Free Associations: Psychoanalysis and Culture, Media, Groups, Politics
Number 92, Autumn 2024 ISSN: 2047-0622
URL: http://www.freeassociations.org.uk/

Mind, Body, Memory: Making sense of my brother's dementia

Michael Chanan

I

It's difficult to throw off the idea 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. On the other hand, science is paradoxical, and at the same time, some scientists tell us we can create artificial minds in the circuits of electronic machinery. I've written before in these pages about why Artificial Intelligence should be called Artificial Stupidity.[1] What concerns me here, however, is neither neuroscience nor cybernetics but lived experience, the subjectivity of sentience that the former is unable to explain and is lacking in the latter, and in this perspective, specifically the experience of growing old, when you become aware that mind and body have different rhythms. What normally happens is that the mind stays on track while the body ages. You begin to realise that you look older than you feel. It creeps up on you. You enter a crowded train carriage and someone offers you their seat. The people you see on a regular basis don't seem to notice, and unless you fall ill, nor do you, but you begin to realise that your mind and your body are out of sync. You have to admit to yourself that you're getting older.

Then memory steps in and brings your life back to you, along with the circumstances that have shaped it, some of which are private and autobiographical while others are social, cultural and historical. If, like me, you're a teacher, you come to realise that the history you take for granted is remote from your students, and is not just about facts. It is also the domain of culture, and culture is a form of intersubjectivity disseminated through signs and symbols which are constantly changing. Central to the transmission of culture is the way the visual arts generate 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 body is a constant but attitudes towards it, and the discourses which form around it, shift through time. A cultural revolution began when photography was invented and inaugurated a new age of self-consciousness and narcissism which now assaults us at every turn, in which old age comes off poorly. It isn't just a question of ageism.

---

[1] Michael Chanan, 'Artificial Stupidity: On the alienation of intelligence', Free Associations: Psychoanalysis and Culture, Media, Groups, Politics Number 88, Spring 2023 http://www.freeassociations.org.uk

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 the 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 neurodiverse have become more visible, both in the street and on the screen, and have begun to speak for themselves. The senile, however, remain disadvantaged, normally hidden from view and voiceless. When the camera invades their space, the image is all too easily voyeuristic, and nor does filming them bring them alive, but often presents them as either zombie-like or talking nonsense, or at best, joining in sessions of music therapy like marionettes.

II

Growing old isn't just about your body coming under strain, often long before you feel the approach of death. Death arrives when it will, and the best you can do is come to terms with the prospect. But it's not just about your own demise. Wittgenstein held the view that death is not an event in life. He should have said, in your own life, because it is in other people's. I don't mean the deaths you learn about in the news, innumerable victims of wars, earthquakes, floods, terrorism and murders, which affect you at a distance, but those of people you know in the flesh, your intimates, friends, associates and acquaintances. The representation of distant death is constant, but you start to feel its approach when those of your own generation begin to die, relatives, friends, people you've worked with, some of them older, some younger, some after falling ill, some suddenly. The last of these are the most distressing. When my eldest brother died three months after his ninetieth birthday, it was not unexpected, and it was not a shock. A few months earlier, when one of my closest friends was found dead on her doorstep by a neighbour, I experienced what Freud called the first stage of mourning, the 'it's not true' with which people often greet sudden news of bereavement.

My brother was a religious believer. Did he have a fear of death? Only, I think, in the religious sense, not personally. I know from what he once told me that he had a fatalistic attitude towards death, having once narrowly missed being blown up by a terrorist bomb (in Israel, in the 1950s). For an atheist like myself, there is no fear in death, but only the hope of dying well, that is, peacefully, quickly, without pain, and in dignity. Our contemporary culture makes this difficult. The dying are sucked in to a system of health care that despite its professionalism (and partly because of it) inevitably depersonalises them, and is particularly unkind to those who linger. What is most disquieting, however, is the deaths a person may suffer before they die. The victim of a car crash who only survives thanks to a life-support system which encases them in the latest medical technology. The terminal ill, suspended in a medicated haze. The patient in an ICU struck down with Covid19. But there are other kinds of death before death, which act more slowly and don't actually kill you, but reduce the sufferer's life to the barest minimum. My mother lived for twenty years with Parkinson's, dying almost twenty years after my father (from cancer) in her early 90s after years of immobility, during which her eyesight deteriorated, she seemed to shrink into herself, her conversation became sparse, and her only real pleasure was visits from her grandchildren and eating her favourite foods. She lost her will to live, and once said to me that she wished there was a pill she could take. It made me see how death can become seductive, and inclined me to the opinion that a humane society should consider the option of assisted dying (under appropriate conditions). It's a very difficult question, but as things currently stand, medics are expected to do everything they can to preserve life, which often means extending it beyond its natural term.

The immediate cause of Parkinson's is a chemical imbalance in the brain which affects control of bodily movement, but not necessarily the mind, at least directly. The effect is a slow subsidence of mental life into a psychosomatic fog, a kind of death looming up within life. Even more insidious is another brain disease which does not affect the body or its vital organs but only the mind. It creeps up slowly, and before the emergence of modern psychiatry 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'. We now call it dementia, the Latin word for 'out of one's mind'. Demented, but not in the same way as the forms of mental breakdown that are treated in mental hospitals. These may sometimes by alleviated, or at least held at bay by drugs. Senile dementia is progressive and has no cure, although scientists are busy looking for one, and meanwhile there are only palliative medicines. Since people live longer, the frequency of dementia has increased, and in the UK is now the leading cause of death (11% of all deaths). There are also cases when it strikes at a younger age, and it was one of these that led to the discovery in 1906 by a German psychiatrist and neuropathologist, who observed abnormal clumps of a protein called amyloid in his patient's brain after her death, of the disease that now bears his name. Today, Alzheimer's is the primary, though not the only cause of dementia.

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 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. 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 – 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 cousin on the other side of her family (whom I didn't know) got in touch and told me she'd been taken to hospital in a state, and was being tested for Alzheimer's.

We are a middle-class family. My father died in hospital after an unsuccessful operation, my mother at home in her bed, peacefully, while asleep, three days after falling into a coma. S. spent a few days being tested, then a short while in a dementia care ward, and then came back home with a live-in carer, and a circle of friends who visit and take her out. Aided by medication, she has returned in part to her former sunny personality, although her speech was now garbled, but she was frequently photographed smiling. Finally able to visit, two things struck me. First, that her responses were sometimes very girlish, those of an eight or nine year old, though always even-tempered. And later, that even if she was forgetting words, it didn't get in the way of the instinct to communicate, although that was then. I also couldn't help thinking, paradoxically, of her good fortune in having the resources to be cared for and not be cast away into an institutional care home.

I'm the youngest of four brothers. Nowadays I live alone, not far from G., the brother closest to me; we see each other frequently. Before the pandemic, the four of us used to meet up in London for lunch a couple of times a year. After lockdown, I would visit my eldest brother in North West London occasionally – the last time was his ninetieth birthday party, surrounded by his large family of several generations. My second brother, N., however, lived in the West Country, on his own since his wife died, and I hadn't seen him since before lockdown. We spoke at intervals on the phone. Now the same thing began to happen. Strange phone conversations suggesting strange 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. Perhaps strangest of all, he developed a phobia towards using his computer, although he was previously a swish film editor who started using computer editing when it was first introduced at the start of the 90s, 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 aware only of his confusion. I've read that it's common for someone entering dementia to be unable to recognise 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, still refuse to go and get tested? His GP confirmed he has 'significant cognitive impairment affecting his memory' and 'some paranoid thoughts', but 'has been refusing further investigations' into his 'presumed dementia'. But this is not an official diagnosis, which means he isn't yet registered with the social services where he was living. A problem which is likely to come back to bite. A diagnosis, I learn, is the gateway to the care system.

G., who is closer to N. than I am, went to visit him several times, and a private carer came in most days of the week. Finally, we went to visit him together, and I was shocked to see him looking more gaunt and thinner than when I last saw him. This is how I find him: he seems most at peace with himself when reminiscing about his past, particularly about people he worked with, though his memory is clearly patchy and his attention wanders. His paranoia seems to have retreated, and he's not aggressive. His memory lapses clearly frustrate him, but they only become a practical problem when they occur with recent events. For example, he has written books about nineteenth century photographers, and he proudly showed me the proofs of the latest one, which he finished some time ago and now looks ready for publication, but he's forgotten the arrangements he made with the printer, which G. is now trying to sort out. Since N. always used to be very efficient at running his affairs, G. already has power of attorney for him. This is fortunate, because N.'s most problematic memory lapse is 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. 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, possibly enough to cover his likely future, 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. Now he doesn't seem to register that the house has been sold, and the implications only confuse him.

I readily agreed with G. that N. moving to London was out of the question, but he took a lot of persuading that it was impractical, and he should come and live near us, at least for the time being, where we could look after him, because he's unwell. He seemed to agree, but as the moment approached, he was extremely anxious about it. As he wasn't able to deal with the negotiations himself (without understanding why not), he felt as though the change was being imposed on him. He fluctuated between accepting it and resisting. He wanted to buy somewhere, but we thought it better, given the uncertainty, to rent. We started sharing the tasks of information gathering. I reviewed the availability of sheltered housing, and after running the obstacle race of the Borough's web site and advice lines, 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. The two of us started viewing suitable properties to rent, and found one which although not cheap, was very well situated – a small house, large enough for much of his large library and 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 the park where he could also take Poppy for a walk. We took photographs to show him. The house also has a spare bedroom, in case live-in care becomes necessary, and G. arranged for a private visiting carer, but we didn't tell him these arrangements so as not to overload him with information that would only confuse him further.

III

Wednesday 1st May. First visit to N. after his first night at his new home. His confusion is manifest. He doesn't understand why he's here, and when he arrived yesterday afternoon, he wanted to turn round and go straight home to Taunton. It was a warm sunny morning, so we sat in the garden. Unfortunately, it was a day the planes were flying into Heathrow and the house is right under the flight path, so conversation was regularly interrupted. Often this also interrupted his train of thought, which was tenuous at best of times.

He was very conversational, and on the surface he seems placid. He's not lost his sense of humour and smiles at amusing remarks. (I find this very reassuring – our family shared a sense of humour, and in my teenage years, he was very good at telling jokes at family meals. I still remember one or two of them.) However, he frequently attests to not understanding things. In particular, the sale of his house in Taunton. At one point he came out with a long and incoherent spiel about the economics of house prices. But he still doesn't understand it.

I begin to detect a certain pattern in his memory lapses. As we first sat down, he asked me what I'm doing with myself. I repeated the answer I gave him to the same question when I last saw him a few weeks ago, down in Taunton. On that occasion, he asked me the question twice, having forgotten my first answer. This time, I answered at greater length. When I mentioned that I'm working on an essay about a Bolivian filmmaker whom he met when he came to London in the 1980s, he said he remembered him. His more recent memory, however, seems shot through. He couldn't get his head round the fact that I live in Windsor, although I've been here for almost four years, I told him at the time why I moved, and he's sent me things in the post. I reminded him that I moved between the first and second lockdown and he looked puzzled. He seemed to have forgotten about the pandemic. Then he seemed not to know that G. lives nearby in Ascot, and thought he was still working with the old Windsor Arts Centre, which was when G. lived in Windsor and helped to run it. In short, he is clearly disoriented. Will he overcome this as he gets out and about a bit?

The saddest moment was when he became morose and said he wanted to die.

Thursday 2nd May. Not much to add to yesterday. He is still puzzled that I live here in Windsor. He repeated his wish to die. His new carer, D., has also heard him say this. In terms of conversation, he was a bit more hesitant than yesterday and frequently gave up trying to finish a thought.

He's made up some story about why he's had to leave his house in Taunton, nothing to do with yesterday's version. He also told a story, which sounded like a dream, about finding the front door missing, so that anyone could walk in – probably a sign of feeling insecure, but if it was a dream, then also of not recognising the difference between dreams and reality. (Am I over-interpreting?) One small positive development: he sometimes modified his expression when talking about the old house, sometimes referring to it as his current home, and sometimes using the past tense. But he also reverted to paranoid phantasy about things there having gone missing, in this case what I take to be copies of some of his films. This followed a conversation with his second carer about his career as a film editor (and as he reminded us, a director and producer), so there was some connection.

He was upset when he realised he'd forgotten to take Poppy for a walk. (The park is only a short distance away, but he can't go alone. Yesterday D. took them out.)

IV

The growth in the occurrence of dementia is due, we're told, to the fact that people are living longer and it's mainly a disease of old age, which only adds to the strain the ageing population places on a hugely underfunded care system. 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. Some 60% of the social care costs are born by families, to the tune of £8.3b per year, while the state pays £5.2b, and unpaid carers –

usually family members – provide care to the value of £13.9b.[2] I can't quite make sense of these huge figures, which one has to take on trust, but not as transparent truth, for two reasons. In the first place, like all social statistics, they can only be estimates. In this case, the rate of diagnosis is just over 60% (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, studies have suggested that anything between 25-42% of those with dementia reside in care homes. What does this wide variance tell us except that large numbers of people remain outside the care system, looked after by their family, by choice or force of circumstances, who are forced to suffer with them, to the detriment of their financial situation and their own state of mind? For the time being. N. is one of these uncounted statistics, fortunately with sufficient financial resources to pay for private care (for the time being). You might say that not yet being a counted statistic, he doesn't yet qualify to be treated as one.

However – and this is the second reason – the costs just mentioned are deceptive. They reflect the very low rates of pay that prevail in the social care industry. This in turn reflects a structural problem in the neoliberal economy, which not only undervalues care work but also relies on being able to exploit immigrant workers whom it treats like a reserve army of labour.

V

Friday 3rd May. Today my brother was incommunicative. When I arrived, our niece J. was with him. He doesn't know her well, and the conversation was sparse. Sometimes he points at something and makes an observation, but you can't always tell if he's pointing at something real or in an imaginary space. Sitting with him on the sofa, he sometimes looks me in the eyes, holding his gaze blankly. He never used to do this. Perhaps he's asking for pity. His body is shriveled – he's not eating properly and has bowel problems. This will be top of the agenda when we take him to meet the doctor next Tuesday. It won't be easy persuading him to go. He doesn't like doctors.

*

I find myself attending closely to matters of language. His speech is peppered with unspecified pronouns, it, they, he, so it becomes very difficult to follow what he's talking about. This isn't new. I first noticed it months ago in our phone conversations. He's stopped using names but employs metonymy, which if you know the reference, helps you understand who or what he's talking about. I find myself wondering at what level this speech disorder is functioning. Does it make sense to him as he's speaking, or is it more like an infant's babbling? Is it perhaps full of hidden Freudian slips?

---

[2] www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers

Returning to the internet, I find a helpful article by a psychoanalyst which says that dementia is not like child development in reverse, dementia sufferers are adults losing their minds in a non-linear fashion.[3] Sandra Evans speaks of three broad and rather arbitrary stages of development. The first is dominated by anxiety, depression, repression and denial. I can 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 final stages are those of extreme dependency. There's no way of knowing how far away this is. In between, the defences of the reality principle give way to the pleasure principle and the loss of inhibitions. This hasn't so far happened to N., but clearly his sense of reality has evaporated. On one level, he knows this. He remarked, in a context that made his meaning clear, that he had 'lost contact with the world'. I could only reply, 'That may not be such a bad thing, it's in a terrible mess', and leave it at that. Myself, I'm a news junkie, but I've long avoided talking about politics with N. in any shape or form, not since a violent argument decades ago about the trade union that as filmmakers we both belonged to. He is resolutely anti-fascist but the kind of liberal who argues with the left more than the right. Our eldest brother was far more reactionary, but also more tolerant of my Marxism, and he and I used to humour each other. Both of them, however, were Zionists, although N. only passively, and I'm relieved that he doesn't follow the news, and seems unaware of what is going on in Gaza.

Going back to the psychoanalyst's article, I read that 'deterioration and regression must be differentiated,' and that 'the amnesia in Alzheimer's is retrograde, making early childhood memories more prominent, and the hold on recent memory less so'. It occurs to me that N.'s condition is bringing back my own memories of our growing up together. I remember that as children we used to have fierce arguments, and have to hope that he won't regress to their repetition. I suppose that both of us felt that the other somehow attacked our ego. In Freudian psychology, only the ego can feel anxiety, and in the early stages of dementia, when the ego is still very present, the sufferer feels under attack and threatened with the loss of its objects, without understanding why. Confabulation becomes a way of covering the gaps and concealing them, because after all, storytelling is a human instinct. But these are stories untrammelled by reality and closer to the illogic of

---

[3] Sandra Evans, 'Beyond forgetfulness', Psychoanalytic Psychotherapy,Vol. 22, No. 3, September 2008, 155–176 www.tandfonline.com/doi/epdf/10.1080/02668730802323494?needAccess=true

dreams, governed by the irrationality of the primary process of the unconscious id. I think of N.'s dream-like story about the missing front door, and cannot help wondering if the dream state has not invaded his waking life, blurring with reality, and at times he can't tell the difference anymore. 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.

Of course we are all liable to confabulate, in different ways and for various purposes. Perhaps we should not call it confabulation when we edit an event which we're recounting, but when we think about the state of society or the world, in a word, when it comes to politics, the confabulations are often ideological. The confabulations of someone with progressive dementia are neither, although as a human rights lawyer I interviewed in Washington many years ago remarked to me, 'We could have Alzheimer's, but we still remember our prejudices'.[4]

Saturday 4th May. When I arrived this afternoon, N. had two visitors, G.'s first wife L. and their daughter J., who had taken him out for a walk with Poppy, and he was in a good mood. That changed after we sat down. He'd been speaking to L. about his trips to India, where he took many fine photographs, and now he began talking about wanting to go home again, only this time he said back to England. He confabulated a story about his former neighbour giving him tickets to go to India, which metamorphosed into his somehow ending up here after a plane trip, although a couple of days ago he agreed he'd come here by car. If he couldn't get home, he said, he would kill himself. We tried to reassure him and explain that he was now with us in Windsor so we could look after him, but he wasn't convinced. He was worried about the 'disappearance' of his belongings, only some of which had so far been moved in.

Monday 6th May. I never know which of the things I tell him he's going to remember. His memory shifts even during the same visit. At the beginning of the visit today, he knew L. was coming later to take him out for a walk with Poppy, later he wasn't sure if she was coming. Also, to start with he still thought he wasn't in England, and then I reminded him he'd seen Windsor Castle on his walk, and everyone knows that's in England. I reminded him I lived here with our mother for a while back in the 80s, which he didn't seem to remember. But he dropped his earlier idea that he was in India and got here by plane, and accepted he'd come by car with D., whose name he couldn't identify when I first mentioned him. He continues to be haunted by thoughts of death – yesterday he said the way things were going he thought he would have a heart attack. D. is also

---

[4] In *Human Wrongs* (Michael Chanan, 2001)

aware of his death wish and concerned with taking due precautions.

VI

Reading and watching films about dementia and Alzheimer's, a frequent topic is the problem of spatial disorientation, and the tendency of the sufferer to go wandering and get lost, even when they're living at home and the neighbourhood is familiar, but they lose their sense of direction. N. is further disadvantaged by not even knowing where he is, and we wait to see if he will do this. G. likens it to someone returning to the neighbourhood where they grew up and finding the old landmarks gone or altered, the district rendered unfamiliar. The cognitive geography they acquired growing up no longer obtains. Their world has both shrunk and been set adrift.

Meanwhile, N.'s sense of time is kaput, as if time were no longer the fourth dimension in which we move through space but has gone wandering off on its own. This is obviously connected to his short-term memory loss, which throws time out of kilter, but our perception of time is more complex than that, because of the difference between chronometric time, which governs the organisation of social and economic life, and our subjective experience. Subjectively, time moves at different speeds, faster or slower according to mood. (We can also hand over our subjective sense of time to external influence through aesthetic representation, particularly narrative forms, and especially music, which affects the body's autonomic system directly.) But our perception of time is not a unitary construct.

Neuroscience tells us that the human brain is a distributed system of interacting networks, which draws on interacting levels of mental activity with their own jobs to do. Coordination is achieved through 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, and sometimes jumps to mind by train of association. The types commonly identified in clinical psychiatry are working or short-term memory, where things are held in the back of the mind for as long as they need to be and are then discarded; 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 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 reside in the muscles of the body and are performed without conscious thought of the steps involved, like riding a bicycle, playing a musical instrument, or writing, which become second nature, freeing 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 just crossing the road to playing games to complex procedures like cooking, over which we have exquisite control (I'm not talking about the alienation of paid labour here). All such activities involve estimating the passage of time and duration, as well as making and remembering decisions and choices. These also pertain to what cognitive psychology calls predictive or sometimes proactive memory, by which we navigate both the immediate and the more distant future. Dementia takes effect at these levels too, making sufferers clumsy or incapable of their performance.

The frustration that results is only the least of it. Neuroscience also tells us that the roots of emotion are deeply buried beneath the cortex that houses higher order cognition, 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 and loss of reasoning make it hard to track the passage of time, and making plans or observing a schedule becomes difficult, if not impossible. Predictive memory disappears. This is N.'s current condition. 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 rather 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.

In formal language, neurodegenerative disorders present with significant disruptions to both time perception in the present and mental time travel, both backwards and forwards, the ordinary experience of thinking back to past events and forwards to the future, in life or imagination. I would also surmise that emotions may be invoked by recessive memories for both good and ill. The emotions called up by looking at photographs and hearing music would be beneficent, but at other times, unknowable associations could produce detached emotions which result in what the observer sees as irrational behaviour. N. is not at this stage, his manner being generally placid and his speech hesitant. On the other hand, when he gets angry, he expresses himself loudly and clearly.

Watching the progress of my brother's dementia (as yet undiagnosed but looks likely to be Alzheimer's) makes me think about the ways memory ordinarily works. This opens two lines of thought, one about my own memory, its quirks and its gaps, and one about family memory, specifically, the different memories of the same events shared, or not shared, by we four brothers (of whom I'm the youngest). In turning to these topics, I'm aware of two general considerations about memory. First, that there are the different types just mentioned. Second, that there are what could be called different modes of memory and imagination, such as the visual, the auditory, and the linguistic, which vary from one person to another. It is probable that some of these differences are genetic – musical gifts, for example, frequently run in families – but they also come from training, learning and practice, in short, the nurture of the natural. It seems that early-onset Alzheimer's, which may strike in the sufferer's fifties, is also genetic, but that doesn't apply to either N. or S. All the same, that doesn't mean it couldn't still happen to anyone else in the family.

For my part, I think of myself as having a good-enough memory for most purposes, but with certain weaknesses – I'm not good at remembering sequences of numbers, for example, or doing mental arithmetic – and also several quirks. When I think about friends and colleagues, for example, I sometimes remember our first meeting and sometimes not but I cannot find any pattern or logic as to which is which. (The exception to this randomness is that I do believe I can remember the first time of meeting my various girlfriends.) I remember all the places I've lived, in chronological order, and can picture them to myself, but I don't always remember dates without working them out. My visual memory is not very detailed, but as a cineaste, the films that mean something to me always invoke visual imagery, either a composite of what they looked like, or particular scenes. As a documentarist, I certainly remember, in considerable detail, the production history – the events and circumstances – of all the films I've made, the people involved, and every shot used. This includes a visual memory of taking the shot, the 'when' and 'where' that belong to one's episodic memory. The task of editing, cutting what you've shot into pieces which you then re-assemble, is to discard the episodic and transfer selected images to the cultural sphere. (The advantage for a director working with an editor, as I did several times with N., is that the editor aids the process because they have no episodic memory of the shoot. There's another advantage when your editor is your brother: he lets you sit by his side watching what he's doing, when most editors prefer you to go away and come back later to see the results. I learnt the theory of editing from books, it was from N. that I learned the nuts and bolts of how to do it.)

Film editing is a form of writing. But writing literary texts, like the one you're reading, is different, because the material, language, being semantic, is already cultural. Both, however, and any comparable activity, call on the work of imagination, which stretches the reach of working memory beyond the short-term to the months or years required to complete the project. But I still notice a difference between my films and my books. Until the book is finished, I remember all the research, the films viewed, the people interviewed, but once it's published, much of the empirical detail drops away. I suppose this is because very little of it is held in my episodic memory, and instead it falls under the rubric of selective forgetting, the economy of memory which allows one to discard what you don't need to remember because you know where you can find it. Hence, when teaching a topic I've written about, all I needed to do was read over the passage concerned to refresh my memory and then deliver the class ad lib. I suspect that this is a predigital way of thinking that is disrupted by the internet, which induces a different mental economy, wherein your own semantic memory map is replaced by the search engine, which delivers its store of information and misinformation in disconnected fragments. Some would say this leads to the dispersal of attention for which the internet, especially the social media, is alleged to be responsible. Taking the long view, this might be seen as the sudden atrophy of the critical powers of memory cultivated by the culture of literacy. N.'s dispersal of attention is different. He's proud of his large library with its special collections, but I don't think he reads anything anymore. I haven't found him doing so.

Then there's music, which occupies yet another memory space, and in my own case was my first love as a child, and although I wasn't a good performer, led me to my first employment as a music critic and my first documentaries for television. The subject is too complex to go into here, except to say that partly because of its direct connection with the autonomic system, the power of music is deeply rooted in both the brain and the psyche. The science tells us that its neural processing is more widely dispersed throughout the brain than any other activity, and music is much used as therapy in the treatment of Alzheimer's, including its late stages. N. had a good ear for music but no formal knowledge. He was good at laying images to music and would sometimes call me and ask me to identify a piece he wanted to use but couldn't name by whistling it to me over the phone for me to identify it. I have no idea, however, of how he'd respond to music therapy. He admits he hasn't listened to any kind of music for a long time.

When I now sit and talk with N., I cannot immediately tell how much of our shared past he remembers. He is seven years older than me and was already a freelance film editor working for television when I started making films. We worked together several times, myself directing and N. either producing or editing or both. I've reminded him of the cutting rooms where I worked with him, and in another conversation, of places where I know that he lived. He clearly remembers these things, but I cannot tell in how much detail since he acknowledges what I tell him but doesn't elaborate. I could do that myself, of course, but I don't, because then I'd be telling him *my* memories, and his perspective would inevitably be different, since no two people ever remember the same events the same way. Shared memories are only partially shared. This came home to me on two occasions when we four brothers were having lunch together, which we used to do a couple of times a year in beforetimes. The first was when an interactive map was published on *The Guardian* website showing the locations of bombs which fell across London during the war. There was a bombed site I remember quite clearly on a corner quite close to where we lived when I was growing up, although on the opposite corner to where it was shown on the map, which also showed another four, so I printed out the relevant page and took it along to see what the others remembered. None of us could agree about what the map showed. This would not be news to the good doctor Oliver Sacks, who grew up a few streets away, and in his autobiography *Uncle Tungsten*, remembers a bomb falling next door in 1940. Actually, two bombs, but after the book was published, his brother told him the second memory was false – they were neither of them there: they'd been evacuated. However, their other brother had been there and described it in a letter to them. Sacks concluded that he'd adopted the letter as his own memory. But he also believed that there's no such thing as fixed memories, only the act of remembering.

The second occasion was prompted by a television programme about 'extreme' weather events in London which made reference to an event I remember well but could not have dated, a tornado which ripped across north-west London in December 1954, when I was eight, and tore slates off the roof of our house. I remember the scaffolding around the house afterwards, when the builders came to repair it. I may be conflating two memories but I also recall standing by the kitchen door yelling for my mother who had gone out shopping before the storm struck. This time, none of my brothers remembered anything at all about it. Since the event in question was for real and obviously dramatic, we had to stop and work out why not. Easy in the case of G., whom we quickly concluded was away at boarding school, and D. who was thirteen years older than me, and wasn't living at home anymore. The mystery is why N. didn't remember it. There's no solution to this puzzle. As the Uruguayan poet Mario Benedetti put it, 'El olvido está lleno de memoria' – the forgotten is full of memory. That is certainly true of N.'s current condition.

VII

In some of the films about Alzheimer's I've been watching on YouTube, the sufferer is living at home, has had a diagnosis that they know about, and are still articulate enough to speak coherently. These films are often vivid, instructive and full of good advice, but not always directly relevant to my brother's condition, which is quite advanced but not yet formally diagnosed, and since diagnosis is the gateway to the care system, he's therefore in limbo. I registered him in advance of his arrival with my own GP, and with D.'s assistance, took him to see her, despite his reluctance – he doesn't like doctors – and then get all the usual tests done (blood, urine and stool) so he can be referred to the Memory Clinic. He is now 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 the GP referred me to their own Social Care Prescriber, who explained to me how the system works, or is supposed to, and told me that the waiting time for the Memory Clinic in this district is four to six months.

Meanwhile the only provision available to him, as I discover it is to every pensioner, is called Attendance Allowance, a pretty measly sum which requires filling out a complex form of 30 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 then has to be posted back with enclosures. It's a clunky method. So is the NHS app, which is supposed to optimise 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 digitalisation, 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 now trained to act as a guard-dog. 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 centralised application of digital technology to improve the efficiency of the service, but its effects are counter-intentional. I'm not a Luddite, nor a bleeding heart liberal, but a sceptic about the claims made for IT. What of those who are in limbo like N.? What happens when people don't know which way to turn, not when there's a crisis or an accident when they call an ambulance or go to A&E, but when a situation develops for which the doctor's is the natural first port of call, because that's the way primary care is designed – as a universal service within the community which provides personal attention. Because that's what care is about.

The NHS app on your smartphone doesn't personalise the service, it has the opposite effect, that of depersonalisation. It's also impossible to use by someone like my brother. When he started becoming paranoid, his previous carer got him one of those alarms you can wear round 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 has been stolen is nothing of that kind, but the integrity of the world he lives in as he now perceives it, fading away like a screen going to static.

Sunday 12 May. N. was much calmer this afternoon. We talked about his career, working together, and the places where he's lived. That's to say, I did the talking, he mostly just listened, but attentively. At one point he returned to his conviction that he's dying, then said he couldn't kill himself because he's got to look after his dog Poppy. Then he made me promise that if I come one day and find him dead, that I'd look after her. I take this as a good sign that he's not going to try and put an end to himself, and D. agrees, but is duly cautious and has hidden away a large bottle of paracetamol he found in N.'s bedroom, not because he thinks he might take them all in one go, but because he forgets when he's done so, and could take too many by accident.

Sunday 19 May. Today N. went out with Poppy by himself and got lost. He was found wandering around. At half past six I got a phone call from the out-of-hours duty doctor. A kindly person had called 999, and according to the report I got later, the police had not been much help but the ambulance service referred the case to the out-of-hours doctor who was able to locate his GP record, discover his address (all he knew was the house number but not the street) and get him home, and then she called my number as next-of-kin. According to one report he was trying to open the door to someone's else's house in another street. Then D. turned up to collect me and when we got there I found Noel perfectly calm, and even ready to admit that he'd made a mistake trying to get home. Shortly afterwards, the doctor arrived. Her examination was more thorough than the one he had when I took him to meet the GP the week before last (not a complaint against the GP, since she was fully briefed and only seeking confirmation).

He was perfectly respectful towards her (at this stage) and didn't invent answers he didn't know, including (as before) date, day of the week, and month, and when asked what season of the year we're in, he answered after a pause, February. She did some more memory and cognitive tests whose poor results did not surprise me (though I confess I was impressed he could spell 'world' backwards). There was a little confusion when he answered her questions about his physical condition, saying he didn't have any issues. He didn't say anything about his bowel problems, and when I mentioned later that I'd seen him in pain a few days earlier, he seemed to have forgotten and denied it.

The long and the short of it is that the doctor said she didn't think it would be safe for him now to be left alone overnight and she wanted to send him to hospital and get tested. D. agreed, and over the phone, so did G. The doctor tried explaining this to him and at that point he turned against her and flatly refused. D. came up with a ruse (not for the first time; he's good at that) and to avoid calling an ambulance, suggested we go out to a take-away he knew in Slough (where the hospital is located).

N. warmed to the idea and came along placidly. We took him to the hospital, armed with a letter from the doctor. Arriving at A&E, I sat with him while D. presented the letter, and while we were waiting, N. didn't seem to recognise where he was but confabulated that he'd been here before, a good while ago, with a friend who brought him here for a meal. Fortunately, A&E wasn't too crowded and he was seen by the triage nurse within little more than half an hour. From there he was moved to a cubicle, without too much delay, protesting as we left him in the hands of the medics, us promising him to come back tomorrow morning. Leaving the hospital, I just wanted to cry. I got back after 11, and Poppy is now here with me.

The hospital won't let him go home without the assurance of adequate 24-hour care, so we now have to step up the care arrangements. Our fear is that the longer he stays in hospital, the more likely the deterioration in his condition. The hospital environment is inevitably alienating. However kindly the staff, they won't be able to understand much of what he speaks about, which already isn't always easy for us, his brothers. When we come to see him the next day we're taken straight through to the cubicle we left him in – he has to stay there till a bed in a ward becomes available. We find him under guard – there are two security people standing outside the cubicle, thankfully out of his view. By the time we come next (after a day with no contact from the hospital), he's in a secure ward, and we arrive to find him being interviewed by a woman from the Mental Health Department of 'Psych Liaison'; she smiles when I say this sounds like a division at GCHQ, not a hospital.

Both she and the doctor we speak to after her introduce a new term into the conversation: he has what they refer to as delirium. This, as I subsequently learn from a web search, is a medical term for an acute but fluctuating impairment of mental functions like memory, orientation, language and so forth, which may have several causes, not necessarily dementia. To us it sounds like a label attached to him in lieu of a diagnosis, and suggests to us a problem not with N., who is certainly confused but placid, but a symptom of the system's need to log every stage of the treatment without adequate knowledge of his situation, because their examinations are being carried out before they know his history. This is not in any way a criticism of the very professional hospital staff but of a disjointed system, which the doctor refers to as a 'multidisciplinary approach', but which we experience as a compartmentalised apparatus in which information doesn't flow freely, and which needs to engage family members from the very start. The response is fast but at each stage, N. is given the same memory and cognitive tests, with the same poor results, and no one seems to have seen the full medical history which is held by the GP. The only saving grace is that these days might result in a proper diagnosis, or at least a more rapid referral to the Memory Clinic. They've already carried out a CT scan, but this is only an initial screening tool when dementia is suspected, since it cannot detect the amyloid plaques or other hallmarks of Alzheimer's. This I again discovered from the web.

VIII

It is difficult to see how the care of people suffering from Alzheimer's or other dementias can be improved without a radical overhaul of the system to make it more responsive and more integrated. This also requires a lot more investment, because the personal care the sufferer comes to need makes it a particularly expensive business, which few people can easily afford and which it seems, in actually existing democracy, the state doesn’t want to pay for. It relies instead on the fact that the best place for the sufferer to be is in their home, in familiar surroundings and with people they know, and if there’s no alternative, families make sacrifices to keep them there.

From where I’m sitting, it’s clear that the care system is currently split along several axes. First, between the public health service and social care, which are subject to different funding regimes. The NHS was partly protected from austerity but experienced a prolonged squeeze as its budget was increased by only a very modest amount while demand has increased faster than it could cope with. Leave aside the disruption of the NHS caused by the Coronavirus pandemic. The problems go back to beforetimes, and arise in large part because social care is funded through local councils whose budgets have indeed been brutally cut by austerity measures, with disastrous effects on the provision of services, exacerbated by increased costs due to the deteriorating state of the economy; some local authorities have even been driven into bankruptcy. My own has just asked the government for emergency financial support after discovering mismanagement going back several years, which the new councillor in charge of finance blamed in part on pressures from government underfunding, higher inflation and previous council tax reductions.[5] She added, on the neighbourhood website, that the 23/24 budget was underfunded in social care by at least £5-6m.

At the same time, increasing numbers suffer deprivation as a result of caps on benefits, including child benefits, while subject to public sector pay freezes, zero-hours contracts, and the loss of other elements of social provision, and finally inflation, leaving them unable to make ends meet and forced to have recourse to food banks even when they have a job, and all this in one of the richest countries in the world. The result is increasing strain on primary care in the community, with more demand put on GPs dealing with more patients with more complex needs but without the resources or workforce to match (as Phil Whitaker, who is one of them, has explained[6]). Despite

---

[5] ‘Council requests emergency government loan’, www.bbc.co.uk/news/articles/cn004rdpkqno

[6] Most recently in the New Statesman, 24 May-6 June 2024

government promises, the number of GPs has declined and the service altered to cope. Patients no longer have a family doctor who knows them, you have to phone at set hours to consult whoever's available, and that's likely to be a short phone call. There is also, says Whitaker, a drive to replace the GP, who has wide all-round knowledge, with different types of specialised professional. The result is a fragmentation of services which makes nonsense of the aspiration to integrated care. In this environment, the number of over-65s – the highest users of health services, with an increased liability to co-morbidities to boot – have gone up by about a third since 2010, but dementia is only one of several problems of increasing incidence over these years in different sectors of the population, including poor mental health among children and long-term sickness among those of working age. Moreover, with dementia there's also only a limited amount a GP can do, and their diagnosis is only provisional.

The inevitable consequence is an existential split between a minority who can afford private care, at home or in a care facility, and the vast majority without the necessary resources, who have to look after their own at home and to struggle with the burden, both personal and financial, until they can't cope any more, and public provision takes over. Then they're faced with a shortfall of care home beds, and if the sufferer ends up in hospital they may have to stay there until a bed can be found, an obvious strain on the hospital. Despite the projected increase in Alzheimer's, the damaged economy has led to care homes closing down because of rising costs and insufficient local authority funding. There's a shortage of qualified care workers, carers are likely to be underpaid and the workforce understaffed, resulting in high turnover and potentially lower quality care. As D. puts it, the system disadvantages you if you have money. If you don't, care is provided for free, although the quality is potluck.

How much money? This brings us to a third split, between the state and the family, whose relationship has atrophied since the heyday of the welfare state. The turning point came with the ascendency of neoliberalism, epitomised by Mrs Thatcher's infamous denial of society, and further exacerbated by the decline in the traditional nuclear family and the contradiction between an ageing population and families with fewer children. The parameters are set by the government. To qualify for a free place in a care home, your assets must not exceed around £23,000, including savings and investments, pension payments, and the value of your property (unless shared by your partner). The figure is arbitrary, little more than a sop. Trying to make sense of it, I again consult the web, this time by interrogating a couple of AI chatbots, and I learn that in 2018 around 50% of households headed by someone over 65 were estimated to exceed the £23K cut-off, although other research from two years earlier estimated it as only 33%. Take your pick. Either way, the sum is so low compared to the true costs that it appears designed to throw the burden back onto families. If the projected figures for the growing incidence of Alzheimer's are anything like correct, this is not a problem which will be solved by seeing it through the blinkers of money but only by recovering and rethinking the nature and values of society. This puts it on a par with the crisis of climate change, which threatens all of us and is not going to be solved by money either.

Michael Chanan is a documentary filmmaker, writer and an Emeritus Professor of Film & Video at the University of Roehampton. His latest film is *Cuba: Living Between Hurricanes* (2019), about ecology and sustainable development in Cuba in the face of climate change. His latest book is *From Printing to Streaming, Cultural Production Under Capitalism* (2022). He is currently working on a book about the representation of dementia on screen.