed up living where he was and put his house on the market, saying he wanted to move back to London where he had friends. We doubted that London was viable, being far too expensive, and the only feasible solution was having him come to live near us and, given his uncertain future, not to buy somewhere but to rent. Events proceeded rapidly, and G. took on the arrangements. A number of people came to view and within a few weeks a sale was agreed, at a very good price, but N. couldn't keep track of what was going on, even though G. went to visit him several times and kept him up to date. However, he didn't seem to register that his house had been sold, and the implications only confused him. G. recalls what happened:

> It meant that some decisions he had been used to taking himself now increasingly bypassed him, so he genuinely couldn't remember them because he hadn't experienced them. This meant his memory seemed even worse than it was. For example, he remembered putting the house on the market and people coming round to see it but when it came to the offer, I had to tell him what it was and get his agreement, which I did, but he then forgot that because, he said, 'they never came back to me'.

Part of the problem has to do with the enigma of money. Money is a paradoxical medium, simultaneously concrete and abstract, a symbolic form combining numeracy and a designation of value. As a condition of competent citizenship, children learn the mental arithmetic that becomes second nature, and how to judge price not in theory but in everyday life. In neurological terms, this is a complex negotiation between different faculties. To go shopping, operate a bank account, and nowadays handle electronic payment, involves working memory for numbers and calculation; semantic knowledge of financial terminology; reviewing multiple items of financial information simultaneously and making choices. This engages the skills of planning, organizing and decision making – what neuroscientists call 'executive function', as if the brain were a business. (The term

is a euphemism for what the science cannot explain – the autonomous nature of consciousness that used to be called 'free will', which is lost in dementia.) People who develop special skills in handling money go on to prosper in the world of finance, but the impairment of any of these capacities leads to the breakdown of the whole chain. What starts when short-term memory begins to lapse, perhaps with a mistake proffering money at the till, may soon turn into an inability to make sense of a receipt or a bank statement, or making irrational purchases, not to mention falling for scams more easily.

Some of these symptoms are demonstrated by G.'s account of his dealings over the sale of N.'s house.

> One of the most fraught repeated anxieties (for me as well as him) was his repeated insistence that he had no money. This began way back, at least a year ago, when his bank changed the format of his monthly statement and he could no longer distinguish income from expenditure. Banks and other institutions proudly tell you they have a new format, without a thought for the effect on many people who – with or without dementia – are not good at reading financial documents, which are also in very small print. Showing him that he did have income, from the DWP and an annuity, and savings, reassured him for a time but as he was no longer handling his own money, it didn't stick. He wanted to be able to go into a bank, as he had been used to do, and get money over the counter. I accompanied him doing this a couple of times before he lost his card, and also his building society pass book for the third time. Then of course the banks started closing their branches and moving everything on line – which, as you say, had now become impossible for him.

We started sharing the tasks now facing us. I ran the obstacle race of the borough's website and advice lines, and established that no assistance would be forthcoming from social care services, on two counts: he isn't registered with social care where he currently lives, and his assets are too great to qualify. We reviewed the availability of sheltered housing but decided instead to rent a small house where we could try and make him feel at home, large enough to accommodate a good part of his considerable library and collection of artworks as well as some of his furniture, and a garden for his dog Poppy, a short distance from my own flat and close to a park where he could take Poppy for a walk. It also had a spare bedroom, in case live-in care became necessary, and G. arranged for a private visiting carer, but we didn't tell N. these arrangements so as not to overload him with information that would only confuse him further.

When it came to the move, we told him many times that it was going to happen, and that the removals people were coming to pack stuff up (with a preliminary visit by the manager, whom N. had met before, to discuss how it would be done). But after they packed everything up he said 'People came in and took all my books away and I never saw them again.' When we showed him the books in the new house, placed on shelves somewhat similar to the way they had been before, he said, 'Oh, someone's brought them back.'

Development: Costs

The fact that people are living longer and dementia is mainly a disease of old age increases the strain the ageing population places on a care system which is fragmented, largely privatized and a drain on household finances. A few minutes' internet search informs me that on the eve of the Covid-19 pandemic, there were around 900,000 people with dementia in the UK, and growing. The latest projections predict as many as 1.7 million people could be living with dementia in England and Wales by 2040 and one in three people born in the UK today will develop the condition in their lifetime.[19] Projections like these are both frightening and problematic. Designed to grab attention, they reduce the data to ambiguous slogans, so I decide to ask an AI chatbot what 'born today' means in this context and it tells me that 'While "today" might seem to indicate a single day, in demographic projections it often represents a current time period, which could be this year or a span of a few years centred around the present.'

I also learn from web searches that in the UK in 2024 some 60 per cent of social care costs were borne by families, to the tune of £8.3b per year, while the state pays £5.2b, but unpaid carers – usually family members – provide care to the value of £13.9b, or more than the first two sums combined. It isn't easy to make sense of these huge figures, which one has to take on trust, but they're not transparent. In the first place, like all social statistics, they can only be estimates. For example, we learn that the rate of diagnosis is a little over 60 per cent (which is better than it was) but how does anyone know how many people are not diagnosed? The figure can only be an extrapolation from other data. Or again, different studies suggest that anything between 25 per cent and 42 per cent of those with dementia reside in care homes. What does this wide variance tell us except that large numbers of people remain at the margins of the care system? They are looked after by their family, who are obliged to suffer with them, whether by choice or force of circumstances, to the detriment of their financial situation and their own state of well-being, or else by private carers who most people can barely afford.

According to Age UK, when people say they don't want their children looking after them, what they generally mean is that they don't want their children providing intimate care. There is little doubt that remaining at home is best for the sufferer, but to keep them there needs professional carers far beyond the current system of social support, leaving a care home as a last resort. As someone from the Alzheimer's Society puts it, 'the reality is 92% of unpaid care is provided by family, a fact which, as a society, we seem strangely in denial about'.[20] Again, if it's unpaid, and therefore submerged, how do they know it's 92 per cent? Whatever the criteria, it's clear that the system is dysfunctional.

There's another problem. The costs of paid care are deceptive. They reflect the very low rates of pay that prevail in the social care sector. This is due to a structural problem in the neoliberal economy, which not only undervalues care work but also relies on being able to treat immigrant workers as a reserve army of labour. Brexit and the Covid-19 pandemic both played a part in a dramatic rise in the number of migrants from the Global South working in the British care system,

but according to the Royal College of Nursing (RCN), the UK has been recruiting them from the same countries on which it has imposed cuts in foreign aid. The RCN's general secretary calls this 'a double whammy for some of the world's most fragile healthcare systems', and 'a damning indictment of successive governments' unwillingness to properly fund and grow our own domestic nursing profession'.[21] A previous report from the same organization found serious instances of exploitation and mistreatment of this immigrant workforce, including cases amounting to forced labour, punitive debts for spurious visa costs, and other practices associated, according to lawyers, with modern slavery and human trafficking.[22] Meanwhile, in the countries these immigrants come from, millions of sufferers have no form of public social care available to them at all, and in many cases, dementia is not distinguished in common experience from dotage.

Another web search brings up some more statistics, no easier to comprehend or tally, but a certain pattern can be observed. The worldwide costs of dementia and Alzheimer's are enormous. One source, dated 2013, says they amount to around 1 per cent of the world's GDP, whatever that's worth; another, in 2019, says $1 trillion. A recent estimate predicts $2.8 trillion by 2030. Whatever the values, they're distributed inequitably between the Global North and the Global South. An estimated 50 million people live with dementia globally, more than two-thirds of them in 'low- and middle-income countries', but the greater part of the attributable costs belong to the Global North, where there is public or private provision that someone's paying for, so it can be counted. The rest of the world can't afford it, and care is principally informal and submerged. Even in rich countries, as just noted, only a proportion of sufferers are covered and a huge part of the burden falls on kinfolk, especially women, who are unpaid and unaccounted. That this fate is even more common in the countries the immigrants to the Global North come from is hardly surprising, but reflects the underdevelopment that the history of colonialism bequeathed to the geopolitical reality of the twenty-first century.

However, as the scholar Raquel Medina attests, although dementia is a global problem, that doesn't mean that it's perceived, defined or represented uniformly in different cultures.[23] Each culture perceives ageing and senility differently according to its own prevailing social and cultural values. In occidental cultures, to contract Alzheimer's is to be marked out for a fate worse than death itself. Not necessarily so in other cultures, which are more accepting of death, and more attuned to the social presence of the person with dementia rather than their isolation. In several films from non-Western cultures that Medina analyses, dementia is seen in a wider perspective, and the screen becomes a prism for problems of a social, cultural, national, and political nature, and not least, gender issues, although the latter are not absent in films from the North.

There is also a difference in the status of memory. The way memory is negotiated by different cultures is always an unfinished dialectic, but, at the risk of over-generalizing, there is a salient difference between occidental cultures, which give prominence to memory as personal and private, and those with a strong sense of memory as social and collective. Of course it's both. Moreover, both are malleable and suggestible and prone to lapses and distortion. But the occidental portrayal of

dementia is liable to turn inward, under the sway of the ideology of individualism, whereas cultures with stronger collective frameworks might understand it as a rupture in the social fabric, a loss in the web of relationships and shared narratives distributed across the community rather than confined to an individual.

First Variation: Symptomology

Returning to the internet, I find a helpful article by a psychoanalyst which says that dementia is not like child development in reverse. The amnesia in Alzheimer's is retrograde but sufferers are adults losing their minds in a non-linear fashion.[24] It begins with lapses of attention in the present, disrupting the subject's sense of ongoing time, before it attacks the integrity of past memories. That is, short-term memory malfunctions first, while the past still remains. Sandra Evans speaks of three broad and perhaps arbitrary stages of development (though others identify more). The first is dominated by anxiety, depression, repression and denial. I could see all of these in my brother, but what strikes me about both N. and S. before him, is the paranoia that announced their loss of grip on reality. Evans says about this that 'the abnormally functioning mind is split off and projected into others. The individual with dementia cannot remember where they put things; someone (usually a relative or the "home help") stole it – no matter how unlikely.' The camera has no direct access to internal forgetfulness, which fiction is able to reveal through dramatization more readily than documentary observation. Accusations of someone stealing things are a common early symptom, difficult for an observational camera to catch, but easy to dramatize.

In the earliest stages of the affliction, which in some accounts occurs prior to the Evans' first stage, and for which the medicalized term is 'mild cognitive impairment' (MCI), the sufferer themself is largely unaware of their own cognitive deficits. Not surprisingly, people living alone, like both my cousin and my brother, are more likely to escape early detection. If MCI is noticed at all, it's often put down to the so-called 'senior moments' of normal ageing. By the time the symptoms of dementia become demonstrable through cognitive testing, the disease has already advanced and is entering the next stage. These tests, which are eminently filmable and crop up in both fiction and documentary, are the first steps in bringing the subject under the watchful medical gaze. They consist of a series of questions or tasks covering different forms of linguistic comprehension and language skill, short-term memory, attention span, passage of time, spatial perception, numerical ability and abstract thinking. These questions reveal forgetfulness, temporal and spatial disorientation, depleted language skills and other impairments. All are at play but develop differently in each individual. I watched my brother being given cognitive tests, of different degrees of complexity, four times, and saw all of these. What he made of these tests is difficult to gauge, but he was aware of his loss of connection with the outside world and remarked on it. He was still the same person and mostly placid and polite to the testers, but as the phrase goes, 'not all there'. In fact, since we had to move him, he doesn't know where he is, and is given to confabulation

to cover up the gaps in his comprehension, sometimes telling fantastic stories untrammelled by reality and closer to the illogic of dreams and the irrationality of the undifferentiated primary process of the unconscious. In one of them, having forgotten that he was brought here by car, he spun a tale in which his neighbour had given him a ticket to fly to India, where he had indeed made several trips to take photographs. I couldn't help wondering if the dream state had not invaded his waking life, blurring with reality, and at times he couldn't tell the difference any more. It must be like living in a waking nightmare, like being thrown into a novel by Kafka, except that it's not a book that can be put away on the shelf.

The final stages are those of total withdrawal and extreme dependency. N. has not yet reached this stage, but there's no way of knowing how far away it is.

Of course everyone is liable to confabulate in different ways and for various purposes. The possibility of doing so is inherent in language. Maybe it isn't confabulation when we edit an event which we're recounting to suit the circumstance of the telling and without actually inventing anything. But try to talk about the state of society or the world, and it's difficult not to fall into the confabulations of ideology (whatever your political persuasion). The cleverest people do it. Politicians are especially prone, particularly during election campaigns (like the one going on as I begin this study). The confabulations of someone with dementia are quite different. They are mental phantasies designed to cover gaps in memory. Judging from conversations with my brother, they're not just passing delusions but take hold of his mind sometimes for several days at a time, before giving way to another. According to Evans, the confabulation that occurs in early dementia is a way subjects have of concealing their difficulties to both themselves and others. 'Some claims are quite remarkable and have a manic quality, a clear defence against the anxiety and depression of loss.'

Evans explains that because of the retrograde character of amnesia in Alzheimer's, early childhood memories remain prominent and the hold on recent memory less so. I can see this in my brother, but what I observe is more complex. His short-term memory is kaput, both across the day and even in the same conversation, but his amnesia seems to extend back over several years, and prior to that, his memories have become detached from their historical moment. He remembers high points in his career and certain people he was close to, more or less in the right order but without being able to date them or place them historically. For example, he thinks he joined the BBC, where he trained as a film editor, in the 1940s; I gently remind him it was in the early 1960s. I do this by recounting what psychologists call a 'flashback memory' of mine, in which N. figures centrally and I think he might also remember, at least if reminded. These are memories in which an historical event makes such an impact that people remember not just the event but the scene at the moment they heard about it. The phenomenon is cross-cultural, and I once discussed the memory I'm about to recount with a group of Latin American friends over dinner in Caracas, and all but the youngest, still a child at the time, remembered it this way. Mine goes like this. The date was 22nd November 1963. I was seventeen, N. was working as a trainee at the BBC, or perhaps already as an assistant editor; the family was gathering at home for the

Friday evening meal when the phone rang, and by chance it was me who answered it. 'I remember exactly what you said', I now told him, 'You said "In case you haven't heard, Kennedy's been assassinated and I'm not coming home until further notice"'. His response was a broad smile as he nodded in acknowledgement. Whether this is a memory he can retrieve at will and date correctly is another matter. G. offers a slightly different interpretation. If his memories are indeed detached from their historical moment, 'perhaps he said "1940s" meaning "a long time ago", like the Old Testament's "forty years in the wilderness" just means "a long time"'. In other words, not a mistake but a metonym.

Second Variation: Memory

Flashback memories are a special type of autobiographical memory, or what psychiatry calls 'episodic' memory. I've known about this for a long time, prompted by studying philosophy at university to read widely across psychology, psychoanalysis and even neuroscience. I therefore now approach the topic equipped with a degree of already acquired knowledge, although when it comes to neuroscience, with reservations about its aporias, especially concerning the psyche and the domain of imagination. Notwithstanding, neuroscience tells us that the human brain is a distributed and multitasking system of parallel networks operating below consciousness, which draws on interacting functions of mental activity each with its own jobs to do – visual and auditory processing, language, proprioception and motor skills, and so forth.

Consciousness is modulated by the still mysterious process of attention, which can be narrowed by concentration, or broadened by letting your mind wander. These networks include different types of memory, whose contents can sometimes be invoked at will, and sometimes jump to mind by train of association – the basis of both psychoanalytic free association and the creativity at play in art, science and invention. (Evans comments that whereas the psychoanalyst has to explain to their client the need for free association, someone with dementia seems to fall into it quite naturally.) The types of memory commonly identified by cognitive psychologists are *short-term* or *working memory*, where things are held in the back of the mind for as long as they need to be and are then discarded, sometimes described as the economy of memory; *episodic memory*, which is autobiographical, the story of your life and the people in it, what happened, when and where, and how you felt; *semantic memory*, which is linguistic, cultural, social, and independent of the time and place of personal memories; and *procedural or implicit memory*, the cognitive and motor skills that once learnt seem to reside in the muscles of the body and are performed without conscious thought of the steps involved; the toddler learning to walk, riding a bicycle, playing a musical instrument, or the act of writing, actions that become what we call second nature and free the conscious mind to pursue the purpose of the activity rather than the mechanics.

To coordinate these different mental functions, which stand ready in the preconscious, we ordinarily rely on a whole number of highly dependable but barely conscious cognitive processes, learned skills and habits, which range from

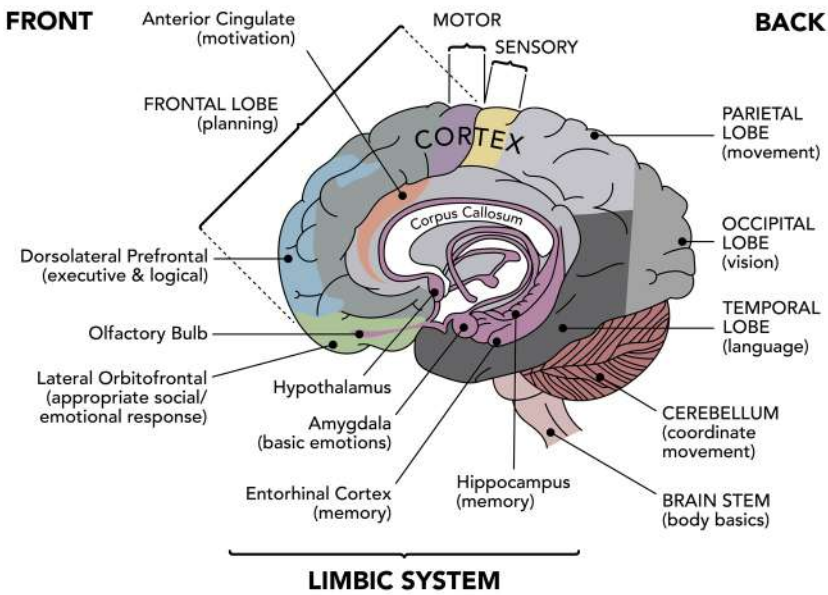


Figure 1 Diagram of the human brain.

Brain diagram from The Brainwaves Center (brainwaves.com). © 2016 Allen D. Bragdon Publishers, Inc. All rights reserved.

just crossing the road safely to playing games to complex procedures like cooking, over which we have exquisite control (I'm not talking here about the alienation of paid labour). All such activities involve estimating the passage of time and duration, as well as making and remembering choices and decisions. These also pertain to what cognitive psychology calls *predictive or proactive memory*, by which we navigate both the immediate and the more distant future. I now learn that dementia quite rapidly takes effect at these levels too, slowing sufferers down, making them clumsy and in the end, incapable of performing habitual activities. What I sense when I visit my brother – I feel it the moment I walk through the door – is not just that he loses track of time but that the tempo of his existence is stretched and distorted, as if time itself runs slower, haltingly and unchained. A little like daydreaming, but you can't snap out of it. The challenge for cinema, a collective form of daydreaming, is how to communicate this unfettered sense of time on the screen through its own forms of malleable temporality.

The frustration this condition produces is only the least of it. The science teaches that the roots of emotion are deeply buried in the brain and that feeling remains intact while the cortical, thinking and deliberative areas deteriorate unpredictably. The sufferer is faced with the problem of these different levels becoming decoupled. According to the model I'm following here, this would have several effects. The dysfunction of short-term memory makes it hard to track the passage of time, and making plans or observing a schedule becomes difficult, if not impossible. Predictive memory disappears. (This had already happened to my brother.) Older memories remain available, but become detached, and as in dreams, disconnected from their

historical time and place. Autobiographical memory loses its thread. The term 'episodic memory' here becomes ironic, because the episodes they represent are no longer gathered in the continuous form that gives us our sense of self, but simply serve as badges or medals of identity. N. is proud of his professional achievements, but has said to me he doesn't know who he is. The narrative of a life has evaporated.

In formal language, neurodegenerative disorders present with significant disruptions to time perception both in the present and in mental time travel, the ordinary experience of thinking back to past events and forwards to the future, in life or imagination. The confusion is compounded by loss of language. N.'s speech is interrupted by his frustration when he fails to find the right words ('I can't speak any more') or loses his train of thought ([pause] 'doesn't matter'). But as the disease advances and memory and language disintegrate, the deep structure of personality persists. As a human rights lawyer I interviewed in Washington many years ago wryly observed, 'We could have Alzheimer's, but we still remember our prejudices.'[25] Other more positive traits also remain. N. has not lost his sense of humour, and smiles when I tell him a joke. It's a good way to get him away from obsessive thoughts.

Third Variation: Disconnect

In some of the documentaries about dementia I've been watching on YouTube, the sufferer is living at home, has had a diagnosis that they know about, usually Alzheimer's, and is still articulate enough to speak coherently about what they feel happening to them. These films are often instructive and full of good advice, but tend not to address the family's social or economic circumstances, or the politics of the administered society which they have to manoeuvre. This comes home to me as we take over my brother's care arrangements and find ourselves exposed to the disconnect between the different parts of the health and social care system. I've not previously had need of dealing with social care, and my GP, with whom I registered N. in advance of his arrival, referred me to their own Social Care Prescriber, who explained how the system works, or is supposed to, and told me that in this district the waiting time for the Memory Clinic, who carry out diagnosis, is four to six months.

I can only speak of the conditions which confront me here in England, where dementia has been called 'one of the hidden forces reshaping Britain's political landscape' by a journalist who describes social care as a time bomb.[26] According to a report by the Alzheimer's Society, the number of people suffering from dementia in the UK is forecast to grow by about 40 per cent by 2040, but there aren't enough care home beds or staff as it is. Already, in consequence, 'an unacceptable amount of the financial burden' falls on individuals and families.[27] (Arrangements are slightly different in Scotland, where personal and nursing care are theoretically free, but care homes are underfunded and some of the costs still fall on families.) The problem is exacerbated by a disconnect between medical and social care. The former is provided by the NHS (National Health Service), the latter is the responsibility

of local authorities, whose funding has been slashed by the austerity measures introduced by the Tory-led government in 2010 and who nowadays mostly contract out their responsibilities to private providers. The journalist sums up, 'the costs to the state are dwarfed by the cost to sufferers themselves, draining life savings to pay for nursing care that if they had cancer they'd get for free, and to families left picking up the pieces … navigating the bureaucratic maze that conceals whatever help they're entitled to'. According to another report, there are about 18,500 care providers, mostly very small homes or home-care services, but 13 per cent are owned by private equity chains, and the proportion owned by local councils has been estimated to be as low as 3 per cent. Half the residents in care homes pay for themselves, as do a third receiving care in their own home.[28]

That last statistic includes my brother, and we now discover that the only provision available to him, as it is to every pensioner, is called Attendance Allowance. I don't know where it appears in the government's financial accounting, but it's a pretty measly sum which requires filling out a complex form of thirty pages with sixty or so often multi-part questions, which you can download as a PDF that you can fill in on your computer, but which then has to be posted back with enclosures. It's a clunky method. So is the NHS app, which is supposed to optimize the primary care system, but in my experience suffers from bugs. If you're reading this in the UK, then you'll probably be familiar with other symptoms of the combination of underfunding and digitization, like the difficulty of getting a face-to-face appointment with the doctor, or seeing the same one you saw last time, which requires the infamous early morning phone call with a receptionist who is nowadays trained to act as a guard dog to keep the doctors safe from people who might waste their highly pressed time. But what if they're calling because they're not sure what's wrong with them or someone they look after, and need the time to discuss it? If what's needed is personal interaction, then the automation of the system doesn't help. Doubtless this has come about from the best intentions, the centralized application of digital technology to improve the efficiency of the service, but that depends on what is meant by efficiency. I'm not a Luddite, nor a bleeding heart liberal, but a sceptic about the claims made for IT, and repetitive form filling online in order to get to speak to a doctor is no alternative to waiting your turn in a phone queue; in fact it's worse. As the GP Phil Whitaker has written, there is no continuity of care, the family doctor no longer exists, the way primary care was originally designed is gone – as a universal service within the community which provides ongoing personal attention at the point of need.[29]

The NHS app on your smartphone doesn't personalize the service; it has the opposite effect, that of depersonalization. It's also impossible to use by someone like N. When he started becoming paranoid, his previous carer got him one of those alarms you can wear around your neck and use to call for help. She had to take it away when he started using it to call the police when he couldn't find something and thought someone had stolen it. What was stolen was nothing physical, but the integrity of the world he lives in as he now perceives it, fading away like a screen going to static.

I have seen none of this bureaucratic maze in the films I've been watching, with only one or two exceptions.

Fugue: Time

I learn that the disorders of dementia have been clinically mapped and classified.[30] The main headings are *amnesia*, for all forms of memory impairment; *aphasia*, indicating language disturbances; *apraxia*, referring to impaired ability to carry out motor activities; *agnosia*, or failure to recognize objects, and *prosopagnosia*, or 'face blindness', which usually comes later; and the disturbances in planning, organizing, sequencing and abstracting known as ~~the~~ 'executive function', which tend to develop early. All have subcategories. The sufferer's inability to orient themself in their environment, to recognize familiar surroundings and landmarks, is called *topographical agnosia*. Disorders of time perception are *chronoagnosia*. Language disorders are especially well differentiated. The repetition of phrases just spoken is *echolalia*, *palilalia* is the repetition of words, and repetition of the last syllable is *logoclonia*. Failure to name objects is *nominal dysphasia*, difficulty in reading is *alexia*, and *agraphia* is difficulty in writing. Incapacity in handling numbers is *acalculia*. There is also the pseudobulbar affect, consisting in uncontrollable and exaggerated episodes of laughing or crying.

I recognize many of these in my brother in one degree or another, but not all. Not, for example, the last. Also, his speech is slow and hesitant, but free of echolalia, palilalia and logoclonia. His sentences are often unfinished and full of nominal dysphasia, but it isn't clear whether this is because he doesn't recognize the object or he can't find the word. G. mentions to me that 'sometimes his getting the wrong word gives an impression of an even more random thought than he is struggling with, as for example when he told me that the short morning walk with Poppy was "about 35 miles" and I realized later he meant 35 minutes'. As for face blindness, it would seem he can recognize faces without being able to put a name to them, for instance, in the case of relatives he doesn't see often, but also his carers, who for him are strangers who come and go. But in the latter case, he doesn't really understand that the reason they're there is to care for him.

While cognitive testing is employed to gauge these symptoms, many of them are readily apparent to the film camera, like aphasia, or the clumsy performance of everyday actions like getting dressed. Since the representation of space is the very métier of cinema, it's easy enough to portray spatial disorientation, although fiction and documentary work differently in the way they do this. In observational documentary, the sufferer may be seen to wander aimlessly around their own home in a bewildered state, but the possibilities are much greater in fiction, which not only brings into play a panoply of visual effects through lensing and montage, but can also show the sufferer roaming outside and getting lost. Like someone returning to the neighbourhood where they grew up and finding the old landmarks gone or altered, the district rendered unfamiliar, their cognitive geography of the place no longer obtains. They find themselves in any-space-whatsoever. Their world has both shrunk and been set adrift. The difference here between fiction and documentary is that you can't normally expect someone with dementia to be able to act, and you can't follow them around the streets with a camera as they lose their way. Documentary makes ethical demands which are absent in fiction, or different.

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