Where Memories Go

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WHY DEMENTIA CHANGES EVERYTHING

SALLY MAGNUSSON

TWO
ROADS

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For Anna Lisa, Calum, Ellie, Jamie, Louis,
Magnus, Robbie, Rossie and Siggy.
To replenish your own memories.

To a steigh brae, a stubborn back
Addressin' daily;
An' up the rude, unbieldy track
O' life, gang gaily.

Robert Louis Stevenson,
'The Counterblast', 1886

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Preface

This is a book about the life of my mother, the writer and raconteur Mamie Baird Magnusson, and the way dementia changed it for her and for everyone who loved her.

It is also a book about dementia itself, and how society regards the most fragile of its citizens, and how urgently this needs to change.

Mamie was never famous in the way her husband Magnus became, when he found himself in the living rooms of the land for twenty-five years as the stern interrogator on the BBC quiz game *Mastermind*. She came not from saga-steeped Reykjavík and a douce Edinburgh villa, as he did, but from the poor tenements of a small industrial town on the edge of Glasgow, where she developed the keen eye and light, humorous writing style that would make her what the great *Daily Express* editor Arthur Christiansen was to describe as 'a very fine journalist indeed'.

She loved words and taught her children to cherish them, too. Then, little by little, she lost them. What follows are my words for my mother, words to recover a life forgotten.

I have agonised over publishing so personal a story. But then I meet someone else's family, and someone else's, and another, and another, each one struggling to balance a great love with the overwhelming demands of looking after a person with dementia, at home or elsewhere. And I read yet another account of gross institutional neglect in a world that has woken up too slowly to the implications of longevity and the brain diseases to which it is rendering more and more of us vulnerable. And I think then that our story matters. Not because it is ours, but because it could be anybody's.

'All this ought to be written down,' says Chekhov's Irina in *The Three Sisters*. We can't all be professors, doctors or policy-makers, but there are other ways of advancing the understanding of dementia. Writing and talking about our experiences is the best way to undermine the stigma surrounding this condition and enable it to be seen as perhaps the greatest social, medical, economic, scientific, philosophical and ethical challenge of our times.

I began documenting the progression of my mother's illness in early 2009, although I had kept jottings before that. For her past life I was able to mine a rich seam of recordings from nearly twenty years earlier. I made these not because I sensed that my mother might one day lose those memories, but rather because I knew that in the natural scheme of things I would one day lose her. It was my own memory I mistrusted, always a flimsier instrument than hers and more like that of my father, who, when I approached him with the microphone to solicit his own reminiscences, backed away hastily, protesting that he could remember nothing about anything. My mother, typically, flew for the kettle at once and was rattling off stories while I was still wrestling with the cassette record button. These anecdotes form the basis of the account of her life here.

The writing began as an attempt to keep hold of my mother as her personality changed shape. I'm a reporter. I wanted a record of the fun, the wit, the banter, the normal, the joyously happy times as well as the not so good. I found myself, quite naturally, talking to her as I wrote.

Later, as the enormity of the social phenomenon in which we were caught up began to dawn – one I discovered we were sharing with more than a third of the UK population who have a close friend or relative with dementia – I wrote with the thought that other invisible lives might be nudged into the light through the telling of this one story and the questions it made me ask.

To be clear, it was never my intention to attempt a comprehensive critique of social policy, which varies too widely across the UK anyway and is being modified all the time, nor to take political sides. But living closely with dementia for more than a decade has changed me, just as in a different way it changed my mother. It has made me think deeply about what it means to be, first, a human being and, second, a community, and the kinds of societal change we need to strive for if we are genuinely to call ourselves civilised. In that sense I found the memoir evolving into a *credo*.

It is as faithful an account as I could make it. The names of those who appear inadvertently, without having had the chance to be consulted, have been altered. Some of the investigation of the broader issues was done at a later point than it appears in the narrative (indeed a few of the inquiry reports and interviews post-date my mother's death in April 2012), but the questions that stimulated the journalism occurred as described.

I may be kidding myself to think that my mother herself, inveterate storyteller as she was, would have approved of this venture, but I do have one piece of evidence. One evening she noticed me scribbling on a piece of paper and asked what I was writing.

'I'm noting down what you just said.'

She laughed. 'Oh, was it interesting?'

'Very. Actually, I'm thinking of writing a book about you. How would you feel about that?'

'I'd be honoured,' she beamed.

'Listen, Mum. If I were to write about our conversations,' I said carefully, conscious all at once of framing a question that mattered, 'and about, you know, the things you find hard and the things we all do to help you, would it feel invasive?'

I wish now that she had asked me what I meant by 'invasive', but instead she batted straight back with a smile.

'No, I'd be absolutely thrilled.'

'You'd trust me?'

'Of course. Yes.'

We carried on nibbling our chocolate biscuits and sipping our tea, with a feeling on my part of having settled something. Far though this exchange was in reality from any meaningful concept of consent, I felt as if I had received a kind of blessing to carry on reporting the biggest story of my life.

But I have to acknowledge a cost here. In writing so personally I am sharing a mother – and a father – who belong equally to my sisters and brother. Every relationship with a parent in any family is different and uniquely nuanced: my siblings, Margaret, Anna (alias Topsy) and Jon Magnusson, have been staggeringly generous in allowing me to write in a way that mainly reflects mine. Our mother's twin sister, Anna Baird, has been equally gracious in permitting me to share her own part in the story, in the hope that it might help others.

But that doesn't mean it is anything other than painful for any of them. I am offering up to the gaze and comment of strangers an experience exquisitely precious to us all. Saying thank you does not begin to express what I owe them.

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Let me count the ways

Elizabeth Barrett Browning, Sonnet 43

'Things I Love About You', I write, thinking about you in the sturdy old family house three miles along the road where I have just tucked you into bed. It is dark outside. A half-hearted line of snow has settled along the bottom of the window.

On the wall in front of my desk it is summertime. There is a photo of you in your most vibrantly pink jacket and lipstick, arm flung around my father's shoulder with the eye-dancing smile you have not lost. It was taken on your fiftieth wedding anniversary. The rest of us are clustered around you both in the June sunshine – four children, nine grandchildren, your twin sister Anna – all grinning madly, as well we might. We were hardly able to believe our luck that day that Magnus was alive at all.

I look across at the picture and think about you now, four and a half years on from that golden afternoon, not always sure who this 'Magnus' refers to but still indisputably the girl with the merry smile he fell for across a clattering newspaper office all those decades ago. I think, too, of the fun you and I had earlier this evening when I bundled you into the car on a whim and off on a wintry adventure; of your continuing capacity for wonder, your infectious joy in the moment.

And I start to count the ways I love you.

Memories go, as you know better than anyone, and there are some I badly want to hold fast. In the jargon in which, thanks to you, I have lately become proficient, I have to find ways of ensuring that the axons in my brain grow fresh synapses and new proteins are produced in the cytoplasm of a neuron so that certain scenes involving you will be embedded in my long-term memory, where with any luck they will stay for a while.

What I mean is that I want to remember you. I want to remember everything about you.

I tap late into the night, eager to round up your slippery self before it slides into yet another shape. It's as if I have to catch you now, as if by the time I see you again tomorrow it may all have changed, as indeed there is every chance it will. If I can only pin you by the bullet point, secure you with headings, trap you in words, corral you within a list, then perhaps I can hold you beside me here for ever, the mother who clapped her hands to see the snow at night, who has lost so much of her self but not yet, not yet, the thrill of being alive.

So I write my list. And somehow it happens that I find myself talking to you.

Things I love about you

Your delight in the mad whirl of snow. Remember, Mum, the way it skipped off the windscreen on our way home this evening? I suppose you'll have forgotten by now, but I remember. The snow rushing towards us in the beam of the headlights, making it feel more of a blizzard than it really was. You were pink-faced with exhilaration. 'What a great journey,' you kept saying.

Your unquenchable enthusiasm for sliding down banisters.

'That's how I'd like to go down these stairs,' you murmured the other day, eyeing the one outside your bedroom with alarming intent.

'You're eighty-three, Mum,' I said. 'You broke your hip four weeks ago.'

You looked at it longingly all the same. I like to imagine that same gleam in your eye just before you vaulted a dustbin on Buchanan Street on the way to your first interview with the *Sunday Post*.

'For goodness sake, Mamie,' your mother had sighed when you landed, 'try and act like a lady.'

Those husky harmonies layering every song you have ever sung. And the way, when everything else is slipping away, every skill, every talent, you still want to sing. Last Sunday we stood swaying with our arms around each other in the middle of my kitchen, crooning an old Ink Spots number. Your fifteen-year-old grandson Magnus muttered to his friend Jason: 'You may have noticed we have a mad family.' Jason doesn't know the half of it. But song brings you alive. Your ear for harmony is as keen as ever.

The way you peer into the mirror, push your fingers through your hair and sculpt it forward into a wave. Strong hair, white with a few fugitive threads of black; hair that has always scorned a curler. I've been watching you do this all my life.

Your eyes. Brown, and still shining more often than I dared hope when I first realised the journey we were on. The old glee sparkles on. You respond to banter and teasing with such a whoosh of merriment that it feels as if you're back.

Your wit. It keeps surprising us. Even in your foggiest moments it flashes through just often enough to remind us how sharp you were, how dry, how you used to make audiences cry with laughter.

'It's as well I've got two ears,' you murmured a few nights ago during our routine bedtime combat with your poloneck. 'Perhaps you could leave me the other one.'

The way you stroke my hair when I'm kneeling to take your socks off. You do it almost apologetically, as if to say, 'You shouldn't be doing this.' But you've no idea how to do it yourself. Not the faintest idea how to start. The tenderness more than makes up for your having lately introduced me to my sister with the words, ‘Now, do you two know each other?’

Things I miss about you

The way you would offer stories of your life to the most casual stranger on a bus, train or aeroplane and extract theirs in an instant.

The stories themselves. Your childhood. Your war. Those adventures on the newspaper beat you never tired of recounting. Like the time you got your fur glove stuck in the doorbell of the house near Balmoral being prepared for Princess Elizabeth and Prince Philip’s honeymoon: a Post Office engineer was summoned to mend the interminably clanging bell while you talked the housekeeper into a world-exclusive tour of the house. The first trip to Iceland with your new husband, when you were served raw shark and sank under the weight of cream in the pastries. Your incompetent attempts to bake a cake or sew on a button. Your spontaneous serenading of the Queen at a posh banquet you graced with my father, which led to the whole staid Edinburgh table joining in to bellow ‘Will ye no come back again?’ to an astonished monarch.

So many stories. You still try to tell them. But now they wander far and wide in search of a lost punchline.

The sight of you striding along the road with those long legs, exulting in the wind on your face.

Your knack of arriving unannounced exactly when I need you.

'I thought you sounded a bit desperate on the phone last night, so here I am,' you once explained blithely after materialising unexpectedly on my doorstep like Mary Poppins, though I lived hundreds of miles away in the south-east of England at the time. You promptly rounded up four children under six and sent me to bed.

You were thrilled, of course, when a fifth pregnancy enticed me back to Scotland. For years you had been plying me with For Sale notices from the property pages of the *Glasgow Herald*. I would find them tucked into letters with a scribbled note: 'Just in case.' In the end one torn cutting advertising a house in the next village popped through the post and that was that. I think I had an inkling, even then, that by returning to live within a five-minute drive of my childhood home I was putting down a marker for a distant future when our roles might be reversed. But at the time I was the one who needed you, the all-singing, wisecracking, up-for-anything grandma on the other side of the hill.

The words I miss most: 'You look tired. Let me do that.'

Things I observe with dread

Empty eyes.

Grim mouth.

Vacant expression.

Stony face. In a memoir of his novelist wife, Iris Murdoch, John Bayley calls this the 'lion face', a look of leonine impassivity. It makes me think of the stone lion that a previous owner with a taste for the grandiose left on your garden patio. He lies there, custodian of the pansy pots, eyes dead. Truth to tell, he gives me the shivers – and so do you when you look like that.

Aggressive sniping at the twin sister whose mind has remained lively while yours has not. This is the worst thing, the very worst thing, of all.

*

If dementia care were a country, it would be the world's eighteenth largest economy: somewhere between Turkey and Indonesia, they reckon. As a company measured by annual revenue, it would be the world's largest. Dementia is one of the biggest healthcare challenges on the planet.

There are thought to be 35.6 million people with it across the world – the ones we know about anyway – with an extra 7.7 million cases predicted every year. There are some 800,000 in the UK and around 5 million in the US. Nor is it just a disease of the West. More than half of those with dementia are in developing countries, a number expected to rise to 71% by 2050, with the fastest growth projected in China, India, South Asia and the Western Pacific. Although there are hopes – and even a little evidence – that healthier, more active ageing might delay the condition enough to mitigate the most apocalyptic predictions, the numbers are likely to remain alarming. The World Health Organisation estimates one new case every four seconds and thinks the global figure is likely to double every twenty years, reaching 115 million by 2050.

So this is a disease that respects neither geography, ethnicity, class nor gender. You, my darling mother, are unique in all sorts of ways, but not in succumbing to this disease. Not by a long way.

The cost of care is astronomical. Looking after people with the various symptoms of dementia, whether caused by Alzheimer's or one of the other forms, is already costing 1% of global GDP – that's around £400 billion a year. In the UK the figure is over £23 billion, more than the cost of care for stroke, heart disease and cancer combined. All those bills are poised to rise to dizzying levels in years to come.

Most of us will be touched by dementia in one way or another, either as relatives, friends or the one in three over the age of sixty-five who will eventually die with it ourselves. Those not immediately affected will be contributing to the health and social care bills, so nobody escapes. More than any other modern ailment we really are all in this together.

Dementia is not a form of natural ageing. Having watched a pair of twins approach old age together, I can see this as well as anyone. As you, my mother, succumb to a vicious brain affliction that hijacks memory, personality and functional capacity, I observe your non-identical twin slowing down gradually while retaining a sure ability to name half the British cabinet, beat the family at crosswords and spot a bank statement error from five paces. Dementia might be increasingly common, but it is not 'normal'.

On the other hand, dementia is certainly age-related. The longer we live, the higher our chance of contracting it, which is why the ageing of the world's population (with 22% predicted to be over sixty by 2050) is leading to such a rise in numbers.

Some people develop symptoms as early as their thirties or forties, but the vast majority of people with dementia are old. And being old, some are treated as if they are barely human, *de facto* as expendable as the children of the nineteenth-century poor. At least Oliver Twist had the advantage of looking cute under the grime. Our society likes cute. We coo over pandas and agonise over seals but are too busy running away from our own mortality to confront the fate of the elderly, who don't by and large have the advantage of being very cute at all.

Early one morning I woke to a radio interview with the National Health Service ombudsman for England, Ann Abraham, on Radio 4. *Today*'s normally dispassionate inquisitor John Humphrys was struggling to keep his voice under control as he questioned her about a report showing that hospitals in England were processing elderly people without care, dignity or respect. He suggested that the case-studies of patients routinely denied enough food or water, or left in beds reeking of faeces, must surely beggar belief.

'Sadly,' Abraham replied drily, 'it doesn't beggar belief.'

That autumn the Care Quality Commission in England found that more than half the hospitals it visited unannounced were failing to offer basic care to elderly patients. Lack of money was not the main problem, the inspectors said, but lack of imagination and empathy.

The following year the same regulator disclosed that almost half of all care homes and treatment centres were failing to protect elderly and disabled people. The report described staff refusing to take residents to the toilet, shouting at them and failing to respond to call bells. It made chilling reading. I imagined you as the one being yelled at, you who would hardly know how to locate a call bell, never mind ring it.

Not that we should forget the good practice, the people who dedicate lives of unheralded service to caring properly, the hospitals trying to do better and the majority of care homes where staff *can* be bothered to take residents to the toilet. But well into the second decade of the twenty-first century there is an under-the-radar culture of poor practice in a system never designed for the longevity we have created for ourselves and painfully slow to adapt to the explosion in dementia numbers.

Dearest mother, as I watch your own sparky intellect flounder and your very identity dissolve before my eyes, I am beginning to conclude that dementia holds a dagger to the heart of Western morality. It confronts us with profound philosophical as well as scientific questions about what it means to be human. It challenges our social complacency and our financial priorities. It compels us to ask whether we have any right to call ourselves a civilised society at all.

*

Things I want never to forget about you even, as Shakespeare would say, to the edge of doom (or at least until the day I have trouble remembering my own children's names, too)

Your voice. Low and slightly throaty. Often on the edge of laughter. Accent and idioms emphatically west of Scotland, but without the glottal stop.

In a recording I made of your memories back in 1990 there's a part where you say, 'We were poor but we learned to talk properly. My father came from Ayrshire stock and he taught us some good Scots words. He always said, "Use them. It's fine to call your stomach a *wain*. But if you're speaking English, don't say *walkin'* when it should be *walking*."'

You never do.

I can still read the transcripts of those reminiscences to hear you talking the way you used to: fluent and funny, every narrative peppered with direct speech, syntax irreproachable, grammar perfect. It's hard to think of a happier complement to a husband who believed splitting an infinitive to be a capital offence.

Your laugh. The way you hurl your head back and show off a row of fine teeth, all your own and still more or less even, although one of the front two has edged slightly over its partner. You used to be more proud of those teeth, brushed with soot during the war and kept ever after when all around were losing theirs, than just about anything else – with the possible exception of hailing from the Royal Burgh of Rutherglen and having a granny from the Isle of Mull whose cow once swam all the way home.

Your smile. Dazzling, people say, which is a bit of a cliché, but yours does have an almost tangible radiance. It reminds my sister Topsy of an image from Gerard Manley Hopkins: ‘It will flame out, like shining from shook foil.’ She calls it your nuclear smile.

If I forget everything else, let me not forget this.