

A Carer's Story

My father's dementia was diagnosed a year after he had undergone major surgery in his eighties. Whilst caring for him during a long convalescence, it became apparent that his memory was severely affected, despite a good recovery. As soon as he was able to, he insisted on returning home to live independently.

For the next two years, I watched as he became increasingly forgetful and I found myself stepping in more and more frequently to support him and take over some of the everyday tasks that he was no longer able to cope with.

To begin with, this had a minimal impact on my own life but very soon, it moved from two or three visits a week to popping in every day; from an occasional evening phone call to every night and morning and sometimes several times during each day.

Following a fall resulting in a fracture, my dad was hospitalised for several weeks and became very distressed and confused. On discharge, he came to convalesce with me and received daily visits for six weeks from the NHS re-ablement team, to encourage him to regain as much independence as possible.

Unfortunately, this excellent service stopped soon after he returned home and was replaced by a package of care from the council. The three daily visits that were supposed to ensure his medications and meals were taken at the right time, were often less than 15 minutes long and at totally inappropriate times.

A constantly changing team of carers, both male and female, would arrive to deliver personal care, often letting themselves into the house using the key safe and seemingly unaware of how frightening this would be to someone who could not remember who they were or why they had come. It soon became obvious that, far from being helpful, these visits often created more problems.

My dad would tell carers he had already eaten, but I would find meals in the bin. Medicines were left within his reach so that he would take repeat doses. Often he would wander out, forgetting that carers were coming and all they could do was alert me that he was missing. In short, the 'package of care' that might have been helpful to someone with physical needs was totally inappropriate for a dementia sufferer. Many staff had little training in this area and those who did were frustrated by the lack of time they had to deliver meaningful care.

As with many dementia sufferers, my dad had little insight into his condition and refused to contemplate leaving his own home, so the next phase involved looking for other forms of support – a day centre, a befriender, a household help, the Telecare service and even a system of sensors which enabled me to monitor his movements at home on my computer. The most frustrating aspect of this was the length of time it took to track down and set up each service, only to find his needs had outstripped what had just been put in place. His behaviour was also

becoming more disturbed, and sometimes physically and verbally aggressive. All of this was extremely stressful and emotionally draining and life became one long round of crisis management. Having a break or a holiday seemed impossible and social events had to be cancelled so regularly it became easier not to make any plans. The crisis came when he was found wandering outside in the middle of the night, at which point I felt there was no option but to try to care for him myself.

However I was unprepared for the devastating changes in his behaviour that emerged at this stage in his dementia. Night was turned into day and he would wander the house all night long sometimes forcing me out of bed to make breakfast or switching on kettles, lights and fires. He was unable to be left safely alone in the house, requiring someone in constant attendance and his moods were so unpredictable it was hard to carry on normal social activities with friends and family. After a few months, I was on the verge of total mental and physical exhaustion and was hugely relieved to be offered a few days respite care.

It's hard to describe the trauma of taking your father to a strange place and leaving him in the care of strangers, especially when he is resisting with every fibre of his being. My dad repeatedly tried to escape and demanded to be allowed to phone me to tell me how much he resented my treatment of him. Thankfully, the care home staff were supportive and reassuring and we got through the experience but it forced me to confront the fact that I could not continue as before and would have to look for long term care. I am grateful to the professionals who helped me understand that this devastating illness sometimes requires much more care than one family can provide.