

CHAPTER ONE: ROLLING UP THE RUG

ALZHEIMER'S DISEASE IS the only medical condition that I know of which affects the family of the patient more than it appears to affect the patient themselves.

The long tentacles of its colourful fantasies reach out in all directions at once, touching, clawing, caressing and embracing all who pass within their reach, until each is drawn into the labyrinthine tragedy and made to become an actor in the drama. While all of this is going on, the patient continues to move through their own little world, interacting with all of its colours, contours and characters as though nothing had happened or changed, blissfully unaware of the emotional turmoil they are causing in the outside universe.

If you break your leg, it incommodes you. *You* sit at home in plaster; *you* suffer and *you* deal with it: it's *your* problem. Your family members may be slightly inconvenienced, inasmuch as they will fetch and carry for you, but that's about the extent of their forced participation in your altered condition. With Alzheimer's, it's the other way around. If you have Alzheimer's disease, it becomes everyone else's problem; you behave as though nothing has changed, while everyone around you has to cope with your radically altered mentality.

'It's like rolling up a rug,' said the consultant. My mother and I were sitting in the Caludon Centre, at Coventry's Walsgrave Hospital, where she had been referred by her GP. He had suspected the onset of dementia when mum went to his surgery to complain about a little girl who was living inside a radiator at home, and who was whispering to her the most disturbing things about other members of our family. When the receptionist at the surgery heard this she had sent for the doctor, who had come out of his consulting room into the main waiting area to find mum causing mayhem among his other patients; she was climbing on one of the chairs and trying to take down his curtains, because they were too short and didn't reach the windowsill.

Now, the specialist looked across his desk at me and ignored my mum, who was sitting next to me, apparently unaware that she was being discussed at all.

'Imagine you're standing at one end of a long carpet,' he said. 'The end nearest to you represents the present, and the other end represents your mother's childhood. As we begin to roll up the rug, the memories inside the roll are erased and lost forever, and her reality slips backwards in time. The more we roll up the rug, the further back in time she has to travel to find a point in her life that she remembers.'

I nodded slowly, trying to understand. My mother looked at his burnt-orange curtains with a disgusted and professional eye. They were tatty and frayed, and had probably hung on the window for years. I knew she was thinking about how she could run up a much nicer pair for him in no time at all. In fact, I was waiting for her to ask him for the job.

'I want to ask your mother a few simple questions,' he said, finally looking at her. She smiled back at him, amiably.

'What year is it now, Rose?'

My mother began to frown.

'Now that's a hard one,' she replied. 'Let me think. Is the war still on?'

The consultant smiled. 'Do you mean the Second World War?'

Mum nodded.

'No, that ended in 1945,' he said. 'What year is it now?'

'Then it must be after that,' she replied.

'It's 2002,' he said.

'Yes, that's right,' said mum, who would have agreed if he had said it was 1812, and Napoleon was running France.

I squeezed her hand gently, and she turned her head towards me and smiled.

'I am going to ask you to remember a few things, Rose,' he said, 'and then in a few minutes I will ask you to tell me what those things were. Is that okay?'

'Yes, that's okay,' said mum, looking back at him, and smiling.

'A pen, a newspaper, a pair of scissors, a clock and a pair of shoes,' he said slowly.

Mum nodded confidently.

'Who is the Prime Minister today?'

'Margaret Thatcher, the milk snatcher!' announced my mum, triumphantly.

'No, it's Tony Blair at the moment,' replied the consultant.

'Oh, I see,' said mum. 'I don't like him.'

'What month is it?' asked the consultant.

'April!' said mum, with some certainty.

'No, it's August,' said the consultant.

'Yes, that's right,' said mum.

'Now, I want you to tell me, Rose, the list of items I gave you to remember a few minutes ago. Can you recall them?'

'Yes, I can,' she said. 'A pair of scissors.'

'Very good.' The consultant was nodding.

'A bicycle, a fur hat, and a box of chocolates!'

Mum looked very pleased with herself. The consultant had stopped nodding. 'I think we need to do some more tests,' he said.

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THERE IS NO WAY of proving it now, but I am convinced that my mother's dementia began the day my father died. I believe the shock of his death somehow triggered the Alzheimer's condition in her.

My parents were married for over fifty years, and they were never apart during that time. Each was the other's right arm. My dad had undergone a triple heart bypass operation fifteen years before; it gave him another decade and a half of life, but his health was broken. Slowly, very slowly, he had become an invalid; in the last year of my father's life, my mother had nursed him like he was a sick child, and, even though it was seen coming a long way off, when death finally arrived she went into shock.

My parents were from Dublin; they had met and married there, and I was born in Ireland at a time when work and money were scarce. The family story goes that, in 1961, when I was four years old, the three of us were in the market in Dublin, and I asked for an apple. Mum rummaged through her purse and found she hadn't enough money.

'It's come to something when I can't even afford to buy my son a bloody apple!' said my dad, and within a week we had emigrated to Coventry. These days, like most places, it's struggling a little, but back then it was a thriving engineering city, the home of Jaguar cars – where my dad worked – Massey Ferguson tractors, the black London taxi and lots of other household names.

My mum was a talented seamstress, and she started a little business in our two-bedroomed bungalow, making curtains and matching bedspreads to order for people she knew. As word of her work spread, her orders increased, and my father built her an extension out into the back garden. This workroom was her world for the next twenty years: I can hardly recall a time when she wasn't back there, cutting, stitching, hand-sewing or measuring material. Hundreds of different coloured threads stuck out of the walls on little dowelling racks which my dad had made for her, and a long worktable and three industrial sewing machines completed her little factory. I mention my mother's sewing now as it explains her interest in her doctors' shabby old curtains, and becomes more relevant still later on.

The months leading up to and following my dad's death were difficult. During the same period, my own marriage was coming to an end, which was why I found myself,

a year after he'd gone, sitting in my mum's kitchen and telling her I was going to move back in with her.

'Oh, that would be lovely!' she cried. 'But what about your wife, doesn't she mind?'

'We've split up,' I said, simply.

My mother looked at me vacantly; she didn't seem to understand what I was saying.

'Is she coming to stay, too?'

'No, we've separated, mum,' I said. 'We're going to get a divorce. Rebecca and Daniel will continue to live there, and I'll move back here. I mean, if that's all right with you?'

'That's great!' she announced. 'We can have tea together every day!'

For various reasons I'd not visited mum that often – once a week or so, and only then for a short while at a time – so I hadn't really seen the dementia ebbing and flowing through her mind like a slowly rising tide. But as I sat there, I realised that she was now noticeably worse than when we'd visited the consultant at the Caludon Centre a few months earlier. I moved back over the next day or two, filling the bedroom of my childhood with the remnants of my married life. Once I was ensconced, mum's decline quickly became more apparent to me.

I remember getting out of the shower one morning as I was preparing to go to work – at the time, I was a community warden for Coventry City Council. I stepped from the shower cubicle onto the mat in the bathroom and reached over to take a fresh towel from the rack. I was surprised when it just fell away into a series of perfectly cut strips – about twelve of them, all exactly the same width, each running the full length of the towel, and all laid back on the rack in perfect symmetry, one beside the other, like a row of soldiers on parade. As I would later learn, it is a characteristic trait of the victims of Alzheimer's disease, and dementia generally, that they continue obsessively to carry out once-familiar physical tasks, perhaps in an attempt to anchor themselves in the strange and unfamiliar new seas of their lives. In mum's mind, she was still at work, still cutting material to make curtains and bedding. It took me a long time to understand that.

'What's happened to this towel, mum?' I asked, standing in the hall naked and dripping with water, and holding up the perfect strips in either hand for my mother to see.

'I don't know,' she called back from the kitchen. 'What are you asking me for? It must have been Peggy. Ask her.'

'Peggy who?' I replied.

'Your aunt Peggy, of course,' she said. 'She's always doing things like that.'

'Mum,' I said, softly, 'Aunt Peggy's been dead for five years.'

'She is *not!*' insisted my mum. 'I spoke to her only yesterday. What are you saying things like that for?'

I thought about what the consultant had said... The rolling up of my mother's mental rug. If mum believed my aunt Peggy was still alive, then she must be living in a time at least five years in the past.

I found another towel.

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OVER THE NEXT TWO or three years, mum's decline was gradual, but inexorable. It wasn't just her mental faculties: she was fading away physically, too. I didn't notice this at first, but in late 2005 I suddenly realised that she was getting very thin.

She had always been petite, and had never put on weight despite having a good appetite. I think she lived on nervous energy most of her adult life – she never did fewer than three things at a time. She'd be out in her workroom making curtains or something, for instance, and would keep popping into the kitchen to peel a bowlful of potatoes for the family dinner, and dashing off a few lines of a letter to someone. (She was a compulsive letter writer, of which more later.) Then she would return to the workroom and carry on with her curtains. So she simply burned off whatever calories she consumed.

Now, I noticed, she was getting seriously thin. Clearly, I needed to get her eating properly. I decided to cook her a decent meal, and opened the cupboards to start rooting around for ingredients. Every packet, tin and box of food in the kitchen was months or even years out of date. She'd been less than assiduous in restocking the kitchen cupboards since my father had died.

'All this stuff is way past its best, mum,' I said, rummaging in a drawer for a roll of black bags.

She sat with her head in her hands and watched me empty all the old tins and packets into the bags for the bin men to collect on Thursday.

'You're going to starve me to death,' she sobbed. 'Wait until your father gets home. He'll have something to say about this!'

She used to say that to me when I had been a naughty child, and it still made me feel uncomfortable. Dad had always been the one to punish me, to stop my pocket money, to send me to my room. I suppose I was a handful as a kid, and I always seemed to be waiting for him to come home.

'You can't eat this stuff,' I said. 'Half of it would give you food poisoning.'

Mum shook her head. 'Your father won't be happy.'

'Dad's dead, mum,' I replied, bluntly. Too bluntly.

She looked at me with disgust in her eyes.

'How could you be so cruel as to say that to me? When I think of how much your father loves you, and all the things he does for you.'

'I know all that, mum, and I loved him too. But he's dead now, don't you understand that?'

The brutality of ignorance: later, much later, when I understood better how Alzheimer's worked, I was more tactful.

Mum simply continued to stare at me, shaking her head slowly from side to side in disbelief. 'Your father will be *very* angry with you when he gets home.'

I finished emptying the cupboards out, there was nothing left. I made a list of stuff we needed, and then turned to my mother.

'We have to go shopping now, mum,' I said. 'It's cold outside, put a coat on.'

Like an obedient child, she rose from the kitchen table and went into the hall. She took a pale beige belted raincoat from the closet and put it on. It should have reached down to her knees, but as she stood there in the hallway I saw that it ended at her waist. Underneath the beltline it was all tattered; it had been cut in half.

'I'm ready,' she said.

'What happened to your coat?' I sighed.

'Peggy shortened it for me,' she said.

I took a deep breath. 'You can't wear that,' I replied.

I went into her bedroom and removed another coat from her wardrobe. 'Put this one on,' I said, handing it to her, without looking at it too much.

'You're being very bossy with me today,' replied mum. She took off the half-a-raincoat and dropped it on the floor, slipping on the other in its place. It was a dark blue cashmere affair; I remembered my father buying it one year for her birthday.

'Now can we go?' she said.

The stitching around the left shoulder seam of the blue coat had been unpicked and the sleeve removed.

'For Christ's sakes, mother!' I exclaimed.

'What's the matter now?' she shouted.

'It's only got one fucking sleeve!' I screamed.

'Don't you dare swear at me!' she yelled back. 'You wait until your father gets home!'

'Dad's fucking dead!' I bellowed.

Mum ran into her bedroom and threw herself down on her bed, sobbing louder and harder than I can ever remember. I stood in the hall feeling like a complete shit. I went into her bedroom and held her in my arms, and we cried together.

Eventually we stood up, and I went back to her wardrobe. I took out another coat, checked to see that it was okay, and got her to put that one on. It was bright green, it didn't match anything she was wearing, but I didn't care. At least it was intact.

'Peggy must have taken the sleeve off the blue one,' said mum. 'She's a bitch for doing that, isn't she?'

We drove to Tesco and parked the car.

'Can we buy some cream cakes and chocolate biscuits?' asked mum brightly, seeming to have forgotten the events back at the house.

'Sure we can,' I replied. 'We can buy whatever you want.'

She beamed at me.

It was Saturday morning, a cold, late November day, and Christmas was only a month away. The supermarket was packed with shoppers, and the shelves were stacked with fancy Christmas knick-knacks. Mum was like a little girl again. In the centre of the store stood a huge Christmas tree with tinsel and streamers all around its splayed branches. Hundreds of little fairy lights winked magically on and off.

'That's so beautiful,' observed my mother, standing and gazing at the tree. 'I wish we had a tree like that.'

'We will have,' I replied. 'I'll put our tree up in a week or so, we can decorate it together.'

She opened her mouth wide with delight.

'Can we really?' she gasped.

I nodded.

Suddenly, unexpectedly, she hugged me. Mum had never really been one for hugs, and it took me by surprise.

We started to shop for tinsel and cream cakes. Mum would see a chocolate éclair and put it in the trolley. Then we would move on to another aisle, suddenly she would rush back and get another cream cake.

'Just in case,' she would say, putting the extra one in the trolley.

We wandered around Tesco that morning stocking up on all the healthy stuff: chocolate biscuits, chocolate bars, jam sponges, éclairs, jam doughnuts, and ice cream. I think we bought one or two bits of the boring stuff as well, for form's sake – a chicken and some potatoes come to mind – but they were more of an afterthought.

'This is lovely!' declared mum, as we wandered about. I had not seen her this happy in ages.

When we came to the Christmas decorations she really went to town, strewing tinsels of a dozen glittering hues around our shopping trolley. She found an illuminated pair of plastic elf ears, and put them on. She looked like Mr Spock on acid as we bustled through the busy supermarket. She was clearly having the time of her life.

'You didn't tell me it was Christmas,' she said. 'I haven't bought anyone a present yet.'

'We can sort that out later,' I replied, hoping she would forget about it. The thought of buying presents for all our dead relatives didn't really appeal to me.

Mum nodded thoughtfully and pressed on through the busy aisles, totally heedless of the amused glances she was drawing from passers-by, her elf ears flashing like mad as she went.