

#### 4. Memory and Forgetting

'All this goes on inside me, in the vast cloisters of my memory.  
In it are the sky, the earth and the sea, ready at my summons . . .  
In it I meet myself as well.'

My father might have been absent-minded, but he was very good at remembering things: the speed of light, the dates of battles, the periodic table, the Latin names of plants and the English ones of wildflowers, the bones in the body, mathematical equations and chemical formulae, whole chunks of poems, the colours of flags, capital cities . . . Then he began to forget and the painstaking acquisition built up over a lifetime gradually fell away.

When did my father's dementia begin? We don't know. We'll never be able to put a finger on the danger spot: *there*. Like fog that creeps up stealthily, imperceptibly, until the foghorn booms and suddenly there are dark shapes looming at you out of shrouded darkness – you think you'll notice, but often you don't. Then you can't.

I wonder when it began for my father, that unobtrusive slide of memory, the wind going out of his sails. I'm sure my mother sensed it before the rest of us. But what about him? When did he hear the boom of the foghorn? Was he very scared? Was he sad?

'Life without memory is no life at all.' Without memory, things don't fit together; the narrative of one's life crumbles,

the walls of one's self tumble down. Without memory, you are adrift in a helpless present tense, and 'the world glides through you without leaving a trace'. How can we love without memory, have relationships, empathize or plan or imagine or anticipate, keep track of oneself, stand on firm ground? Memory as thought before thought and knowledge before knowledge; memory as a way of editing our own life; memory as a way of joining all our different selves together into a coherent whole; not a tool for thinking but an act of thinking; memory as a lie, a creation, a different kind of truth. Collective. Deeply personal. At war with death.

The terror of losing memories is the terror of losing the active self: that which holds us precariously together into the shape we have built up over our lives. To have and to make memories enables us to be the (often inaccurate, self-deceiving or misinformed) narrator of our own lives. Memories connect us to our past and launch us into our future; they link us to other people and bridge the labyrinths of the inner self to the abundance of the outer world. But memory's vast cloisters can crumble and fall into darkness; are the memories still in there, like restless ghosts, or have they been obliterated? Where, as Sally Magnusson asks in the title of her groundbreaking book about her mother's dementia, do memories go? And what are memories anyway?

In the summer of 2017, my mother and I revisited the house where our family lived for the first nineteen years of my life. It was something I had wanted to do for a long time. I drive past it every time I go to see my mother, and catching a glimpse through the trees my heart skips a beat: that was my past; there, half hidden, was where I used to be young. My siblings and I all grew up in the house; it was the architecture of our childhood, where we became the people we are. I had vivid

memories of the place – too vivid, too sunlit, glowing with colour and replete with feelings; not just a home but a locus of selfhood and a place of innocence.

My mother and I went up the drive together and rang on the bell. They let us in.

Forty years had passed since we were here, and the house had changed a great deal. Walls had been knocked through and other walls built; rooms rearranged and joined together; trees chopped down and others grown tall. And inevitably, our memories had hardened into shapes that perhaps had more to do with how we wanted to remember those times than with reality. The two of us walked inside, stared about us, waited for something to happen.

Then, all of a sudden, at a twist in the stairs, the past gushed back so powerfully and purely that it didn't feel like memory. It felt like being there, being young again, and I was almost sick with longing and distress. And then again, those black and red tiles by the front door; that larder built into the sandstone; that cornfield by the side of the house that I used to run down with my siblings, and I was there once more, trying to keep up, bare, scratched legs and eyes full of the sky, and I could almost see our dog, Candy she was called, a golden retriever with sorrowful eyes. Now the house was full of ghosts. My mother stood by the window of the bedroom that used to be hers and my father's and she looked out at the garden, tears streaming from her nearly blind eyes, down her old and captivating face. Some memory is muscle-memory; much is voluntary – we search around for the memory, like opening drawers in the mind, make an effort to recall it. But here, memory was involuntary and engulfing, and felt more like a return to the past than a recollection of it. We were in the 'perma-store' of long-term memory storage, where the past becomes

ever more vivid. These flash-memories, which like lightning in the sky can suddenly illuminate a hidden landscape, strike everyone: they are a gift, an injury, seemingly random, triggered by the smell of sweet peas, a bar of music, the way light falls through the trees. Back come our former selves, unbearably familiar and yet almost strangers. Where have they been hiding all this time?

Sometimes I remember my father because I think about him; I make a hard effort to see his face or recall his words, summoning him back from the dead. Sometimes out of the blue he returns to me: when I see the birds come to our bird table (for he would always gather crumbs from a meal and put them out for the long-tailed tits and the finches). When I notice the wildflowers (he knew all their names and tried to teach me, though I retain only a few of them). When water boatmen skim across the surface of some pond or ditch. When I'm by a rock pool and it's almost as if he is suddenly beside me, peering into the crannies like a dreamy boy. Or looking at star-spangled skies and not knowing the names of constellations (but he would have). Or walking along overgrown footpaths and I remember how he would take his time tying back wayward brambles for walkers who might come after us. Moths knocking against the window with their powdery wings (he would catch them in his hands, carefully). Bees (he built habitats for them, to encourage them into the garden). Bonfires. A certain gesture. A figure in the distance (who isn't him). The sound of a chuckle. And there he is, unlooked for, alive again.

My father, in his years of forgetting, would gather stories about him in an act of self-protection. He had revisited them so often they were safe places for him. He didn't get lost in them: he knew his way around and was agile and sure. His path was

worn smooth by repeated use, and nothing tripped him up or ambushed him, no shadows in the corners or craters to fall into. He had memories he could enter through any portal, wander around, touching familiar things, seeing them again, smelling pine trees and mushrooms and bonfire, fresh paint and the sea, hearing voices of old friends. His face would ease and look younger. He remembered being evacuated during the war and tramping the countryside; Finland and the saunas he took there; Egypt, where he was sent on his National Service; his university days. He remembered being carefree and youthful, just starting out – and the photographs of him when he was young show someone slim and buoyant, a zest about him. But bit by bit through those dementia years the gates of memory started to close; he would falter and stumble in the telling. There were fewer and fewer places he could enter, until finally, there was nowhere left to return to where the ground did not shift and ooze under his feet. No safe place.

We picture the memory as a place in which things are conserved and stored: a library, an archive, a chest, a wax tablet on which impressions are made and then rubbed away, a filing cabinet, a computer . . . Things are 'burnt' or 'imprinted' on to our memory. Trying to remember something feels like rummaging around in the attic of our mind, in dusty corners, in search of that elusive object: where have we put it? 'If only this could be your memory. A spacious room. Light falls through big windows. Everything is clean and orderly. Your memories stand in rows along the walls, meticulously updated.'

But memory is an 'an activity, not a vault . . . a process not a place': stored in different parts of the brain, memories are synchronized and work together 'like an orchestra'. Virginia

Woolf compares memory to a 'seamstress, and a capricious one at that', running her needle 'in and out, up and down, hither and thither', so that a whole ragbag of experiences is delicately, intricately joined together. And memories are no older than the last time they are thought of; 'there are no "read only" files'. To remember something is to create something new: it happens in the present tense, so that in the act of memory old selves are created afresh – the rough draft of a life that is being continually revised. Subjectivity is built into the very nature of memory. Memories are fallible, frail and representational – and at the same time, imaginative, flexible, creative and re-creative. They are the stories we tell others and tell ourselves, and they are the way we can recognize a self that persists over time.

Memory is always dominated by forgetting. If memory is the library or the cabinet, forgetting is the sieve, the thing with gaps – it's 'the minus sign' and 'exists within remembering like yeast in dough'. We have to forget or we will go almost mad with the overload, as is demonstrated by the sixty or so people identified thus far who possess the highly superior autobiographical memory known as HSAM. They can remember most of the days of their life as clearly as most of us remember the recent past. They can give the day and date thirty years ago, say, on which they did a particular exam, or tell you what the weather was like, what they and all their friends were wearing; they can remember a smell, a feeling, a mood . . . One middle-aged HSAM woman recalls a remark her mother made to her when she was a small child, and the memory brings back the flare of resentment that she felt all those years ago.

Memory needs its 'garbage heap'. Recent research has shown a connection between disturbed sleep and cognitive impairment. We have a nocturnal cleaning system (the glymphatic) that removes proteins called amyloid-beta, which accumulate

into the plaques that contribute to Alzheimer's and dementia. During sleep, cerebrospinal fluid flows through the spaces between neurons, flushing proteins and other neural waste into the circulatory system and away. This is one reason why chronic insomnia is a risk factor for dementia. Another is that, in deep sleep, with its large, slow brain waves, fragile new memory traces are consolidated into more permanent forms of long-term storage. The memories initially encoded in the hippocampus are moved to other areas of the brain, clearing the slate, as it were.

The body is unimaginably complicated and clever. It 'knows' that the weight of remembering, the hoard of recollections, is an impossible burden. It knows we need to remember but we also need to forget. Sometimes when memory floods back pure and raw, as it did when my mother and I went to visit our old house, it can feel like a curse. Intense memory hurts; we need to recover from its injury. It does not feel like recollection – a dispassionate and voluntary pondering on past events – but more like an ambush from within, grabbing us, dragging us back to the past that we thought had vanished, or we thought we had escaped. Memory is also trauma; to forget the past is to lose our memory of loss. If love is intimately bound up with remembering, so too is grief. Love and grief and loss can overwhelm us.

My mother used to tell a story from her childhood: it was one among her collections of anecdotes, shaped and polished and taken out at family gatherings. In 1941, during the war, she was evacuated from Palestine with her mother and brother. She would have been nine. The ship they were on, the *Georgic*, was bombed in the Gulf of Suez and they were put in a lifeboat, while behind them the ship slowly went down. My mother would tell us about the strong young sailor who picked

her up and swung her over the side into the boat. And how when they were back on the safety of land a cry went up that someone's handbag had been found. The group of people, who had been leaving Palestine with all their worldly possessions on board, went eagerly to see whose it was – and of course, it was my mother's toy bag, containing no treasures.

That was the little story. I never really thought about what lay around its neat, domestic edges. Then a few years ago, out of the blue, she started to talk about another memory: the bombing had created a massive oil spillage on the surface of the sea. The water was on fire, and in the water – burning, drowning – were people crying out for rescue. Some of them she knew; they had been her neighbours and friends and now she saw their faces in the flames. But the lifeboats were already too full and so they rowed through the figures in the water. Her memory, her little story, was a screen against this terrifying episode; the bag had been a flimsy shield against the horror, but it had served her for a remarkably long time, until in age it would no longer do. We all have the stories that we polish and pass around, and we all have screen memories. But they can be fragile defences against the floods: my mother's story has ceased to protect her from what happened nearly eighty years ago. Now she remembers what she tried to forget and she dreams of people reaching out to her from the flaming water.

Remembering gives us our sense of self, our narrative, our identity. Forgetting keeps us sane. In dementia, this subtle negotiation between what we keep and what we let go of can break down. The distant past floods back, unmediated, with a freshness that can be joyful or tormenting, while the recent past fractures and disappears. Yesterday is swallowed up by darkness, but sixty years ago remains vivid. My father was

lucky; he most often remembered saunas in Finland, carefree days at university. That old woman I saw in the hospital bed who was shouting out: 'No, no, please don't. Teacher, don't. It's down there' – she wasn't so lucky.

To lose one's power of remembering is not like losing a tool that is broken: you can look at the tool and see it is damaged, but here you *are* the tool; you *are* the process: forgetting wipes away the traces of itself. You don't notice the fog descending, though perhaps there is the warning boom in the gathering night. Things are gone without being missed; forgetting takes place unnoticed and you don't see that you aren't seeing. There is a special kind of terror in this silent obliteration that ploughs through the self like a furrow.

I read on a government website that you should seek advice and help if you: struggle to remember recent events, forget the names of friends and everyday objects, lose the thread of what you're saying, cannot recall things you have seen or heard, have problems thinking or reasoning, sometimes feel anxious, depressed or angry, get lost on familiar journey, often feel confused . . .

When I have no memory whatsoever of a film I saw the week before; when I find yoghurt on the bookshelf and crisps in the fridge; when I make the whole family look for my watch that I remember dropping on the floor somewhere in the house and then discover a few hours later is actually on my wrist, obscured by a long sleeve; when I order the same shirt online three times; when I carefully pour ground coffee into the little dishwasher capsule for soap; when I go upstairs for something but then have no idea what; when I point at the Thermos flask and call it a Tupperware; when I can't find my way home though I know I know the way; when I open the

door and for one terrifying moment don't recognize the familiar face; when I look in the mirror and see my shirt is inside out and I only have one earring in; when I lose my supermarket trolley; when I can't remember where I parked; when my dreams leak into my day so I can't tell them apart; when I see people exchanging glances as I speak and realize that I'm repeating myself; when I have that sudden flushing awareness that I've somehow lost my grip on what's going on around me, the wind going out of my sails.

When does forgetfulness that is natural and part of getting older become something more sinister? How do we know when to be worried? When does the foghorn boom?

'Ah yes, worried-wellness,' says Sube Barnerjee wryly when I talk to him about how my middle-age forgetfulness always triggers the terror of dementia. He is an old-age psychiatrist and Professor of Dementia and Associate Dean at Brighton and Sussex Medical School who has served as the UK Department of Health's senior professional advisor on dementia. His research focuses on quality of life in dementia, and he is energetic, articulate, optimistic. 'Worried-wellness as in when I call my kid Sandy, which is actually the name of my dog. A life can be poisoned by the fear.'

Dr Claudia Wald is consultant psychiatrist at the Kensington & Chelsea and Westminster Memory Service, which provides dementia assessment and diagnosis and ongoing support for people with memory difficulties. Memory clinics like this are based on models from the US and were set up in the early eighties in every region of the country. She sits in her pleasant room, sunlight falling through the window. She is tall and open-faced, and her voice is reassuring; she feels a kind place to be.

'People of your age,' she says, 'start to fear their fading memories. With age comes effortful thinking and remembering: much forgetfulness is age-related and non-problematic. We all forget as we get older, and this is normal, natural, part of the ageing process. Dementia is not natural, it is a disease. Nevertheless, there is a grey area, a place of uncertainty and trepidation, when forgetfulness deepens – when, as so many people with dementia say, something seems 'not quite right'.

In her diagnostic work, Claudia Wald is looking for changes in behaviour. Almost always, the initial assessment is done in the person's home, where the atmosphere is more relaxed, less contrived, and where much can be learned from context (the state of the house, of the fridge). She takes a detailed clinical history and uses scans only where there is diagnostic uncertainty: 'I am trying to find out who the person was; I am looking for change.' She must assess what part of the memory is affected: long-term memory? Language? (The language centre is next to the memory centre.) 'The bank of words seeping away,' she says – then adds: 'This happens to us anyway.' Recalling names? Faces? In her diagnostic criteria, at least two domains must be affected (language and memory, say; or memory and behaviour; or memory and sense of direction), before she gives a formal name to the symptoms she finds.

Between the inevitable process of ageing and the clear diagnosis of dementia lies the swampy territory of mild cognitive impairment (MCI), an interim stage which some see as a pathologizing of natural forgetfulness and others as a helpful indication of future problems. For there is no scientific boundary between disease and normality; lines may be drawn, but their exact location is a matter of evaluative judgement. 'It's a grey area,' says Claudia Wald. 'And at what point in that grey area is treatment appropriate? What is "normal" as we get older?'

Often she will find that circumstances have changed, so that props are stripped away: the death of a spouse who had been compensating for failing cognitive function, going into hospital, breaking a leg, moving house. 'These things can expose difficulties that had been hidden.' Depression, she says, 'can be a precursor and a risk factor', and it can be very difficult to treat. 'Old age brings with it profound losses: the loss of a spouse, of family, of friends, of work, of health. There is huge loneliness and fear of death.'

All this means that the diagnosis is often not straightforward, and often it is the relative or carer who notices the change – because how can the *I* know that the *I* is slipping?

William Utermohlen, that thin and sad-faced man who became one of the great chroniclers of dementia's self-loss, did not know, or if he did he withdrew from the knowledge. He was living with his wife, Patricia, in their London flat overlooking the canal, a book-lined, painting-hung space where they both worked, he in the attic studio with a skylight. I sit in that flat now with Patricia, who is soon to be ninety, although she still teaches an art class and is eloquent and vital and pin-sharp. Her husband's paintings are on every wall; his face and hers stare down at me; the table at which they sit is the table at which I sit now.

She talks about her husband with tenderness and honesty: how he courted her (she had been married before, to a man she had been head-over-heels in love with, so was resistant at first); how they never had children and in some ways she was his mother-figure; how he never achieved the recognition he wanted. A figurative painter in a period when conceptual painting was dominant, he had some success in the early sixties but was then, in an exhibition of 1969, demolished by

critics. He was 'destroyed', Patricia says, and perhaps he never quite recovered from the trauma, although the French art historian who represents Utermohlen believes that he started getting his energy back in the late eighties.

In the early nineties, several years before the official diagnosis, he became increasingly anxious. 'He was always an anxious man,' his wife tells me. 'But he became more and more so – and more withdrawn.' It was at this time that he began his 'Conversation Pieces', a series of paintings which French psychoanalyst Patrice Polini thinks were born out of a need to 'define his existential references and capture his familiar surroundings', and show a 'sense of urgency in the face of a gradually fading memory and disorientation'. Their titles – *Maida Vale, Snow, Bed, Night, W9* – fix the images in time and in space. These paintings are in many ways a celebration of the life that he and his wife shared: he returns over and over again to their large living room, flooded with light; through one window a view of the garden and another the canal, houseboats and the great city stretching out beyond. At the centre is always their table, at which Patricia sits, alone or with friends. Figures lean into each other, smoke cigarettes, drink wine, talk. There are cats (there are still cats); a rubber plant (and there is one still), coffee cups and wine bottles and ashtrays. The same decorated jugs stand on shelves. There are books everywhere. A sense of companionship fills the paintings – intimate talk is what these 'Conversation Pieces' evoke – and Pat is unequivocally at the centre. But it is possible to see the illness lurking, not just because some of the perspectives are starting to tip and solid objects are precarious, but because of the sense of the artist's loneliness. When he puts himself into his paintings, he is on the edge, a solitary and watchful figure; there's a painful sense of exclusion. He is painting himself out

of the circle of warmth and vitality. In *Bed*, he shows Patricia sitting up, reading, cats winding their way about her; she's the painting's focus and it is on her that light falls, the vital centre. The artist lies next to her, on the far edge of the bed, the covers pulled over him so that only his small head is visible and there's no suggestion of a body attached to it. Is he dreaming? Is he awake? It's a profoundly troubling image. At the time it was painted, the disease was progressing in an 'underhand' way; he may have had a sense of it but he had no name for it. Just a sense of dread.

Patricia tells me of the watershed time he went to Paris, a city he knew very well, and got hopelessly lost. 'It shocked him deeply.' And shortly after that came another, much more ominous sign: he had been commissioned to do a family portrait for friends, grouped around their own table. 'For a whole year he sat in front of the canvas and he did nothing. Nothing. And then we knew.' He had always drawn, wherever he was. That was how he communicated. But now he had stopped dead. Pat thinks that he had some sense of what was happening to him before she did, but he did not say, could not say. He was still young. How could he have dementia?

Rebecca Myer's mother both knew and did not know. Rebecca is a nurse who works in the community, often with people with dementia. When she tells me her story, her manner is thoughtful and candid. She has a way of pausing after a question, thinking carefully before answering. Her thoughts take her back to a dark time, for the story of her mother's dementia is also the story of a close family struggling to manage chaos and disintegration. Her mother was an 'immensely gracious woman, thoughtful and kind'. She met Rebecca's father when they were both young, at an ice rink: 'she thought he was a

show-off, twirling round and coming to a stop in front of her. Dad used to say that he wore her down.' They married when they were both twenty-one and were parents by the time they were twenty-two. 'They were *very* close,' she says. 'They'd hold hands in the back row of the cinema. I've a photo of them and they are just looking at each other and it says it all. The degree of loss,' she says, 'is relative to the degree of love.'

When Rebecca talks about the terrible years that tore her life in two, her face is bright with love and sorrow. Her mother was clever, and had been a grammar-school girl, but her parents had no expectations for her when she was growing up and she lacked confidence. She had part-time jobs and did voluntary work for a charity. She liked books, poetry, puzzles. She always read stories to her children and played games with them: Rebecca starts to tell me about a game of cat-and-mouse she and her mother used to play when as a tiny child she would help her mother make the beds – and then she stops and smiles. 'Strange what one remembers,' she says softly. 'So strange.'

'But what I really remember was that she was always there. When I came out of school, she'd be there; or later, when I came home from school on my own, she'd be there. When we watched TV, I'd sit by her and put my head on her shoulder. I'd tell her everything and she would listen to me for hour after hour. When I left home to train to be a nurse in London, I was very homesick. I missed them. I still miss them.'

Rebecca's mother was in her fifties when her family started to notice that something wasn't right. She had always been 'a worrier' but now she became more so, and was struggling. 'Now, in hindsight, I see there were signs,' says Rebecca. Her mother could no longer work out money. She couldn't measure out the formula for the baby milk for Rebecca's baby daughter. It was Rebecca's sister-in-law who eventually said:

'Your mum's not right; something's wrong.' But Rebecca's father was hiding it from everyone, and from himself: 'He just couldn't deal with the distress. Mum would say to him that she thought something was wrong, and he would tell her no, everything was fine, she wasn't to worry. His desire to protect us was incredibly strong.' And so he wouldn't confront what was happening in the heart of the family, and he wouldn't let her confront it either.

Tommy Dunne did not know. I visit him and his wife, Joyce, in Liverpool, where they live in a small, neat bungalow with flowers outside the front door and everything in its proper place – this is where they moved after he knew that he was ill, leaving their 'dream home'. He and Joyce sit together on a sofa, facing me as we talk, telling their story between them. They met each other when they were both sixteen, at a skating rink, like Rebecca's parents – though they weren't skating but going to an Edwin Starr concert. Tommy and his friend were sitting at the bar drinking (illegally). Joyce didn't fancy him at first; it was when she saw how kind he was to her baby sister that she started to take notice. They are both one of eight siblings and so they have a clan-like family in Liverpool. After they married, Joyce did odd jobs and Tommy worked on the railways, at first as a driver and then in management. Their son was born when they were just eighteen, their daughter several years later. They had, says Joyce, 'a good life. Everything was going the way we wanted.'

Tommy has a round face and is a man of smiles; he smiles as he talks now, but the years leading up to his diagnosis were hellish ones. His first symptoms were not of memory loss but of his world shrinking, and he takes out his iPad to pull up a diagram showing a series of concentric circles, each differently



coloured ring representing aspects of an individual's world, from the bull's eye of *me*, to *family, friends, work, community, city* . . . 'The outer rings begin to fall away,' he says. He swipes left, left again. Circle after circle disappears.

Joyce joins in: 'I had noticed years before, perhaps as many as ten years before, that something was wrong. Tommy's job was quite stressful; he became absent-minded; got very quiet – he didn't speak as much as he used to. But I put it down to stress. You dismiss things and think, "Just get on with life." We didn't talk about it, but gradually I started to wonder if he had Alzheimer's. It wasn't just his memory. For example, we had this glass cabinet for appointment cards and things, and he couldn't see them. He couldn't find his coat when it was right in front of him.'

And then, 'One bad day at work' – Tommy goes on, smiling – 'I could feel it happening and I could see it. It was like one of those old films unravelling.' He makes a violent gesture with his hands. He stops talking.

'He shut down,' finishes Joyce for him. 'Completely shut down. I came home and he was lying in bed, shaking and shivering. I took him to the doctor and he was signed off for two weeks.'

Two weeks passed. Tommy went to see the work doctor who said, in front of him, 'This man will never work again.' He went to see the work psychologist, who thought he was having a nervous breakdown. Nothing changed. Tommy lay in his bed in a state of terror. Six months later, a psychiatrist diagnosed him as bipolar and he was put on lithium, gradually increasing the dose. 'I knew he wasn't bipolar,' says Joyce. 'He'd always been quick-tempered, but it wasn't that. I knew.'

Three times a day, he was visited by health professionals because he was believed to be a suicide risk. For a year, he

lived with a sense of oppressive foreboding: 'A dread. I could feel it coming. Twenty-four hours a day. I thought I was going to explode, like a spring compressed and compressed and compressed inside me.' When Joyce left the house he would unplug the phone. If someone knocked at the door, he would go to bed and pull the covers over his head and wait for whoever was outside to go away. 'Time slowed right down. I was never going to get out of it, like a snowball rolling down a hill, worse and worse and worse.'

But he didn't know he had dementia.

Pauline's mother in the Netherlands did not know 'until that test drawing of the clock . . . She was constantly laughing, fearfully, at the silly mistakes that she made.'

And my father? It's like mortality: until there's a test, a diagnosis, a name, knowing isn't *knowing*.

'You are no different the day after diagnosis,' says Sube Banerjee. 'Except that you recognize what you are facing.'

I nod. That's quite a large *except*.

'A diagnosis,' says Claudia Wald, 'is just the start of learning how to live well with this condition. There can be a paradoxical comfort from knowing there's a name and a reason for this changed sense of self, but some people do not want to know.'

I notice a subtle change in her manner. She picks up her pen: 'Are you ready?'

My racing heart, my sweating palms. It's like being back at school and doing an exam – except I am the exam that I don't want to fail.

'Remember these words,' she instructs. '“Apple”, “penny”, “table”. I will ask you for them later.'

I nod. *Apple, penny, table. Apple, penny, table.*

'I am going to give you an address which I want you to remember. David Barnes, 73 Orchard Drive, Kingsbridge, Devon. Have you got that?'

'Yes.' I am holding the lines in my head, repeating them to myself. *Apple, penny, table. David Barnes, 73 Orchard Drive, Kingsbridge, Devon.*

She asks me the date and I get it wrong by a day. My heart bangs harder. She asks me who the prime minister is and this I get right – though I am talking in an oddly jocose, self-conscious manner that I don't like at all. My face feels stretched.

She asks tells me to count back in sevens from a hundred. I was never quick at maths. 'Ninety-three,' I say. 'Eighty-six. Seventy-nine.' *Apple, penny, table. 'Seventy-two.' David Barnes.*

Next I have to give as many words as possible starting with 'P'. My mind blanks but off I shoot, hectic; my voice comes out scratchy and I am grinning foolishly. The words arrive as jerky Latinate multisyllables – *parsimonious, peri-menopausal, penitential, patriarchal, pertinacious, programmatic, plausibility* – with the occasional home-run of simple ones: *put, plant, pot, press, poppy, potato, poem*. As I reach the end of my minute, I realize I forgot all the 'ph's.

I haven't told her how I find it increasingly hard to recognize faces. I haven't told her that sometimes I'll fail to see what's in front of my eyes.

I repeat the address, and the burden of holding it in my mind lifts from me. I say: 'Apple, penny, table.' My heartbeat is slowing. She asks me to draw a clock. I do so and then see, appalled, that I've put one o'clock at midnight and midnight nowhere at all.

'You're fine,' says Claudia Wald. I know I am really, but I want to weep.

## 5. The Diagnosis

'We have heard the chimes at midnight.'

Leaving the memory clinic, I am slightly breathless. I feel thin-boned and insubstantial. Relief hasn't yet flowed into the place where anxiety had been; I have a sense of being scraped out. But I've been reassured that I'm still on track. Those appalling blanks, those moments of addled vacancy when I scramble around in my mind for names, dates, certainty, a sense of connectedness to the world around me, are simply a product of age and normal forgetting. I unlock my bike, put on my helmet, cycle off, the wind in my face.

However kindly and tactfully it's delivered, however parenthetical, it's a sentence. *You have dementia*. We all know that we are going to die, but we don't really know, not until we are sentenced. Dementia is a terminal illness, one that usually works with grinding slowness, chipping away at the mind's sense of itself.

'Do I use the "D" word?' asks Claudia Wald. 'It depends.'

'I felt cold water running down my spine,' says Tommy Dunne in his little bungalow in Liverpool. Beside him, Joyce sits quite upright, her face calm, her hands folded on her lap. 'I thought: "My life is over. I'll become one of those people sitting in a chair. My family will come and visit me, first once a day, then once a week, then once in months, until they don't come at all. Just me, a chair, a bed, a room."' The countdown.

'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'

ISBN 978-0-241-34745-4



NICCI GERRARD

WHAT DEMENTIA TEACHES US ABOUT LOVE

616  
831

# What Dementia Teaches Us about Love

