
Opening Extract from...

Keeper

Written by Andrea Gillies

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ANDREA GILLIES

KEEPER

a book about memory,
identity, isolation,
Wordsworth and cake...

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I am – yet what I am, none cares or knows;
My friends forsake me like a memory lost: –
I am the self-consumer of my woes: –
They rise and vanish in oblivion's host,
Like shadows in love's frenzied stifled throes: –
And yet I am, and live – like vapours tossed

Into the nothingness of scorn and noise, –
Into the living sea of waking dreams,
Where there is neither sense of life or joys,
But the vast shipwreck of my life's esteems;
Even the dearest, that I love the best
Are strange – nay, rather stranger than the rest.

John Clare
c 1840

INTRODUCTION

You have to begin to lose your memory, if only in bits
and pieces, to realise that memory is what makes our lives.
Life without memory is no life at all. Our memory is our
coherence, our reason, our feeling, even our action.
Without it, we are nothing.
Luis Buñuel

It is singular how soon we lose the impression of what ceases
to be constantly before us. A year impairs, a luster obliterates.
There is little distinct left without an effort of memory, then
indeed the lights are rekindled for a moment – but who can be
sure that the Imagination is not the torch bearer?
Lord Byron

THE PROCESS OF writing this book, the physical act of putting it together from diaries, scribbled notes, books about the mind and concentrated bouts of introspection, has proven an illuminating exercise in itself, for me as the writer, demonstrating just what it is that dementia takes away. (Answer: everything; every last thing we reassure ourselves that nothing could take away from us.) The way the brain works, the supercomputer folded modestly into every human head, marshalling its forces, making connections, prompting and synthesising, is dazzling and extraordinary and yet seems every day perfectly, unexceptionally ordinary to us. There's nothing we take more for granted.

Writing *Keeper*, I've found myself preoccupied with unexpected things, more and wider things, my mind disappearing up all kinds of unforeseen alleys, which has been exhilarating but also poignant, in recording the decline of somebody with dementia, and seeing their preoccupations narrow and narrow, and their intellectual pathways block off. I'm left feeling a profound gratitude to the life of the mind, how associative it is and how rich, in its leading on from one thing to another, into that whole interior landscape of yoked-together and often incongruous thoughts that add up to a self. This book has turned out to be as much about the unravelling of a carer as it is about the person cared for, but its starting point was wanting to write about Alzheimer's and about life with an Alzheimer's sufferer, my mother-in-law Nancy.

We spent many years looking after Nancy at one remove, a responsibility made more stressful by distance, and then, until recently, at a big Victorian house in a remote part of Scotland: Nancy and her disabled husband Morris, living with us and our three children. The house was not an ordinary one, and in a way I didn't anticipate has become another character in the story. It's an imposing, draughty mansion house on a wild, near-treeless headland, somewhere we moved specifically to attempt the extended family, and when that failed, had little choice but to leave. The official gloss put upon this exit is of the "phases of life" sort: job done, time to go. The private verdict is soaked marrow-deep in defeat.

I'm aware that in many ways this is a story about privilege. We could afford (could convince the bank we could afford) the big extended-family house, the part-time help, and when push came to shove (and it did, literally), my in-laws could stump up for the fees of a good care home. But there are monetary consequences to caring, above and beyond the obvious weekly bills, and there's been a real financial hangover that we're still working through, caused by months and years of having no choice but to put work second.

Well so what, you may be thinking. *You took in your husband's parents. Boo hoo. Big deal.* Across other, more populous continents, three generation households are the norm after all (the Asiatic three-generational photograph is lodged reprovingly in my brain), and they will likely become more commonplace here, as the care crisis bites harder. It's pretty clear that it will bite. There are over 820,000 people in the UK with dementia, two thirds of them women, and the figure is rising sharply. The world seems to be in the grip of a dementia epidemic. There are estimated to be more than 35 million dementia sufferers across the globe, with 65 million forecast for 2030 and over 115 million for 2050 – figures near doubling every twenty years. That's why the phrase Dementia Time Bomb is beginning to be used. The devastating extra sting of dementia is that unlike heart disease and cancer, it doesn't shorten life. It's a cruelly lengthy business. The changes in the brain can begin twenty years before a formal diagnosis, and the average life expectancy afterwards is eight years.

Alzheimer's Disease is only one of many varieties of dementia, though by far the commonest one. Over 60% of diagnosed British dementia sufferers have Alzheimer's Disease. BBC News back in 2002 reported that 40% of UK home carers of someone with Alz heimer's have been forced to give up work in order to look after them. I quote this statistic as a roundabout way of answering my own question. Why write this book at all? Unselfish answer: to show that Alzheimer's isn't just about memory loss; that *memory loss* isn't just about memory loss, but leads to disintegration; to kick the system ineffectually in the shins; to give a glimpse into the dementia abyss; to show that for every 'client' in the statistics, there are one, two, four, six others whos lives are blighted in addition (a.k.a. the family); in short, to give a little insight into the reality that ensues – one particular reality that ensued – from the state's piously worded support for Home-Based Care.

Question: Do government understand just how dehumanising Alzheimer's is?

Answer: No, or they wouldn't withhold good drug treatments or limit research programmes on grounds of cost.

Question: Does anybody who hasn't been through it understand just how dehumanising caring can be?

Answer: No, or there would be proper care home provision and it would be free. As things stand, dementia patients in homes, unlike cancer patients in hospitals, are regarded as "social care clients" and charged hotel rates, and if they have savings and houses, must give them up to pay the bills.

The selfish answer to why I wrote this book at all: I'm one of the 40% who have found work incompatible with caring, even work that I have always done at home, sitting at a table by a window, or slouched uncomfortably on a sofa, laptop at a precarious angle, mediating child interruptions: work that you might assume would be ideal in the circumstances. It's more than economics, actually, in my case. Writing is more in the way of a compulsion. It may even be a psychiatric disorder. If days pass dryly, that is without sentences being made and remade, I find that I begin to drift into the arena of the unwell. Throughout the caring years, the drive was there to produce something saleable, but other than for the occasional article, the content wouldn't follow the impulse. Following an early career producing sensible non-fiction and then a long hiatus while having and raising children, I was supposed to be cutting loose and writing a novel – and on the face of it, was immensely productive, almost manically so. I wrote two and a half novels. I wrote them in a rush, thinking "I can make some money at this" (almost a guarantee of failure). The two that were finished were bad, superficial, studded with frustrations like cloves in an orange. The half is still a half; stopped, stalled. The muse left me. She did it quite abruptly, though things had been sticky between us for a while. After that, all I could seem to write about with any passion or conviction was my mother-in-law. Writing about her was sustaining through the dark days of creative roadblock. It was, to be blunt, a way of not cracking up.

This might also be the moment to tell you that names in the account that follows have been changed. Nancy is beyond minding, or even registering the fact that she's the subject of what you might call an Unauthorised Biography, and it's only a tissue-paper thin layer of anonymity, but it feels right nonetheless.

A lot of what follows is taken from unedited diaries, which accounts for the use of the present tense, and also for the emotional rawness of some passages. While filling the diary, I used some of the entries in a newspaper piece about Nancy. It was straightforward and at moments graphic about her problems (and ours), and this didn't go down well with online commentators. Their chief complaint was to do with my having written intrusively about my mother-in-law without her consent. Nancy was even by then long past the point of being able to consent to anything; she found the choice of Weetabix or cornflakes baffling enough. Intellectual competence aside, the argument remains that whatever the truth about rights, it's in bad taste to write in such unsparing detail about another's decline. Margaret Thatcher's daughter Carol has been pelted with rebukes since disclosing her mother's dementia, and her critics have been explicit that the disease should be "kept in the family", which is only a short hop from suggesting that it's stigmatising and shameful. Tony Robinson, the "Baldrick" actor and *Time Team* host, was accused of something similar when he let Channel 4 make a documentary about his mother's last weeks. His response was robust: that no, quite the opposite; he was proud of the programme. There's a campaigning element to allowing media access, even if it might appear to you to be cloaked in voyeurism. Those of us who have loved ones engaged on the dementia journey – and it is a journey, with clearly defined stages – publicise the details of their decline not despite our love, but in large part because of it.

Science still isn't sure precisely what triggers Alzheimer's, though things are moving so fast that the mystery may be solved by the time you get to read this. (In fact, the pattern in the last few years has been that they move fast and get nowhere much.) What's uncontroversial is that Alzheimer's brains show the presence of two weird and provocative things: 1. a wild overproduction of beta-amyloid, a naturally produced and usually soluble protein, contributing to sticky blobs called *plaques*, and 2. the knotting and snagging of the tau protein that forms the "rungs" in the communication ladders within brain cells into *tangles*. The race is still on to determine what the definitive cause is.

An adult brain has about 100,000 million nerve cells, individual *neurons* that each look rather like the branching root of a tuber pulled out of the ground; tubers of different shapes according to flavour. A good analogy, put forward by Professor Susan Greenfield, is to think of it as the Amazon rainforest inside your head. In the Amazon rainforest's 2.7 million square miles, she says, there are about 100,000 million trees. Imagine all that condensed into the size of a cauliflower within your skull: 100,000 million tiny trees, making a dense neuron forest. Our memories and our thoughts travel through the forest as encoded electrical signals. The "roots"of the neuron are called *dendrites* (from the Greek for tree-like), and its stalk (trunk) is called an *axon*. The information enters the *soma* (cell body) of the neuron via the dendrites – that's the front door. It goes out the back door, travels up the axon, along parallel lines of communication called *microtubules*, and out the other end at branches called *synaptic terminals*. It leaps, this information, a tiny leap, from axon to dendrite, from one neuron to the next.

How does it do that? For a while there were two camps, spark versus soup. The "sparkers", who believed in an electrical leap, lost out in the end to the "soupers", who thought that the constituency of the soup was key. The spaces at which the crossing is made are called *synapses*, though they're more like ports than spaces, ports at which clusters of *neurotransmitters* are waiting as a chemical transport system. Subsequent research has shown that, in fact, there are indeed electrical as well as chemical synapses in the brain, though the electrical ones are heavily outnumbered. The number of dendrites and synapses varies hugely according to the neuron's function, but on average a neuron is thought to have around 7000 synaptic terminals. Multiply that by 100,000 million and the mind begins to boggle.

In photographic comparison, a normal brain resembles a fresh peeled chestnut, pale and fat and glistening,and an advanced-Alzheimer-diseased brain looks rather like a walnut, shrunken and shrivelled with bits apparently eaten away. The disease takes place as a physical invasion, involving the progressive destruction of the neuron forest. Under the microscope, the damage is theatrically obvious. There are the *plaques*, fuzzy, rust-coloured accretions of protein fragments, which interfere with the transport network, and there are also the *tangles*, which look rather like strands that have grown over the neurons, like bindweed in a garden, though in fact they're a distortion of the neuron wall itself, its microtubules collapsed into knots. As cells wither and die, gaps form in the tissues, leaving characteristic holes. American researchers working with the new generation of scanners, and thus able for the first time to look into the brains of living Alzheimer's patients, have found that the disease starts in or adjacent to the hippocampus, the memory-processing zone, moves further into the limbic system (our emotional nerve centre), and around eighteen months later, has crept into the frontal lobe, site of the thinking, reflecting self. The disease always starts in the same place and takes the same general route, but proceeds unevenly in its spread. Some sections of the brain will be decimated, but others, neighbouring, might be unaffected and normal. It's rather like a forest fire in which clumps of blackened stumps stand adjacent to trees that seem oblivious to the disaster, untouched, their green canopies intact.

The term dementia – from *de mentis*, out of the mind – was coined in 1801 in the Parisian asylums. These days it is used to mean Brain Failure, and in just the same way that Heart Failure is a condition caused by a whole host of problems, Brain Failure has many sponsors. One in fourteen UK citizens over 65 has some form of dementia and one in six over 80, but for UK citizens reaching 65 this year, the risk of developing dementia is one in three. And that's the trouble with it, in terms of PR. It's an old person's disease, by and large, and elderly ill people aren't easy to "sell". The issue is confused by our muddle about what's normal in old age, the idea that senility is an ordinary part of it, part of the human condition, is ageing itself made manifest, and thus can't be cured. Progress is slow. Research funds aren't generous, despite the fact that currently, dementia is costing about 23 billion pounds a year to the UK alone, just in dealing with damage limitation and long-term care. Unpaid carers, their lives transformed into a round-the-clock vigil, are saving the British economy almost 12.5 billion of this. The Alzheimer's Society says that two thirds of people with late-onset dementia are living in a family home.

At the time of writing, only £61 is spent per head in the UK per Alzheimer's victim on research, though the figure is £295 a head for cancer. In fact it's worse than that sounds: twelve times more (£600 million) was spent in 2008 on cancer research than on dementia research (£50 million). In the USA in 2008 $5.6 billion was spent on cancer research, and only $0.4 billion on dementia science. Cancer has higher cultural status; even, perversely, a twisted, dark kind of glamour. Plucky young people get it, pop stars battle it, pretty wives and dashing young husbands die of it, their pictures spread across the papers. Cancer is a disease that journalists get, that journalists write about on the basis that *if life hands you lemons, make lemonade*. People with dementia don't write about it much because writing isn't something they do, or wasn't, until recently, when the very-early-diagnosed patient lobby sprung into being and people like the writer Terry Pratchett began speaking out. In general, the Alzheimer's demographic and its symptoms mean it's very low caste, something we associate with decay and with the cabbage-and-disinfectant scent of the geriatric ward.

There are widespread misconceptions about the disease. Uncertainty is the midwife of misconception and the trouble is, nobody knows for sure what triggers the thing. All we can hope for is that keeping fit, doing crosswords and eating well will spare us. They don't, necessarily. Iris Murdoch's illness attracted so much interest because people were amazed that someone like that could fall prey to Alzheimer's, someone so clever, articulate, affluent. We live in an age-defying, mortality-denying culture. We don't believe in ourselves as elderly. We're interested in cancer and the carcinogenic because those are words that might turn out to apply to the 38-year-old as much as the 78-year-old: cancer afflicts the young and rich and fit. If Alzheimer's equals old age, then that's something we'll deal with later... though we'll be fine, because we drink soy milk and do sudoku and play tennis at the weekend. The most widespread misconception is that dementia's a good way to go: "they're in their own little world and pretty happy", the misconception goes; "and they've no idea they're going to die of it right up to the very end: this doesn't sound too bad to me". Very occasionally and exceptionally, in the online Alzheimer's community, sweet-tempered-to-the-last is reported; the slow-fade sweetie who was never any trouble and died smiling in bed before indignity could take hold. But that isn't the norm. That hasn't been Nancy's fate, alas.

If I had to pick one catch-all descriptor for Nancy's life in the last few years it would be misery. Profound misery, unceasing and insoluble. She knows that something is wrong, very wrong, but what is it? She's had a series of terrible daily encounters with herself and her environment that might have come directly from an amnesiac thriller: waking to find she has aged 50 years overnight, that her parents have disappeared, that she doesn't know the woman in the mirror, nor the people who claim to be her husband and children, and has never seen the series of rooms and furnishings that everyone around her claims insistently is her home. Time has slipped, gone seriously skew-whiff. Every day for her is spent in an ongoing quest to put things right. The trouble is, she can't seem to concentrate on the question or on possible clues to it. She can't navigate the problem. When she left us for the home, she was engaged daily in a very protracted, slow-motion form of panic. It's been over eight years now since the formal diagnosis and eleven years at least since symptoms began, but even after all this time, she's only at Stage 6 of the disease. Stage 7 looms, the cruellest and last phase, with its loss of continence, motor control, speech and ability to swallow. Eventually her lungs will forget how to breathe, her heart forget how to beat, and her quest will come to an end.

I have thought, and said, and probably even written in here somewhere that Nancy has lost her self. That at least is the impression anyone who knew Nancy twenty years ago would have if they spent a weekend with her. The things that made her herself are all but gone now, I say, but what does it mean to say that? Obviously she is still herself, isn't she? She isn't anyone else. It's just that the self is changed. Disease has changed it, or else, in some vaguely science fiction manner, overlaid it with something new. But what exactly is the self anyway? Must it have unity, continuity, in order to be authentic? Does it exist beyond and beneath the health or otherwise of 100, 000 million neurons? Is there something else that encapsulates the self, something extra, indefinable, that we call the soul? If, as some philosophers of Mind argue, being conscious can't be said to be without content, that it's to do with being aware not only of your own person, but also your past and future, your place in the world, culture and context, hopes and fears, then where does that leave Nancy? John Locke may have come up with the notion of "consciousness" specifically to spike Descartes's idea that we are thinking all the time, even when sleeping, but Locke also thought that we are only ourselves in having our memories, and defined personhood accordingly. Locke's definition, being antique, is easy to forgive. It's surprising, though, to find much more recent definitions that agree broadly with his. As late as 1973 an American philosopher called Mary-Anne Warren demanded of persons that they be conscious, rational, capable of abstract thought, able to communicate, to exercise free will and have self-awareness. According to this severe definition, nobody with brain damage is a person, and Alzheimer's, so often mis-referred to as a mental illness, involves a catastrophic form of brain damage.

Materialists would contend that there is no soul, that we are only a kind of organic machine, our notion of a unique self misguided. It's difficult not to be convinced by this idea, seeing Nancy's selfhood warp and flicker and wane as the disease colonises her. It's not good – not even for privileged bystanders, counting their blessings – to see a self under attack. We prefer to think of our selves as something original in the world, inviolate, independent of our physical bodies. The idea that we are biochemistry, and that's all; that thoughts and feelings are produced by neurons, that neurons can die and our selves die with them… that's a deeply undermining idea. It's far more comforting to contend that Nancy's soul, her essential self, remains intact beyond the reach of her struggle to think and express herself, and will be liberated and restored by immortality. I try hard to believe this when I see her, alone in the day room in the care home, sitting rubbing her hands together and muttering. I can't help wondering what she's thinking. Is she thinking? Is she having a dialogue with her disease, negotiating with it in some way, aware of the great buried store of memory, her past, her self, glimpsed under the tangles of Alzheimer's like a ruined house under the suffocating grip of ivy?

Now that she's at one remove from us again, it's easy to love her, but where love falters, guilt is primed and ready to fill its place.