

11 December 2013

The cup and the knife: the reality of caring for someone with dementia

My mother struggled to cope as her husband's personality and ability disintegrated as his brain rotted and shrank, until she contemplated committing suicide. In the end my dad died of dementia, but also because dying was the easiest way to treat him.

By Rose George



For me, it was the knives. For my mother it was the tea cup. Ordinary household objects that meant such dreadful things.

The cup came first. My mother, Sheila, now 73, asked her husband John, my stepfather for 30 years, to put a cup on a saucer. He couldn't. He waved it about, he put it somewhere else, he put it everywhere but where it should be. She had had memories before then, at his occasional lapses of memory. She joked about him having Alzheimer's as a way of warding it off. At that point she knew the joke was real.

Around that time he started banging his head, saying “What? What?” The neurologist told him what, in 2004, when my dad was 66. He actually said, “Good news. It’s early onset dementia, not a brain tumour.” Good news? “Yes, I could have said he only had three months to live.” The inappropriateness of that neurologist’s words set the tone for the next eight years of “care”, where things got so bad, my strong, powerful mother seriously planned suicide.

She tried to find help. By now they had reluctantly left my beautiful childhood home in Dewsbury, West Yorkshire – to move to a small village near Wakefield where she thought my dad could wander off with less risk. She contacted the local Alzheimer’s Society. They ran a day care centre, but although John soon needed someone to occupy him constantly – slowly he stopped reading, watching TV, socialising – he wasn’t bad enough to tolerate sitting in a circle and throwing a ball around. He knew enough to know that he had suddenly become some kind of patient or problem, and of course he resisted.

After a couple of years, his vocabulary dramatically diminished. He tried his hardest to keep his words, writing every day in his diary. Those entries are heart-breaking to see, as the forms of the letters get shakier and shakier until there are no letters at all. This rapid disintegration of language – aphasia – makes us think now that he had another kind of dementia, but no-one diagnosed it and now we will never know.

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The diagnosis of Alzheimer's was almost rote. He had dementia, so it was probably Alzheimer's. He had dementia, so he was prescribed Aricept, then other drugs that gave him angina bad enough for us to rush to A&E; others that gave him a near stroke; others that caused him – we think – to tip over while seated on the bed and cut his head, needing 14 stitches. The doctors were flailing as much as we were. It was trial-by-drugs.

We kept looking for help. After dozens of phone calls my mother found that she was entitled to an elderly carer's social worker, who was wonderful. We were entitled to some money and found carers through private associations. Plenty came and went. Over the years, there were social workers, health workers, care workers, doctors. But my dad resisted many of them, some were unsuitable, some didn't come back. There was no consistency of care. In the end my mother got a few hours' respite a week.

Anyway they were no use in the middle of the night, when he woke up snarling, terrified and terrifying. We tried to find respite beds in local care homes, to stem her exhaustion, but there were none, or the care homes were horrible. As soon as he became aggressive, the carers stopped coming altogether, for health and safety reasons.

My two brothers, my sister and I took him out as much as we could, while my mother was reduced to begging friends to come and visit. But although she had a close circle of good, kind friends, a number disappeared.

We tried to keep his mind busy for another 20 minutes, and then another, as we tried to calm the rages, the smashed television sets, the fear and panic of a man who had enough brain left to know something scared him, but not what.

My dad could still express himself in other ways, sort of. Almost to the end, his fingers still tapped out music playing on the radio. Once, when he had hardly any words left, we walked through our village churchyard and he said "eerie". I was profoundly shocked. If he had that word, did he have others trapped inside? Were we treating him like a child when he understood more than we knew?

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but the disintegration said otherwise. I don't know if it was more distressing when he shouted and screamed at being washed and showered and helped to the toilet or when he stopped caring that people had to clean him, accompany him to the toilet, show him what to do.

This was a man who was always impeccably dressed, whose handkerchiefs were ironed. His personality and ability disintegrated as his brain rotted and shrank. My mother watched her loving husband look at her with blankness or contempt and sometimes hatred. And yet dementia is classed as a social condition, so that the state is not required to pay for long-term residential care. Calling it what it is – brain damage – is too expensive.

This is not a rant against the NHS. I've had plenty of arguments with my mother about its failings, with me defending it. But in the case of my stepfather, it didn't seem to know what to do. Society didn't know what to do.

Six years after the teacup, I visited my parents' house and noticed that the knives were not in the block on the counter. For months we had suspected that things were worse than my mother admitted. It was obvious that she was exhausted, bereft and stressed. She was getting three hours sleep a night. We knew that he had locked her out of the house at 3am one day, so she was begging him in her nightdress to let her back in, but instead her previously loving husband pelted apples at her head, and spat words at her that he would have been mortified to use before, with pure hate. She called the emergency social services number. Answerphone. She called the police. By the time they turned up, my dad was peaceful, smiling at the constable who couldn't see why she had been called.

My mother didn't tell us that he had struck her a few times, only sometimes accidentally, or that he tried to push her down the stairs as she clung to the banister. But the disappeared knives told me. They told me that the situation had become dangerous, that she was really scared.

At her lowest point, my mother made a plan. My mother, who had seen her first and – my father – drop dead of a heart attack in front of us, who had then brought up two toddlers alone, a widow at 35. This strong, wonderful woman

decided that the best thing for them both would be to drive off a cliff.

Before this could happen, someone luckily gave her the number for the helpline run by Admiral Nurses. I'd heard of them: they are the equivalent of Macmillan nurses for dementia, providing dedicated support to carers. But there were no Admiral Nurses where we lived, sadly. They would have made such a difference. Even so, my mother says the person on the helpline saved her life, because he understood exactly what she was going through, the fear, despair, and shock at your beloved husband treating you now with hatred, blankness or rage.

Not long after the knives, he grabbed the steering wheel while my mother was driving in the fast lane. The car had been the last place he felt calm. We knew then we had to section him. The final decision was made one evening, but a doctor was unavailable and my mother had to spend a night next to her husband knowing it was probably the last they would spend together. Ironically, after so many years of little sleep, she tried to stay awake, to stretch out the last hours.

I hate to remember that morning in May 2010: my mother sobbing and clinging on to him, police, social workers and a doctor we'd never seen before coaxing my dad into the ambulance, pretending it was a trip like any other, lying to him, trapping him like an animal. It was despicable and we had no alternative, because the only care available to aggressive dementia patients, at least where we lived, is to lock them up. We confine them in dirty, horrible 'assessment centres', and we drug them into dribbling passivity. There was nothing else on offer.

Over the next year, my dad was sectioned three times. He emerged briefly, because my mother hated every minute of him being there. She searched desperately for another solution. Eventually she found an expensive care home a few miles from their village that seemed kind and safe, and he went there, until he lashed out, of course. Instead of having a strategy to cope with aggressive dementia – hardly uncommon these days – the home had him sectioned again. They said he was a risk to other residents. My mother arrived with my brother at 2pm to find my dad gagged, slumped in a chair, covered in vomit and having messed himself. No-one had cleaned him up. They sat there until 11pm waiting for a police escort (all the

police were at a football match).

Locked up again, he rapidly deteriorated. My mother visited every day, and still we couldn't stop the weight falling off him. She fed him high-protein food, but she wasn't allowed at meal-times, and there weren't enough staff to make sure he ate, or they weren't bothered. They said Alzheimer's was causing the weight loss. Five stone of it. There was no stimulation beyond a TV. It seemed the only strategy there was to wait for them to die. It worked. In six months, this tall, fastidious, witty man was reduced to a stumbling, dribbling wraith, with bed sores and mysterious abrasions.

I am deeply ashamed of what happened to him. We were a strong, educated, knowledgeable family. Some of our family friends were top consultants, surgeons. If we couldn't navigate through it and find help, who can? Like so many carers, we ended up drained by the disease. Care homes wouldn't keep him. He couldn't be at home. There was nothing in-between. Even now I can't see what else we could have done.

Finally my dad was sent to casualty at Pinderfields hospital in Wakefield when his injuries – three large abrasions on his forehead, bedsores in his groin and behind his knee – turned septic. He was there for several hours, screaming and weeping before being put in a female ward for the night, then a side room. He had no idea where he was and there was no-one to tell him, just a shut door. We wouldn't do that to children but apparently it's fine for someone with less understanding than a five-year-old.

Finally he was put on a geriatric ward. There were kind and lovely nurses on this ward, and some who weren't. Another patient was aggressive and shouting, like my dad used to be before the drugs shut him up and shut him down, and an auxiliary once said loudly, "what a nasty old man". My mother went to her and said forcefully, "don't say that. It's the disease that is nasty, not the man." You would think anyone working on a geriatric ward – where three quarters of patients have some form of dementia – should know the difference.

My mother visited every day. After a week or so we noticed that his drip was

switched off every time we arrived. Sorry, they said, and switched it on again. The next day, it was again off, and so on. Finally I read his medical notes and saw something like 'dying adult care pathway'. No-one had told us. We didn't know he was supposed to be dying. To this day I don't know how he went from ill to terminal without us noticing.

But we didn't protest, because his life was so diminished, and we were grieving and exhausted and stunned. What was the point of fighting for his life, for him only to be locked up again?

We stopped insisting on the drip. We stopped trying to feed him. He was heavily sedated and on January 4, 2012, with us all at his bedside, his breathing turned into bubbling by pneumonia, he died.

The nurses gave us all tea and sandwiches in another room so they had time to clean him. When we went back to his body, someone had laid a sprig of flowers on his chest. I will always be grateful for that small but huge act of kindness.

His death certificate says he died first of pneumonia and secondly of Alzheimer's disease. They could have listed another cause of death: a refusal to properly care for dementia sufferers, even when they are violent, and an equal inability to care for their carers. My dad died of dementia, but also because dying was the easiest way to treat him.



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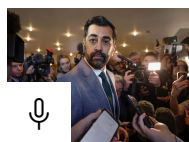
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