Dementia - Caring for the Carers
THE DEBENHAM PROJECT

Case Study: Graham* and Katherine*

My mother was a very intelligent and capable woman, although not highly educated. She was in the ATS and married my father during the Second World War. When the war finished, it was tough times and difficult to make a living, so my family left Essex to go to the North where my grandfather had a market garden. They worked all hours on it. My father became a truant officer (child welfare officer these days!), mother started with a job in a packing room in a fashion house but she eventually became the retail manager. They were committed to each other. But Father had a heart attack and died at 55. At the time, my mother was 49.

After father died, and after various emotional phases, including grief and depression, my mother found she was left with half of a reduced pension. She sold up and moved to the Liverpool where she had got a job as the assistant housekeeper of a large hotel. From there she steadily developed, firstly her career in hotel management, and then in residential social care – achieving all her professional qualifications when she was already over fifty – quite something! She became manager of a care home – a community home for young girls. Finally, she ran a residential care home. In all her posts she brought enthusiasm and innovation. As a care manager, she broke new ground – particularly in the care of older adults. She didn't like them sitting around all day – she got them out, doing activities, she approved of involvement, and friendships were encouraged, she learnt from others and applied them in her own home.

But despite her self-reliance and successful career, my mother had been prone to depression throughout her life.

Eventually, when she reached her late 60s, my mother moved close to Debenham. She was a very independent person who became heavily involved in the local community life. She helped with many of the village activities and made friends easily.

However when she reached her mid 70s, I noticed that she had started to become depressed and withdrawn – particularly in winter. She started withdrawing into herself, also becoming extremely manipulative and cantankerous at times. Then diabetes developed, but staying on a sensible diet and taking medication as prescribed turned out to be difficult as she had become very forgetful. By her late 70s, she had vascular problems in her legs and walking became difficult, yet she had good friends and family who helped her out with shopping and made regular visits. But she would often say "nobody's been to see me" yet I'd been there two days previously. And I knew others had seen her that very morning! Her short-term memory had become almost non-existent – yet she was still capable of living (mostly) independently. Gradually she lost interest in the garden and other hobbies and would just sit in a chair until someone came. She had changed.

She also began to eat unhealthily – we couldn't stop her. At this point, it was really becoming difficult for me to cope. When you've had the same question five times in the last half hour, and you had been to see her four times that day…

We couldn't have my mother live with us because we were certain the constant requirements, sheer frustration and family conflicts would break up our marriage / family. We insisted that she have care in her home and she agreed. But even with care at home, she ended up not caring for herself, no bath, not washing, not showering or eating properly - just living on ice cream and biscuits.

How do you manage her diabetes when all she ate, and wanted to eat was biscuits and cake? We'd strip her bed and find biscuits in the pillow case, pills on the floor, knickers in the freezer, biscuits in the wash… She threw a large nurse out and wouldn't take her insulin because, she'd say: "it hurts."

I felt guilty – you want to shout 'just do it' and "you don't want to be cared for". She was no longer the person I knew – in fact I began to think "I don't even like you" – I was running on fumes as far as love was concerned. I was not sure how I could continue taking responsibility for her. Her friends were a godsend, they would visit regularly. She thought her friends were great, and also my brother, who visited twice a year…and who didn't think there was anything wrong until one day he realised because she kept repeating herself over and over again.

All through this she could appear perfectly normal, friendly, and well balanced – if a bit forgetful – to visitors and others yet with me she would be totally different. Her persona for my brother and the outside was world poles apart from the one she had for her family carer (me!) It felt like one side of the family was taking all the emotional burden - although friends were helping as much as possible.

The crisis point was when she got an infection and ended up in Ipswich Hospital . I had to go in 3 or 4 times a day to take her to the loo – she wouldn't use the commode.

Eventually my wife convinced me that I could not take it any more. So we did something about it. There are plenty who don't get the care they need because they don't know how to get it. Basically we contacted social services and said we couldn't cope alone – my mother could not stay on her own alone. We managed to get her a place in a residential home – they were marvellous – but she withdrew into her room and, although she got to know others to some extent at meal times, she wouldn't participate in any of the activities.

I'd take my grandchild to see her – it taught me that despite the dementia, a person is still there – she loved to get down on the floor with the toys and play with my grandchild. She'd say to me: "its nice of you to come and visit me, but do I know you?"

She ended up spending most of her time in bed. One night I was worried about her breathing and asked them to get the doctor. Pneumonia finally took her away.

I'm not left looking back with fond memories. The dementia took all the love away and she became a stranger. She was always very self-focused and independent, anyway. I am not sure we were ever close. I don't think about her.

It has left me understanding the reality of dementia. It was hard enough being her son, but the sheer frustration and energy required to care for someone with dementia left me with an abiding sense of helplessness. You can’t do anything, and you can’t do anything right.