

restlessness. She went to live abroad in order to learn French, had singing lessons after a lifetime of being pronounced tone-deaf, and developed an unnerving habit of running down hills (blindly) in the middle of the road because she likes to feel the wind in her face and likes to feel free (and to astonish). She pays no attention to our cautions, which alarms and pleases us. She clambers up ladders. She travels to Angola to visit my sister. When I asked her recently, if I asked her to climb Everest with me, would she agree, she said, 'Yes!', her face lighting up as if I might be serious. She wants to learn to scuba dive. Her impulse for adventure is a form of self-preservation: it's her way of staying alive.

'You have to be tough to be old,' she says to me. Or perhaps: 'You have to be old to be tough.' Both, I think.

But really, strong or weak or wise or foolish, you just have to be old to be old. For the rest of us, it's a foreign country that we travel towards and will if we are lucky come to in our time.

3. *The Brain, the Mind and the Self*

'the marvel of consciousness – that sudden window swinging open on a sunlit landscape amidst the night of non-being'

'Something is wrong,' my father said to me, before he could no longer say anything. Sitting on the side of his bed and staring down at his unlaced shoes: 'I don't know what's wrong. Something. What?'

What does one say to such a question? *Nothing is wrong?* (Everything is.) There is such an urge to reassure: *You'll be all right.* (You won't.)

Or this: *There is something wrong with your brain. You have a complex brain disease. There is no cure.*

'Do you want to hold it?'

I nod. The room is bright and cool, full of stainless-steel surfaces, large fridges and freezers that mildly hum, white plastic tubs and Tupperware on shelves in which pieces of the body float in liquid. It looks like a canteen, but without any ovens.

I take the brain. It is heavier than I expected, softer: a gelatinous, pale mass. This soft, inert thing used to be the seat of a self; it contains around 86 billion nerve cells, a dot the size of a sugar grain containing about 10,000 and each one connecting to about 10,000 others, avidly consuming energy and giving life and meaning, magnificently plastic and connective

and dynamic, never asleep even when we are, a miracle of perpetual motion with the body as its battery.

It's usually compared to a walnut, Shakespeare's 'nutshell'. It looks like a foetus, like two clenched fists. It looks like slimy coils of tripe, bloodless, folds within folds. It's impossible not to think of food. And when Steve Gentleman takes a long knife and cuts the brain in half (two observers at this point leave the room, rustling in their paper robes), it looks like a cross-section of cauliflower florets, but with a texture like spam or tofu.

With immense delicacy, Steve Gentleman carves the brain into thin slivers, laying them side by side along the surface.

Here is the left hemisphere; here the right. Here is the hippocampus, named after the seahorse for its curled shape, where long-term memories are stored, and also the memory of objects and people. These holes aren't really holes (there aren't holes that our memories fall through), but shrinkages so that the ventricles become larger. Here at the stem is the crucial medulla oblongata, which controls involuntary functions (breathing, controlling blood pressure). This is the cerebellum, responsible for balance and for voluntary tasks (like reading and writing). Here's the pons, the bridge between the upper and lower brain. This gluey blob that looks a bit like a white tadpole is the olfactory nerve. This is the amygdala, responsible for the memory of emotions, especially fear. Here is hunger; here is desire; here is speech; here is spatial awareness. Here is music, imagination, intuition, creativity, insight. Here is reasoning, logic, analytic thought. Here is damage. Look. The blade points. And here.

Here is loss.

Steve Gentleman (the name is accurate), Professor of Neuropathology in the Department of Medicine at Imperial College

London, is a detective of the brain. He looks for disease, shrinkage, hollows, hardening, white lesions in the limbic system, amyloid deposits. I ask him if he ever feels – I struggle for a right word, can't find it – *odd* about dissecting brains: odd because of what it tells us about identity, and because in the end all the urgent business of being human, all the despair, anxiety, appetite, terror, love and joy, resides in this piece of flesh.

He smiles and shakes his head. He has no faith – perhaps it would be hard to if day after day you slice brains, scalpel out morsels of executive function, episodic memory – but he is full of wonder at how infinitely complex, subtle and plastic the brain is, and how it is still mysterious to us. Because, after all, we are not just our brain: our brain is in a body, is part of it and in the community. There's no end to its possibilities.

Alzheimer's disease leads to nerve-cell death and tissue loss in the brain. Abnormalities include beta-amyloid plaques, tangles of the protein tau, loss of connection between the cells and inflammation. The cortex shrivels up and the ventricles grow larger. Over time the brain shrinks dramatically until every area is affected. Yet some brains, when dissected, show no sign of dementia even when the person has been diagnosed with the illness, while others are badly damaged even though the person seemed not to have shown signs of cognitive impairment. The link between observable deterioration in the brain and the way a person acts, feels and communicates in the world is not straightforward, and this is because the brain lives and works in a network of reciprocal connections. Looking at the brain cannot tell us all we need to know about the brain: it is so much more than itself – a brain in a body in a particular life. Part of Steve Gentleman's research is to compare the brain that he observes with the lifestyle of the man or

woman to whom it belonged, to seek out patterns that will begin to explain why it is that some people are swiftly demolished by the illness when others are able to withstand its attacks for longer. Exercise, diet, geography, career, mood, the state of a relationship: all these things may make a difference to the way a person responds to what is happening in the intricately folded labyrinths of the brain.

The brain on its chopping board is inert, a lifeless beige thing, but neuro-images of the living brain display its fizzing connectivity, its marvel and mystery. Functional magnetic resonance imaging (fMRI) measures brain activity by detecting changes associated with blood flow. The images – still and moving – are like the Northern Lights, like coral reefs or trees in blossom, in kaleidoscopic flux. It may seem, looking at these iridescent patterns, that here's a brain in love, in fear, in envy and in a clutch of hope. But brain-scan images are not straightforward photographs of the brain in action; they are representations of the areas that are working at their hardest. It's a bit like looking at New York City from a helicopter and seeing how the crowds move through the streets: you learn a lot about the movement of people over time and in response to events, but you don't really know what it's like to be in New York. And the brain is not the mind.

Nevertheless, the image of a brain damaged by dementia is dismaying: dead grey patches amid the glorious colour.

'I do *not* like the term "dementia".'

I met Professor Martin Rossor in his room overlooking Queen Square in London, with windows from floor to ceiling. He is the National Institute for Health Research National Director for Dementia Research, Director of the Queen Square Dementia Biomedical Research Unit, Professor of Clinical Neurology and

Consultant Neurologist at the National Hospital for Neurology and Neurosurgery. He's tall and slim, with grey hair and a courteous manner. His cleverness is unintimidating; when he talked to me, he was pragmatic, precise and kind.

'"Dementia" is a catch-all phrase. It's powerful, but it's unhelpful for clinicians and scientists. It just means cognitive impairment that's so great that the person is badly affected.' There is not a 'uniform' breakdown of the brain but 'islands of breakdown'.

Dementia is a syndrome. It describes a set of symptoms of impairment in memory, communication and thinking caused when the brain is damaged by disease and is an umbrella term for a great range of progressive conditions that affect the brain. As Martin Rossor was at pains to emphasize, there are multiple forms of dementia and so there are multiple indicators of the disease. Alzheimer's is the dementia that people are most familiar with and accounts for over half of those affected by dementia. It is a neuro-degenerative disease that sweeps inexorably through the brain: the build-up of tangles and sticky clumps known as plaques used to be thought the cause of brain dysfunction, but scientists now think they may instead be like ash after a fire. Alzheimer's tends to develop gradually over time and is strongly associated with memory loss, poor concentration, confusion, the decline of everyday living skills. Other dementias – such as vascular dementia, which develops when arteries delivering blood to the brain become blocked, commonly after a stroke – frontotemporal dementia, or dementia with Lewy bodies, have different causes and different effects. Frontotemporal dementia, for instance, affects behaviour and personality, sometimes bringing about disinhibition, inappropriate social behaviour, anxiety, stress, even psychosis. And dementia can be a trigger for other mental-health conditions – such as depression – that can too easily be missed.

Even within a particular form of dementia, there are huge variations. Martin Rossor used the example of Alzheimer's: it commonly presents itself as loss of episodic memory and threatens the sense of selfhood that comes from a feeling of continuity between the you of ten or twenty years ago and the you of today. Yet there is a form of Alzheimer's in which memory is largely preserved but visual processing is damaged. Colours extend beyond their boundaries; things seem upside down; you can't locate objects; can't find the door. Often people feel that they are standing at an angle. Or they see a small puddle and think it's a hole. Or, standing at the top of an escalator, they stare down a gushing waterfall. Or reach out to grasp a handle that is in fact several metres away. 'I had a friend who had dementia who would grip on to things very tightly: it wasn't, as people assumed, resistive behaviour but because he thought he was falling.'

There are a bewildering number of cognitive impairments that come under the umbrella term of 'dementia', in part because there are so many kinds of memory, as Steve Gentleman demonstrated with the tip of his knife. (In one book, I read that, at the last count, there were 256.) Take the loss of semantic memory, Professor Rossor said: frontotemporal dementia is a 'horrible degenerative disease' in which a person loses the memory of the 'meaning of things'. Pick's disease, on the other hand, brings about the loss of verbal memory.

'Let's imagine you have a verbal semantic memory impairment. You would remember coming here, crossing the square. You'd remember I wore spectacles for reading. But if I asked you what spectacles were, you'd have no idea what I was talking about.' This incomprehension spreads until 'there is no comprehension of the human word or any output of language' – and with this pouring away of meaning, empathy will also go.

Other people may lose the memory for visual semantics. They 'understand the word "spectacles" but they have no idea what they are when they see them. They would know what a toothbrush was, but they might clean their teeth with the toothpaste tube. The world is breaking selectively around meanings.'

Symptoms can encompass great areas of loss, or be viciously precise: for instance, there's a dementia that can cause anosognosia, where people who are cortically blind nevertheless believe that they can see.

I asked Martin Rossor if he believes that a self is ever wholly lost to the disease, and he pondered. 'Perhaps when all empathy goes,' he replied eventually. 'Perhaps then.'

I asked him – as I will ask all those I speak to who witness the ravages of the disease – if he was scared of dementia himself. He hesitated and then answered that he was not and looked slightly surprised at the answer.

I asked what he makes of advance directives – the legal documents in which a person specifies what actions should be taken for their health if they can no longer make decisions for themselves because of illness or incapacity – for those who live with dementia. He nodded, frowned. 'How can I dictate to my future self?'

'Every death is terrible but we have to die. Your last years of life: how do you want to spend them? As the person you were or as a person who wouldn't recognize that self any longer? Who takes their child for their brother or sister – at their good moments? My life is the life of a thinking person. That is me. If that ends, my body should also end . . . That's why we made our living wills.'

In a tall, lovely old house in Utrecht, gable-roofed and full of

flowers, every wood-panelled room lined with books, rich yellow light falling through the high windows, Gerard de Vries and Pauline Terreehorst talk to me about their decision to appoint each other in their living wills as the one who – if necessary – will confirm to the doctor that they want to die in dignity, should the conditions they have specified in their living wills manifest themselves. She was once a newspaper journalist and columnist and is now a successful director of an arthouse movie theatre; he is a distinguished philosopher, recently retired, who used to advise the Dutch government in The Hague. They are calm, dispassionate, carefully precise as they talk about their arrangements, which are already in place. Assisted dying for patients who are enduring unbearable suffering with no prospect of improvement has been legal in the Netherlands since 2002, provided the doctor complies with the ‘due care’ conditions set by the law. Among other things, he or she has to be sure that the patient’s request for euthanasia is voluntary and well considered. Increasingly, it is acknowledged that not only physical but also mental suffering may be unbearable.

Of course, it’s a controversial issue, regarded by many as the slippery slope that can end in the murder of the old – above all because of the issue of voluntariness. How can a person with dementia make an autonomous decision about ending their life?

‘There is no un-clarity,’ says Gerard firmly. ‘In the later stages of dementia, the notion of a “voluntary, well-considered decision” is void. So, the wish to die with dignity should have been articulated well before those stages, in the limited time slot between being diagnosed with Alzheimer’s and the stages in which one will have become mentally incapable.’

‘I am sure, quite sure, that I want this,’ adds Pauline. ‘Our

life was and is the life of thought. When that goes, well – it’s no longer our life.’

As we talk through the evening, sitting first in their living room, then over a meal in their kitchen (fish baked individually in foil, like little gifts), they pass the conversation about their end-of-life between each other, following threads, correcting any imprecision. They both have a dread of incapacitated and impaired old age, and in part this is because of their very different personal experience of it. Gerard’s father did not have dementia, but he had a serious stroke.

‘He lay there, unable to speak, but he clearly signalled non-verbally he wanted to go. The doctor provided palliative care and let him die.’

His mother lived for many years more, her final ones in a home where she was well cared for, much visited, but her world was shrinking until, at some point, says Gerard, she must have thought, ‘We’re done here’. When, two weeks shy of her ninety-third birthday, she got pneumonia, she declared that she did not want to be treated.

‘She wasn’t depressed; she was clear in her mind. She said it to me and she said it to my brother and my sister: she was adamant that she had reached the end of her life and now was simply sitting, waiting to die. It was hard – but at no point did I try to make her change her mind. She was brave. And she died when she was still in control of her life.’

She said her goodbyes – she told Pauline to take good care of Gerard, her boy. And then she slipped away.

Both of Gerard’s parents decided when they were ready to go. Neither of Pauline’s parents did. When she talks about them she is tense with emotion. Time has not smoothed over the memories.

Pauline’s father – with whom she had a complicated

relationship after he and her mother divorced, although when she was little she adored him and he her – was sixty-five when he started showing signs of the illness. He was forgetting small things but was able to cope for a while. Bit by bit, he slipped through the stages of dementia. He spent the last six or seven years in a nursing home – ‘an awful one’ – where he shared a room with another man.

‘He had nothing left,’ Pauline says. ‘There were just a few photos around his bed. And he was –’ She pauses. ‘A plant. I would say that, yes. He lay in bed. He could do nothing. His wife visited him; we visited him. It was a Christian nursing home. In some places, he would have been allowed to die, but there, life was sacred. He was nursed to the bitter end.’

Pauline’s mother is still alive; in fact, she is in a home just a few minutes’ walk away from this house where we sit in the dusk, drinking wine. Her dementia started about ten years ago, although the symptoms were horribly muddled up with the difficulties in her marriage. Her third husband had suffered a stroke, which had changed his character. He could not cope with Pauline’s mother’s disease, her absent-mindedness; their final years together were filled with ugly minor quarrels, a sense of life tangling up and become disorderly. Pauline’s mother used to be a member of the Union for Euthanasia and had always insisted she would like to die before dementia took its grip on her. But the window of opportunity for such decisions is very small: she missed her chance and is now in the deep darkness of the illness.

‘It’s like she’s the living dead,’ says Pauline. ‘A long time ago, I lost her. I talk, and there’s no reaction. Sometimes, when she laughs, or something in the tone of her voice – then I recognize the way we were twenty years ago. You fill in the gaps and the memories. Then she leaves again. You say goodbye all the time.’

‘The thought,’ says Gerard, ‘of ending my life like Pauline’s

parents is quite appalling to me. We knew we were reaching the age when we had to face such questions.’

I am impressed, unsettled. The present self is making a decision about the future self – but what if the future self does not agree? What if, when they arrive at this conjectural time of diminution, wreckage and loss, they are content and have no wish to die?

They nod. ‘It’s a pre-binding of the self,’ says Gerard. ‘Just as countries have constitutions.’

‘So if the future you,’ I ask, ‘says that you want to live after all – what then?’

‘If Gerard is able to communicate his wish to live, no doctor will perform euthanasia. What we are talking about is the discussion we need to have in the limited time slot between diagnosis and the later stages of Alzheimer’s,’ Pauline replies calmly. ‘Then I’ll help him by reminding him of his past self. If we let that opportunity go, in the later stages of Alzheimer’s only the option of refusing treatment will be available. Because Gerard has appointed me as his representative, I will point out to the doctor that in these circumstances that is what he – his former self – had wished.’

‘But,’ I say. ‘But *could* you?’

‘I take as my example Odysseus and the Sirens,’ Gerard says. ‘His sailors bound him to the mast of the ship and he told them that however much he cried out, begging to be released, they should not do it.’

They look at me with kind expressions.

‘We have to love each other a great deal to do this,’ says Pauline, and I’m reminded of how a friend said to me recently that she would be unable to end the life of her mother, who has advanced dementia, because they had a difficult and damaging relationship and she does not love her enough to kill her.

So Pauline and Gerard have chosen to write a statement, each on the same day, stating their conditions, which are basically the same, and they have discussed their statements with their doctor, to whom they reconfirm their commitment every year. They have named each other as their first representatives and Pauline's daughter and Gerard's son as their second.

Gerard says that writing this down is lifting a burden from their children: 'It's not their decision; you are removing the burden of the very painful decisions that they would otherwise have to make.' The crucial thing, he says, is that he is deciding under certain conditions that he does not want to live. He is *asking* Pauline to grant him that wish; he is *asking* the doctor. 'It's a request.'

They are tranquil and stern, talking about the way they want to die, very sure that at a certain point a life is 'completed' and fulfilled: you cross a line, which is not the line that separates life from death, but the self from its own self-knowledge. 'Identity is not a kernel inside yourself; what we call our "identity" is the *outcome* of our actions, decisions, our personal and professional life, not their *source*. One's "self" is a network of social relationships, all one's attachments. The idea that identity is something *in* us, *inside* us, is part of a Christian heritage. We know as we get older the networks shrink. If they shrink beyond a certain point, your life no longer has meaning.'

On the opening page of *Admissions*, a wry and elegiac account of his life in medicine, the neurosurgeon Henry Marsh writes of the suicide pack he keeps at home, ready for when he is diagnosed with a disease such as dementia. He sees himself as a 'transient electrochemical dance, made of myriad bits of information', and his work has continually forced him to confront

the changeability of personality because of damage in the brain. He wants to die before this happens to him.

Hugo Claus, one of Belgium's most renowned writers, best known for the novel *The Sorrow of Belgium* and his caustic portrayal of his country, was diagnosed with Alzheimer's disease in his late seventies. On 19 March 2008, in the Middelheim Hospital in Antwerp, he died by euthanasia, choosing the time and the place of his death. Friends said that he wanted to depart with dignity and pride. 'He left us as a great glowing star right on time, just before he would have collapsed into a stellar black hole.'

On 20 May 2014, Sandy Bem, a Cornell psychology professor in her sixties, took her life after careful preparation. She was a person whose identity was intimately entwined with her capacity to think and to write, and her diagnosis of Alzheimer's filled her with terror at the prospect of becoming 'hollowed out' by the illness, with no memory or sense of identity. She also hated her powerlessness in the face of the illness: 'She wanted to squeeze in as much intellectual and emotional joy as she could before she died, but she wanted to make sure she didn't wait too long. She needed to be engaged enough in her life to be able to end it.' It is extraordinarily difficult for one's body to die in tandem with the death of one's sense of self; she made a vow that she would take her own life before she lost this sense. She kept a journal that tracked her decline, and she talked to her ex-husband, who had remained her close friend, and to her children, telling them of her decision. 'What I want,' she typed in her journal in an emphatic boldface font, 'is to die on my own timetable and in my own non-violent way.'

She read books to find out gentle ways to die, she continually reaffirmed her decision to take her own life, she became a grandmother, which gave her great joy, she spent much time

with her ex-husband, and she gradually declined, until it became clear that the suicide window was closing and, before long, she would no longer be able to make a decision about ending her life. And at this point she chose a month – May, when the world would be beautiful again, after the winter – and a date, Tuesday 20th. She wrote her death-day on the calendar that hung in her kitchen. She was deteriorating rapidly: a time came when she asked her sister who that woman was who'd just been with them. She was Sandy's daughter. Two days before the date she was to die, her family held a party for her, full of reminiscences about her life. ('Did I really do that?' she would say, pleased.) On Tuesday, 20 May, just as she had planned, she took her drugs of choice with a glass of wine, her ex-husband sat with her, and soon she fell into a sleep. The family were summoned and they watched her breathing and then they watched as the breathing stopped.

The psychiatrist Paul Wolfson did it alone. When he was diagnosed with a rare form of early-onset dementia that erodes the ability to think and speak he was sixty, happily married to his second wife, Lore Windemuth, with two small children. Over several months, he and his wife recorded their discussions about his illness, his slow and relentless decline, their radically altered future. He dreaded going into residential care but equally hated to think of himself still at home, his two young children seeing him 'pissing and shitting', and a carer there to 'contain' him. He foresaw the time – coming towards him swiftly – of not recognizing his children, not caring about them, not caring about his wife, 'only caring about myself . . . It's not brilliant, is it?' And so, aged sixty-one, he took his life. He did it with great thought. His wife took the children out for the day and when she returned he was dead. On the table beside him was a photo of his parents. He had left flowers for

her and a Valium on her bedside table. So he departed from those he loved, in an act of generous love.

I have long believed that for many people, especially those living with dementia, life lasts longer than it should and becomes a cruel burden both for the subject and those who care for them. We should be better able to choose when to take our leave. Yet against the calm certainty and rationality of Gerard and Pauline, the decisiveness of Sandy Bem and Paul Wolfson, I have to set the tiny, dashing figure of Theresa Clarke, a woman with dementia who crackles with the desire to live life to the hilt and possesses a radical optimism that can seem like a kind of fury.

The first time I meet her is in Heathrow Airport. My train is held up and I am late to arrive. As I hurry to Arrivals, a miniature woman with silver hair races towards me, clattering a bag behind her, her eyes glittering, one hand lifted, on her face a look that in its intensity of excitement and fear is almost feverish. I hold up my hand in greeting and she spins to a halt, gives a full-throttle laugh, flings her arms around me. She has flown, unaccompanied, from Antrim to talk at a conference about dementia that is to take place the following day. I am small, but I tower over her. And I'm bowled over by her: her courage and determination, the way she wants to immerse herself in life, her refusal to give up on herself or be scared.

Theresa is the daughter of an Irish labourer, the eleventh of thirteen children, educated in the school of hard knocks. Though her father died when she was four, she remembers him vividly – running to meet him, 'and he would put me on his shoulders and away we'd go'. After his death, the family were very poor. Her mother – all these years later, Theresa still talks of her with a fierce protectiveness – worked in a munitions

factory and as a cleaner. But Theresa remembers her childhood as 'full of fun'. If her mother had a spare 'roughness' (a coin), she would take them all to the seaside for the day or take a tram to the end of the Falls Road and have a sandwich. She remembers being interested in everything: she was a 'tomboy', a footballer. The boys would call at her house and say, 'Can Teasie come and play?' She tells me this and I can picture her as that child, wiry and quick, fierce with hunger for life.

She always wanted to be a nurse, and she always wanted to travel: 'A new country, a new job, new people: I've always been a seeker.' She has worked as a psychiatric nurse and a midwife (the 'most glorious job'), and she has lived in Cyprus, Australia, in Arctic Canada, in America. She loved to camp, to hike. She lived in an ashram in India for seven years. 'I wanted to be free. Twice I was engaged – people expected you to marry. But I'm so glad I held on to my freedom. A free bird.' She worked on social justice projects ('standing for myself, standing for others'), wrote poetry, was a bit of a hippy, a bit of a mystic. It seems to me that she's a woman who has always hurled herself at experience, chin up, plucky (as Helena says of Hermia in *A Midsummer Night's Dream*, 'though she be but little, she is fierce'). Her mother once told her that she had 'a heart like a lion'.

Ten years ago, Theresa Clarke's wandering ended. She came back to Northern Ireland and lived in the Glens for a few happy years with her beloved dog, moving to Antrim when she had heart trouble. In 2010, she was diagnosed with dementia. But she already knew. 'Oh yes!' she gleams. 'I knew *just* what it was. I knew I was forgetting things. I knew there was a wrongness in the way I was thinking. My dog knew as well. She would look at me when I made a mistake: she had different looks for different mistakes and I always understood what she

meant. Well, well: you have to face up to whatever you find in yourself.'

She knows that she is beginning not to know and that the not-knowing is getting worse. She will stop mid-sentence and stare blankly, waiting for the strangeness to recede and saying, 'Where am I? It will come back, it will come back.' She has a phrase she uses quite a lot to cover the lacunae: 'something of that ilk'. Whenever I ring her, which I do fairly often, she greets me with a bark of surprised laughter and then more or less the same words: 'Nicci, where have you been? I thought you had disappeared off the face of the earth.'

She feels the illness *here* – she bangs on her head with the heel of her hand. 'The brain power is running out; things disappear. It's a muddle and I get so tired.' But *here* – and she raps at her chest, as if the door to her heart can open wide – she remains herself. 'I am me, here, now.'

When I visit her in Antrim I see on her noticeboard, among multiple reminders and exhortations, the message: 'You are not this body; you are not this mind.' (The others include: 'Switch off electrical appliances!' 'You're doing well, keep it up.' 'Take your meds.' 'Nicci is coming on Friday.') She does 'walking meditations', pacing her miniature living room and garden, saying to herself, 'I am calm, I am smiling. The present moment is a wonderful moment.' Her insistence both impresses me and makes me uneasy: I wonder if she is hanging on to the notion of life's bounty by her fingertips, and if what she calls joy is actually her way of coping with despair. I don't know.

At the conference, Theresa talked eloquently about how people with dementia are too often treated as if they no longer had a stake in their own lives. 'We can still contribute to society, our family and the world beyond,' she declared in her

quick-fire voice – she talks as if rushing to get a sentence out before she loses its thread. ‘But for this to happen, we need to be part of the conversation about dementia: not just spoken about, like an object, but talked with and to.’ Later in the day, she took part in a round-table discussion with several of the leading spokespeople in the field and was smiling, proud, diminutive, indomitable, sure of her place at the table.

Gerard and Pauline believe that the self exists in a rich and intricate network of connections and relationships; to be alive is to have a narrative of your life, with a past to reach back into and draw upon, and a future to anticipate and project on to. For them, identity involves self-consciousness, memory, language, rationality, all things that are gradually dismantled in dementia. But for Theresa, the self is ‘not just my brain, not just my memories, much more than my experiences. I’m here, in the moment, alive and whole.’ She is aware that her world is shrinking and the horizons are closing in: once, she travelled the globe, followed her questing spirit, went to the source of the Ganges. Once, she read books and wrote poetry. Today, her world is her little bungalow; her past dissolves behind her, everything she does during the day forgotten; her future is unknowable; the structures of her life have fallen away. ‘But I’m still resonating,’ she says. ‘In the present. Now.’

Sean and I often talk about what we would do if we got dementia. After seeing what happened to my father, it’s no longer an abstract question but an urgent, practical one. Would we want to choose our time of death? For a long time we have both supported someone’s right to die if they have a terminal illness – and dementia is a terminal illness, after all; there comes a time when a person is no longer living with it but dying with it, becoming dead. The problem of course is that it

is always too early – before you are ready to leave life but while you still have the capacity to make the decision – or too late; the departure gates have closed. And how do we make a decision for the unknown self we will become?

I’m struck that while both of us would want to accompany and care for the other – or we think that we would, which is something very different – we would not want to be looked after by the other, at the mercy of their kindness and the object of their pity and disgust. I’m also struck by how we talk about these possible selves who exist in the conditional future as dreaded *strangers*. The self of our childhood may feel starkly different from the self of our teenage years, and that self seems barely connected, save by memory and the story memory makes for us, to the self we become. Yet it feels continuous. For Raymond Tallis, ‘It both is and it isn’t. For instance, I still feel responsible for a mistake I made as a junior doctor in 1970. To be exact, 8 March 1970. I do believe it was the same person. There’s a continuation of the body; there’s a psychological continuation.’

We are attached to our past selves because we have been them and they are still lodged within us. All our infinite, shifting versions are contained by the present self – moment after moment, *now* and *now* and *now*, unquantifiably small fragments of experience piled up in the complex formation of the self. The child I was, the awkward teenager I was, the young mother ambushed by love, the woman in her thirties, her forties, have gone and the river of time runs on, and yet they are part of what made me. They are inside me, continually perplexed at my age and my wrinkles and my many follies and mistakes. We can’t escape each other.

But the future self is a dizzying number of continually changing possibilities. To talk of a *me* in the future is just bewildering.

Not long ago, I uploaded a photo of myself on to an age-progressing app, which operates on the same principles used by forensic scientists to work out what missing children would look like today. A woman appeared on the screen: a small, wicked onion face, features barely distinguishable in a scrunch of wrinkle, mouth puckered in what might be the remnant of a smile but looks more like malice. Nope. That's not me. I refuse to become that mean old woman. I'll be someone different.

What is it to be a self, and where does the self end? Does it end with death or, in some cases – where a mind is picked apart by dementia – can it end before that?

The influential utilitarian philosopher Peter Singer has a list of indicators for 'personhood': 'self-awareness, self-control, a sense of the future, a sense of the past, the capacity to relate to others, concern for others, communication and curiosity'. This is a brutal catalogue that dismisses many people who do not possess such 'personhood'. In a society that places high value on reason, agency, memory, instrumental value, people with dementia count less or don't count at all – which in turn can mean that they are no longer treated with love, respect or dignity. If we lose the *sense* of our self – our self-consciousness, that which gives us our identity – do we also lose our self? Our value? Our reason to be alive?

'Neither *cogito* (I think) nor *ergo* (therefore) but *sum*: I am,' writes one passionate champion of the rights and the value of people with dementia, who believes that those with dementia have, individually and collectively, been deprived of their human dignity and respect because of our culture's increasing emphasis on autonomy, rationality and self-possession. This excludes 'the socially outcast, the unwanted, the marginalized and the oppressed'. People living with dementia become, over time and implacable decline, defenceless, powerless, easily

victimized. At the end of their long life, at the time of their greatest need, they cannot speak for themselves. Our moral commitment should be to the vulnerable: fellow human beings on this little planet of ours.

When is it time to say goodbye and leave the party? Is there ever a point at which we cease to be ourselves and become 'a little piece of hell'?

During his last months, the disease attacked my father relentlessly on all sides. He had no way left to defend himself. I used to say that he had lost everything – but that's too simple. In some mysterious way, he did not lose his self. Somewhere inside John Gerrard there was always a John Gerrard. When people (me) reach after metaphors to describe what happens to a person with dementia, nothing quite fits. My father wasn't like a boat slipping its anchor and drifting out to sea – or not only. He wasn't like a landscape, ruined and the wind ripping through it; a city, bombed; a house, demolished; a deck of cards, shuffled; a glass, dropped; a manuscript torn into shreds.

Something is wrong. I don't know what's wrong. Something. What?
A complex brain disease, for which there is no cure . . .

He was like a man, an infinitely helpless and bewildered man, at the mercy of the world.

'Essential reading about love, life and care'

'Ranges widely and wisely, raising questions about what it is to be human and facing truths too deep for tears'

'Evocative and powerful, shining a light on a world which is often hidden and misunderstood'

'Nobody has written on dementia as well as Nicci Gerrard in this new book'

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