ANDREA GILLIES

KEEPER

a book about memory, identity, isolation, Wordsworth and cake...
PRAISE FOR *KEEPER*

“Deeply moving” *Daily Mail*

“A wonderful book - honest, upsetting, tender, sometimes angry, often funny - which takes us on a journey into dementia and explores what it means to be human.”
Deborah Moggach

“A searingly honest account” *Daily Express*

“Terrific, terrifying, absolutely powerful in every choice of word, every sentence, and the whole thrust of it.”
Quentin Cooper, presenter of BBC Radio 4 “Material World”

“*Keeper* is intelligently written and impossible to classify...
Gillies discusses daily activities in the same engagingly frank conversational tone as she recounts flashes of raw emotion, moments when anger and guilt burst through the veneer of capability...”
*Times Literary Supplement*

“Andrea Gillies’s account of living with Alzheimer’s is the perfect fusion of narrative with enough memorable science not to choke you. It’s a fantastic book - down to earth and darkly comic in places. The judges found it compelling.”
Jo Brand, comedian, writer and former psychiatric nurse
“This is one of the most moving and important books that I have read on Alzheimer’s.” John Bayley

“Thoughtful, informative and true... a very good, very necessary book.”
Sir Richard Eyre, patron of the UK Alzheimer’s Research Trust

“An incredibly observant....desperately honest book...
Andrea Gillies is a brilliant prose stylist with a poet’s facility for metaphor and a brave wit born of exasperation and sadness.”
Professor Raymond Tallis, author of The Kingdom of Infinite Space

“In Keeper there is hope and humanity and the warmth of sacrifice...” The Catholic Herald

“The most poignant aspect of Keeper is the way Gillies traces the increasingly unbearable pressures that are placed on carers as patients progress from memory lapses, not remembering important life events, and no longer recognising family members to the final advanced stage that Gillies calls the ‘darkest shadow’.”
The Lancet

“Outstanding” Alzheimer’s Research Trust
To C and the children,
and with love and gratitude to my family and friends
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
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 Alzheimer’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 whose 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.
Three Years Ago

NANCY IS STANDING at the window again, the one with the spectacular view, worrying about how the oil tanker will manage to get out of the bay. She is making her anxious hands, rubbing each palm against the back of the other in turn, brisk and rhythmical.

“I just don’t think it will get out of the space, it’s too big,” she says, rubbing harder, her eyes full of concern.

She is wearing all the cardigans she could find in her bedroom, in layers, having insisted on doing up all the buttons on each and tucking each sleeve under at the wrist. Her mood has improved since breakfast time, when she woke with the now characteristic belief that she was newly discharged from hospital into the care of strangers.

“But where are my family? Are they coming for me?”

“We are your family, honey,” I soothe.
She laughs disdainfully, shaking her head.
“Either you’re a liar, or I’m going mad.”

Most mornings, there are tears. Tears and confusion. Dressing is hard. She wants to do it herself, but bras and trousers go on backwards. If we don’t get to her quickly enough, she wanders the halls in her underwear. She looks younger than 79, everybody says so, and this is especially evident in her near-naked wanderings. She’s physically
amazingly good for her age: unstooping at 5’7”, well proportioned other than for a mildly pot belly, determinedly upright. Her legs are strong and shapely. She can walk for miles, has thick silvery hair cut in a bob (it was sandy coloured once, set into soft curls at the local salon once a month), and a charming smile, her pale face barely lined, though her blue eyes are rheumy now and her nose growing hooky. She’s acquired a prickly white beard under her chin, which my husband Chris shaves off every now and then. She won’t always let him at it. She can be protective of it, sitting stroking it in her chair. Some days it horrifies her. “Who put this here? Where did this come from? Take it away!” Or she thinks it’s a wound, a scab. “I must have tripped and fallen. But it’s getting better now.” Nancy’s at a Good Days and Bad Days stage of Alzheimer’s, and on bad days she accuses Morris of having given her the stubble, perhaps because she recognises that beards are properly the province of men.

She returns to her little sitting room, her coal fire, her husband, and sits in her pale blue winged armchair. She asks, now, if it’s hers and if she can sit there. She hasn’t had it long enough to remember it. Only the very long-term memory is functioning. Morris is sitting in the chair beside her, is always sitting in the chair beside her. His is electrically powered, tips back, is upholstered in orange tapestry. He was stout once, and with his square face, mischievous dark eyes, dark hair combed over and moustache, once resembled a rather better-looking Oliver Hardy, and was just as likely to suffer fools gladly. He’s mellowed. He appears to have shrunk, in all dimensions.

I’ve known Morris and Nancy for 22 years. When I first met them, brought home by Chris from university, I thought
them old-fashioned, thrifty (the washing machine was top-loading), sociable, hard-working, right wing. They were Daily Mail readers but generous about our student leftiness. I don’t recall anything much in the way of ideological stand-off. They were all hospitality, baled us out when we got into financial hot water, had us to stay on an indefinite basis when work plans went awry. Despite finding our postgraduate ideas about office jobs and steady security highly provoking (we didn’t fancy either of these much), they were nothing but kind. Kind but unforthcoming, opinion withheld. This has been a pattern in our relationships.

Nancy and Morris moved here with the rest of us this summer. We have a lot of latitude in where we live. Latitude and longitude. Chris is an internationally known-in-his-own-niche expert on a specific use of new technology, and consults widely, mostly from his home office, though there are bouts of meetings and flying. We have two teenage girls: Millie, who’s tall and dark like her mother; Caitlin, who shares her father’s ash-blond colouring, and a boy called Jack, a senior at primary school, tall and lanky and Italianate with a scruffy dark shock of hair.

Moving house, it turns out, isn’t good for Alzheimer’s patients. Leaving behind the familiar, having to adapt to the new. Nancy’s disorientation is ongoing.

“I don’t know where I am,” she sobs. “I don’t know what I’m supposed to be doing”.

I’ve been reading about memory. In cases of Transient Global Amnesia (total but temporary memory loss), people ask over and over where they are and what they should do, how they got there, what they should do; what should they do now? Doing is a big preoccupation. They don’t ask what
might seem to be the obvious question: who am I? That doesn’t seem to be a question the self asks of the self. Instead, it looks for clues from context. Where, how, what.

Chris and I have different responses to her anxiety. He takes her hand and is tender, explaining that they weren’t coping, she and his father, and have come to live with us. I go for a jollier approach.

“Well, lucky for you you’re retired now and you can sit in this chair by the fire and eat biscuits and watch the afternoon film on the telly,” I say. “Not like poor old me, I’ve got washing to see to, dogs to walk and vacuuming, the dinner to sort out, and you should see Jack’s bedroom.” Jack is proving dedicated to the acquisition of Stuff, particularly electronic Stuff (gadgets, dead laptops), as well as guns, swords and lighters. Sometimes I worry where these interests might lead.

“Oh poor you, having to do all that,” Nancy says, fleetingly lucid, playing along, and I’m embarrassed at being caught out talking to her in this nice-nurse fashion. But the moment passes and she’s back at the window.

“Look at all that water.” Her voice is astonished.

“Yes. We live here, out on the peninsula; the sea’s all around us. Do you remember coming here with us to live? We came last month. Do you remember?”

“Edinburgh,” she says under her breath.

“You used to live in Edinburgh, years ago. But then you moved up to Speyside, near our old house. Do you remember the bungalow? By the river?” She looks blank. “And now you live here, with us.”

She looks at me, grim-faced. “That’s all very well, but they laugh at me, you know. Not you, I’m not talking about
you, but the others. They look me up and down in the street and I can see that they’re thinking, who the hell does she think she is?”

Paranoia, an Alzheimer’s marker, is just beginning to get its grip on her. But she’s been lovely to the children all summer, which is reassuring. Her face lights up when they go into her sitting room. She pats her knee, like she used to; Millie’s 5’10” and can’t help laughing. “Now come and tell me all about it,” Nancy says. About what, she doesn’t specify. The girls are good with her, as Morris is always telling me. They’re patient, tolerant, don’t rise to verbal bait. They do things at Granny’s pace, taking her arm in theirs. “Come on, Gran. Let’s go and make Grandad some tea”, talking her through the operation step by step. “Put the teabags in the pot now. In the pot, not the mug. That’s it. Right. Hot water next, can you manage the kettle okay? That’s the kettle. Yes. Here, let me.”

Morris prefers television to conversation, or indeed anything, and it’s been this way a long time. Depressed and immobile, he is master of the remote, and flicks between channels with a desperate air. It’s like he can’t look away. Things are too awful in his present to contemplate them squarely. Because he’s so focussed on his television day, Nancy’s life is frequently lonely. She can’t any longer follow a television programme. She’s more interested in being with me, because – when running the household, at least – I appear to be doing things. She’s less keen on me when I’m writing, or reading. “The men just sit there,” she tells me scornfully – unable to distinguish between one kind of sitting and another: one at his desk on his laptop and phone, consulting and earning, and the other in the next armchair to her, absorbed fifteen hours
a day by the flickering screen. She follows me around. She wonders half a dozen times a day where the friends are, and if they are coming.

“I don’t want the friends to know I’ve been ill,” she says, as we pick tomatoes in the greenhouse. She eats the ones she picks or puts them slyly in her pocket, thinking I haven’t seen. Or just picks the dried-out leaves from the plants and puts those in the basket, smoothing them carefully. Then she takes them out again. “I don’t think these are ready” she’ll tell me, trying to fix them back on the trusses.

The friends – imaginary friends – visit us sometimes and she has days when she worries about how they’ll get here, and how they’ll get home. In truth, her friends have long deserted her, had deserted the two of them long before their move north. Desertion is a strong word; the truth is it wasn’t anything like as premeditated as that. More a gradual loss of attentiveness, social slippage; the kind that happens when people get sick and have little to talk about other than their problems. Three from their old circle telephone from time to time, but it’s us they want to speak to, for reports.

“I need to say goodbye,” Nancy insists, twisting her handkerchief. “I need to see the friends off.”

“Don’t worry,” Chris says, trying to ease her agitation. “They’ve gone already; I saw them leave earlier”… and then, seeing her expression, adds “but they said to tell you they’d had a lovely day.”

“Gone already? But they didn’t say goodbye.”

“They did, don’t you remember? I think you might have been asleep.”

“They haven’t gone.”

“They have; I saw them; they left on the bus.”
She looks indignant, draws her shoulders up tight. “They didn’t come on a bus.”

She appears to be having hallucinations. These are new, have arrived quite abruptly, and it occurs to me that our moving her here has aggravated the decline somehow, has accelerated it. Guilt is something I’m going to get used to, but for now it’s fresh and new. I take Nancy into the drawing room and we look through a stack of interiors magazines, me commenting and Nancy cooing. My laptop’s open on the table, attention 80% diverted while I trawl the internet for answers. Temporal lobe damage, it seems, can cause autobiographical visions. Does she see the friends striding towards her across the lawn, looking just as they did twenty years ago or more?

Sometimes I think I can see them myself. The house doesn’t feel haunted – some big old houses do, but this one doesn’t – though there have been sightings, I’m told, in years past, of Victorians paused on the stairs, their eyes oblivious to the present. The first day we were here and went to the pub for supper, a fisherman propping up the bar asked how we were getting on with the spooks. I haven’t seen anything or heard spectral footsteps, but the whole property is soaked in what I can only describe as past-fulness. It’s pastful, and sometimes, even though knowing it’s just this and that the details are illusory, I’ve half believed there are women in rustling silk frocks in that part of the wood that was once the rose garden, have half heard brief melodious laughter in the paddock that was once a tennis court. Who are these people, the friends Nancy talks about? It’s occurred to me that the altered perceptions of Alzheimer’s might allow people to see ghosts.
The house sits out in near seclusion at the neck of the headland, at the point where the neck joins onto the shoulder of a second, bigger peninsula land mass, two miles from a village, fifteen miles from a small town and far, far away from everything. It’s a great four-square Victorian house with sash windows, crenellations, crow-step gables, its overgrown walled garden framed in lichen-covered stone. It’s the kind of house which, while not grand enough for Manderley or Gothic enough for Walter Scott or English enough for Jane Austen, might serve as the scene of a death at the vicarage in Agatha Christie. It sticks up high on the low, gently undulating profile of this wind-scoured green promontory like a church, the sea rushing up the cliff faces around it. Building upward in this climate is an act of faith, almost of defiance. The architectural vernacular herabouts favours single-storey longhouses, long and low and hugging the ground, though a good many of these have been weathered into rubble, with kit-build bungalows parked alongside. After the longhouses fell from fashion, the local style became one-and-a-half-storey cottages, high enough to be provided with an upper floor snuggled into the eaves, low enough to brace themselves against the weather. The eighteenth-century terraced housing that lines the two principal streets of the village is fully double storey, held in a self-protective loop around a deep-water harbour.

The house and neighbouring farm were once one property, and together they owned all the land that can be seen from the single third-floor window, the attic window that leads out onto a precarious half-balcony. The original farmhouse is 200 yards down the hill, across the lane, enfolded by its barns and cattle court into a wind-resistant
square. The building of the big house in 1860 marked the achievement of wealth and status, a move up from the cottage to a grander residence on higher ground, one gleefully elaborate in its luxurious details. All that remains of the estate are the four garden acres inside the high wall, the privacy-giving wall, marking off the domestic world from the working one, separating peasant from gentry, keeping the bullocks and harvest workers in the adjoining fields out of the sight of the strolling, tea-taking, tennis-playing manor-dwellers within.

The house layout is ideal for an extended family. The kitchen has two doors: one into Morris and Nancy’s sitting room, and one into the rear corridor, where their bedroom and ensuite were converted from two former maids’ rooms. Off their sitting room in the other direction is a small lobby, which leads into their private daytime bathroom. So Nancy and Morris have, in effect, their own suite of rooms, with only the kitchen shared, and even that is two-family-friendly, having two stoves and two full-size tables along its double length. The original thinking was that Nancy and Morris would self-cater, up to a point and with our assistance. They were keen, Morris said, to have as much independence as possible. They brought what remained of their marital past in packing crates, everything that had survived successive years of downsizing: their 1960s crockery and pastel-coloured kitchenware; tarnished silver cutlery with worn bone handles; old pillows, duvets, blankets, marital linens smelling of cedar wood; boxes of clothes and miscellaneous items dating back 40 years: old toiletries, tights, lampshades; wallets and watches, belts and business paper.

With the exception of a daily excursion into the con-
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servatory for coffee, their world has shrunk into this little sitting room by the kitchen: its two armchairs, a 1960s coffee table, a partner’s desk, a television, a dresser laden with ornaments—unused steak knives and ancient paperwork idling in its drawers—and a bookcase scantily furnished with photograph albums, thrillers, Reader’s Digest, the AA Guide to Great Days Out, 1970s cookery books whose pages are stuck together with cake mix.

Nancy’s Alzheimer’s seems to advance in phases, as if we’re mining underground, into the unknown, towards obliteration. Currently we’ve hit the seam of Lost Prepositions. Morris gets exasperated with her lapses, her confusion, her failure to recognise what’s ordinary and deal with it in the old ordinary way. He has his own health problems: replacement hips that’ve worn out, poor circulation, numbed legs and feet. Walking is a struggle, and in the past he’s relied on his wife to be his legs. She has trouble with this role now.

“No no!” we hear him shouting. “The cup! The cup! In front of the book! No, not under it, in front of it! Now put the spoon in it. In it! In it! Not behind it! That’s a book! Not a book, a cup! Oh for God’s sake, woman!”

She can’t seem to distinguish between cup and book. Parietal-lobe damage is responsible for this, apparently; for failing to match objects with words in that apparently simple but sneakily complex two-hander we call recognition. But telling Morris so and asking him to be less irritable makes no difference. Occasionally, Nancy gets fed up with being yelled at and gets her coat and handbag. On one such day she finds me in the kitchen making soup.

“Excuse me.” A plaintive little voice.
She can’t any longer remember my name.
"Excuse me. Lady. I think I should tell you that I am going to have to find other accommodation." This formal way of speaking is new. Perhaps it stems from uncertainty: her being a stranger in a strange land, needing the help of good Samaritans and needing to be polite to them. If you’re unsure who anybody is, or indeed who you are, come to that – their rank, your rank, what your relationship might be – then you’re likely to be deferential. Either that or bolshy, asserting your position. Bolshy will come later.

When Nancy’s upset, distraction’s the only way out. Everything else, and especially reasoning, only escalates and intensifies the trouble. I take her outside, where flowers and butterflies and birds and trees do the job like nothing else, all upset forgotten. We go down to the road, down the long driveway between looming dark hedges of fuchsia, and stand between the entrance pillars and admire the view. She runs an appreciative finger over the house name, indented in brass set into the stone, and I’m shocked to find that she can’t read the word, the word that’s the house name. She can’t recognise the letters, and even when I tell her what they are, can’t vocalise them into a run of sounds. She’s interested in them though, as something half-remembered, on the tip of her tongue, running her fingers over the brass a second time, frowning and with concentration. I go back to Chris in his office, shocked.

"Your mother can’t read, she can’t read any more," I tell him.

It’s stunning because it’s so absolute, so concrete a loss. Parietal-lobe damage is to blame again, it seems, in that zone of the brain where visual impressions are organised and reading and writing are ordered and understood. I read
about this on the internet, which has become my personal guide, dementia carers’ network, GP and hospital rolled into one handy package.

It isn’t, any of it, a linear progression. Damage, or at least the symptoms of damage can appear to waver like flickering wiring. Some days Nancy has vocabulary, some days not. She’s wandering the house looking for her shoes, and when I ask if I can help, looks down at the floor, offering me a lifted socked foot.

“The things, the things that go on the… that go on the things. I want to. I want the things that go on the end.” Perhaps this is a sign of parietal-lobe damage again, failing to match word and object, or perhaps it’s to do with the plaques/tangles invading Broca’s area, a patch on the left side of the frontal lobe that was named after Pierre Paul Broca (1824–80), who had a patient in 1861 who could only say “tan”. It’s the zone charged specifically with talking. It’s fascinating, this physical loss of abilities in the departments of self, but in tracking Nancy’s neuronal failure, I face self accusations of ghoulishness.

Random stream of consciousness nonsense has become a feature in the mornings. Miscellaneous phrases from the past, from the long-term memory, fall out of the box in random order.

“I’m so glad you’re here,” she’ll say, “because I was worried about that.”

“About what?”

She looks at me appraisingly, as if making a decision about whether she can confide, before launching in.

“It’s been a long time, and I didn’t always do it that way, oh no, don’t you believe him when he puts it off, because I
can tell you, it’s all the other way, really, to be quite truthful, and he knows it is, and I could strangle him sometimes, but the woman said I was to go that way, so I went, and it wasn’t there. Did I tell you that? I said that before and you haven’t got it. I know that. I do know that. I’m not really as stupid as I look, but she says – oh the things I could tell you about her, but I won’t because you shouldn’t – and I have got to find the thing now or I won’t hear the end of it.”

“Her?” I ask.

“The woman,” Nancy says, rolling her eyes.

“But it’s just you and me here,” I say. “We’re the only ones.”

“No no no,” Nancy says briskly. “Not you. The other woman.”

Taking on Nancy’s care, full time, seven days, 24 hours, has been... I wish I could find a better word than shock. It’s been a shock. The thesaurus offers “trauma” but that isn’t remotely it. It hasn’t been a “blow” or an “upset”, a “bomb-shell”, a “blow” or a “jolt”. It’s more like the kind of experience that leaves you staring into space open-mouthed. How on earth did I get here?, you think. And how am I going to extricate myself?

There’s no adequate preparation for the physical demands, the physical hour-after-hour-ness of caring full time. It hadn’t occurred to me that I would need to dress and undress her, for example, and get her toileted and into the shower, and would find myself, in consequence of this, adopting the nice-nurse-ish patter that theoretically I hate.

“Righto Nancy, let’s get you sorted for bed, shall we? Cardigan first.”
When I get her into her nightie and take her trousers off, her feet are blueish: white and blue and mauve, her toenails thickened, opaque and yellowed like smokers’ fingers, her shins crocodile-skinned. Proximity. That’s the key word. Up close and disturbingly personal. There’s emptiness behind her eyes, something missing that used to be there. It’s sinister. It seems sometimes, in fanciful moments, that it’s Nancy who’s missing, though her body continues to live and breathe and walk around in the world, redundantly.

I have a new role, a new identity. Mothering somebody’s mother, and being thanked for it effusively. Nancy comes into the kitchen when I’m cooking and wants to help. I find something for her to do and then she bursts into tears.

“Oh no. What on earth is it?” I put my arm round her and she cries harder.

“It’s just that you’re so-o g-good to me,” she blubs. “You’re so good and kind and you do everything for me. I wish I could do something for you. Tell me what I can do. I want to give you something. A present. Will you take my money out of the bank and get yourself a present?”

“There’s no need, really. I don’t need anything. Really,” I tell her.

She goes back into her sitting room.

“Oh God, what is it now?” I hear Morris asking.

What exactly is my new relationship with my in-laws? I am their housekeeper, something approximating to their parent, their perpetual hostess but also a servant. I send Morris a pot of Earl Grey and a warm Victoria Sponge, still feeling as if I have visitors and need to provide afternoon
tea, and in return he gives Jack a penny and says, “here, give this to the waitress.”

We begin to integrate ourselves a little into peninsula society. First into commerce, then into other people’s kitchens. Professions here are often of the multiple kind. Paul, the gas-fitter, installs an eight-burner stove in place of the inherited curly-plate electric, then makes new stable doors for the yard, and is turning out to be a very nifty tiler. Though tradesmen aren’t easy to find.

At the end of the week, I scissor the local paper, cutting out announcements for the pinboard. The newspaper’s being read everywhere we go on publication day, by shopkeepers, office and health workers, people at the wholesalers and in boatyards; people in tea shops: ordinary routine comes to a halt. There’s a piece about new Neolithic finds made further up the coast. Someone has been shooting seals and the public is appealed to for tip-offs. Wrecks have been plundered by treasure seekers, and a diver is brought up dead. A man’s airlifted from an uninhabited island, injured while birding. A skipper’s been charged with being drunk in charge of a boat. There’s been another suicide, someone who came from England on holiday and leapt off our cliffs to his death. There’s been a country dance, and teenagers hospitalised intoxicated.

All this is absorbing enough, but I’m more interested in the advertising. The advertisements are a godsend. Not every trader has a shop, or even a sign, and lots of the smaller businesses are done anonymously from home. Thus it is that we find ourselves in a barn one morning, choosing tiles, while being watched intently by heifers.

We take afternoon walks on the beach, going down by car
so that Morris can come. He can’t make it over the strip of pebbles, nor manage the low grassy dune, so he sits in the car with the door open, watching and smoking.

I take the dogs to the water’s edge and throw sticks towards America, the retriever plunging in after them and the Jack Russell barking at him from the shallows. Chris walks his mother up and down the length of the sand, Nancy holding onto his arm and striding along. She’s happy, just for this moment, radiant, smiling into the sun. Sometimes a change in the weather is enough to restore our optimism, and this seems truer of Alzheimer’s than is general.

Nancy’s world is re-created every minute. She lives in the moment, and therein lies the problem. Immediately we get back indoors, she’s lobbying to go out for a walk. The walk she’s just had is rendered down into an idea, one that persists and nags at her.

Perhaps the best thing for Alzheimer’s sufferers might be nomadism of a kind. A permanent ambling trek in talkative company, pausing only for meals and to sleep, would make her happy, I think. Everything, every moment, would be new to everybody in her party and they’d all be on a more equal footing of constant change.

It’s our wedding anniversary at the end of the month and Chris and I go to the village restaurant to celebrate, leaving the children in charge. We eat crabcakes, a fish and crustacean stew, lemon tart with marmalade ice-cream, delighting in everything but preoccupied with home, two mobile phones winking on the tablecloth.

“The fish is wonderfully fresh,” Chris tells the owner. “Presumably local. Is it caught in the bay here?”

“Actually, no,” the owner says. “We can’t get the quality
here. All the good stuff goes south. All our fish comes down from Shetland.”