

Pre-senile Dementia



Helen Beaumont's

life changed track when her husband was diagnosed with pre-senile dementia. He was just 46; their children were four and five. She has since helped found The Clive Project, which provides support for people with young-onset dementia, written a book ('Losing Clive', ISBN 978-1843104803) and will shortly start a PhD researching methods for early diagnosis of dementia.

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We were well down the road before we even knew it existed. Clive's diagnosis of "pre-senile dementia" came in November 1993, but I had noticed the first signs in the summer of 1988; the first major row at work came in spring 1991, and redundancy in autumn 1992. By 1993 Clive was incapable of applying for a job, never mind doing one, and yet in the summer he was told there was nothing wrong with him, and by November a different consultant diagnosed the dementia. The consultant never saw Clive to tell him the diagnosis. He told me over the phone, and referred us back to our GP for more information.

Clive was diagnosed just after his 46th birthday. Our children were 4 and 5. I met Clive at university. He was in his last year of biochemistry, I in my first of physics. Subsequently he joined the Army, starting in the Parachute Regiment, and later transferring to become an ammunition specialist. He seemed to be at the start of a glittering career, yet things started to go wrong just after our daughter was born. The expected promotion to Colonel never came, and while Clive was happy in his work, he found it very frustrating when his colleagues were given more responsible jobs, and he wasn't. In 1988 he was fitted with a pacemaker after a diagnosis of sino-atrial disease. Later that year he consulted his GP in case the drugs which were also prescribed might be affecting his memory. The GP took a family history, doubtless did a few other tests, and told Clive to come back if things got worse. I know because I got Clive's medical records; at the time he "didn't want to worry me". I had noticed changes myself, and was already beginning to worry, but we were already having trouble communicating.

It is really difficult to explain how things gradually progressed. The discussion about a cycling holiday in France that was followed by Clive coming home with tickets for a diving holiday in the Canaries. The disaster of an Army curry lunch when Clive sat in the space reserved for the general, and would not move. My concern when our son went missing when I was at work. The son turned up safely (he was three at the time), and Clive laughed at my fears of what might have been. My concern when Clive told me he had applied for redundancy from the Army – of course he would get another job. My irritation when I had to type all the job application letters because Clive could never get to grips with working the computer. My frustration when he decided to do the family washing, and washed all my expensive work clothes on a hot wash. The freezer full of ice-cream, the birthday cake that didn't survive a journey home in Clive's rucksack, Clive never reading to his children, and walking out of the room when I did; with hindsight I wonder how I can have been so blind, yet at the time things changed so slowly, and Clive never admitted that there might be anything wrong with him. And he was so young, so fit; no-one would ever have thought he might be ill.

So the diagnosis came as a shock, and a relief. We could forget about the endless rounds of job hunting, and set about creating a life that would carry us through the next few years. There wasn't a lot of help – Clive didn't fit into any categories, and all the hard-pressed NHS services had a good excuse for refusing to help Clive. The two things that kept me sane were the support from

my GP, and Clive's involvement in the Optima research project. He lost his driving licence quite early on, but he was still mobile, as he had always cycled everywhere. Filling his days and finding ways to channel his boundless energy were a real problem. Clive had started running marathons in 1980, but found them too easy, and progressed to the weekend-long mountain marathons. What can you do with such a man when he can't work, can't read, can't find his way somewhere strange? He had never been a gardener, and although he would mow the lawn, gradually he mowed more and more of the garden, lifting the mower in the air to demolish my carefully planted shrubs and flowers.

And all the while our children were growing up. They never brought school friends home, and were given a hard time by the other children because of their dad's strange behaviour. School tried to stop the bullying, but how can you? I did my best to find time in the day to listen to them, to read to them, to be a normal parent, but as Clive's illness progresses the time it took to keep him going took its toll. He still cycled everywhere, but the bike often got lost, or damaged, and then I had to sort it out. He had three or four baths a day – better than none, I told myself, but it did push up the heating bill. He went swimming, and would come home in the wrong clothing, which I had to retrieve and get back to its rightful owner. He "filed" (and lost) the incoming post while I was out at work, he would sound very plausible as he took telephone messages that never got to me.

We managed until spring 1996, when Clive started to get lost when he was out on his own. He went for a walk one day (actually in the middle of the night), was missing the entire day, and turned up after dark nearly 30 miles away. It was difficult finding a nursing home that would agree to take him; he eventually ended up in a small home 50 miles away. It was a home that specialised in retraining adults with behavioural difficulties: Clive was the first person with dementia they had ever cared for. We chose it because the other occupants were Clive's age, and they had a good program of activities. Clive was happy to begin with, but then he started to try and get home, more than once he was missing overnight. Crunch time came at Christmas. Clive wanted to go for a walk; there were no staff free, and the pavements were icy and unsafe. The home locked Clive in, and Clive forced his way out; they had to sedate him for his own safety, and I moved him to a bigger place in the country that specialised in caring for people with dementia. They had to change their registration, as Clive was so young, but they cared for him very well for several months, until Clive again deteriorated, and had practically no language skills left. He was sectioned and transferred to the local hospital, after a few weeks he was transferred again to a hospital closer to home, where he died in April 1999.

Clive's post-mortem diagnosis was cortico-basal dementia. In the early stages, it was his language and numeracy skills that were most affected, and to some extent his personality. As a result of his illness, The Clive Project started (www.thecliveproject.org.uk), and now offers support to families within Oxfordshire affected by younger-onset dementia. His children are now young adults and at university. ♦