

Living with Early Dementia

Sir Terry Pratchett

Overview

- Clapham Junction days
- Obtaining a diagnosis of early Alzheimer's
- Undeniable signs
- Disease of knowledge

People who have dementia in this country are not heard. I'm fortunate; I can be heard. Regrettably, it's amazing how people listen if you stand up in public and give away \$1million for research into the disease, as I have done. Why did I do it? I regarded finding I had a form of Alzheimer's as an insult and decided to do my best to marshal any kind of forces I could against this wretched disease.

I have posterior cortical atrophy or PCA. They say, rather ingenuously, that if you have Alzheimer's it's the best form of Alzheimer's to have. This is a moot point, but what it does do, while gradually robbing you of memory, visual acuity and other things you didn't know you had until you miss them, is leave you more or less as fluent and coherent as you always have been.

I spoke to a fellow sufferer recently (or as I prefer to say, 'a person who is thoroughly annoyed with the fact they have dementia') who talked in the tones of a university lecturer and in every respect was quite capable of taking part in an animated conversation. Nevertheless, he could not see the teacup in front of him. His eyes knew that the cup was there; his brain was not passing along the information. This disease slips you away a little bit at a time and lets you watch it happen.

This is a slightly edited version of an article first published in the *Daily Mail*.

When I look back now, I suspect there may be some truth in the speculation that dementia (of which Alzheimer's is the most common form) may be present in the body for quite some time before it can be diagnosed. For me, things came to a head in the late summer of 2007. My typing had been getting progressively worse and my spelling had become erratic. I grew to recognize what I came to call Clapham Junction days when the demands of the office grew too much to deal with.

I was initially diagnosed not with Alzheimer's but with an ischemic change, a simple loss of brain cells due to normal ageing. That satisfied me until the next Clapham Junction day. I went back to my GP and said I knew there was something more going on. Fortunately, she knew well enough not to bother with the frankly pathetic MMSE test (the 30-point questionnaire used to determine brain function) and sent me to Addenbrooke's Hospital in Cambridge, where, after examination of my MRI scan and an afternoon of complex tests, I was diagnosed with PCA, an uncommon variant of dementia, which had escaped the eagle eye of the original diagnostician.

When in *Paradise Lost* Milton's Satan stood in the pit of hell and raged at heaven, he was merely a trifle miffed compared to how I felt that day. I felt totally alone, with the world receding from me in every direction and you could have used my anger to weld steel. Only my family and the fact I had fans in the medical profession, who gave me useful advice, got me through that moment. I feel very sorry for, and angry on behalf of, the people who don't have the easy ride I had.

It is astonishing how long it takes some people to get diagnosed (I know because they write to me). I cannot help but wonder if this is because doctors are sometimes reluctant to give the patient the stigma of dementia since there is no cure.

I was extremely fortunate in my GP. I think she was amazed to find that of the two specialists in my area, one had no experience of PCA and therefore did not feel he could help me and the other would only take on patients over 65 – at 59 I was clearly too young to have Alzheimer's.

I remember on that day of rage thinking that if I'd been diagnosed with cancer of any kind, at least there would have opened in front of me a trodden path. There would have been specialists, examinations; there would be in short, some machinery in place. I was not in the mood for a response that said, more or less, 'go away and come back in six years'.

My wife said: 'Thank goodness it isn't a brain tumour', but all I could think then was: 'I know three people who have got better after a brain tumour. I haven't heard of anyone who's got better from Alzheimer's'.

It was my typing and spelling that convinced me the diagnosis was right. They had gone haywire. Other problems I put down to my looming 60th

birthday. I thought no one else had noticed the fumbling with seat belts and the several attempts to get clothing on properly, but my wife and PA were worrying. We still have the occasional Clapham Junction day, now understood and dealt with.

I have written 47 novels in the past 25 years, but now I have to check the spelling of even quite simple words – they just blank on me at random. I would not dare to write this without the once despised checker, and you would have your work cut out to read it, believe me. On the other hand – and this is very typical of PCA – when the kind lady who periodically checks me out asked me to name as many animals as I can, I started with the rock hyrax, the nearest living relative to the elephant, and thylacine – the probably extinct Tasmanian marsupial wolf. That's the gift or the curse of our little variant. We have problems handling the physical world but can come pretty close to talking our way out of it so you don't notice. We might have our shirts done up wrong, but might be able to convince you it's a new style.

I felt that all I had was a voice, and I should make it heard. It never occurred to me not to use it. I went on the net and told, well, everyone. I wish I could say it was an act of bravery. It wasn't and I find that suggestion very nearly obscene. How brave is it to say you have a disease that does not hint of a dissolute youth, riotous living or even terrible eating habits? Anyone can contract dementia; and every day and with a growing momentum, anybody does.

It occurred to me that at one point it was like I had two diseases – one was Alzheimer's and the other was knowing I had Alzheimer's. There were times when I thought I'd have been much happier not knowing, just accepting that I'd lost brain cells and one day they'd probably grow back or whatever. It is better to know, though, and better for it to be known, because it has got people talking, which I rather think was what I had in mind. The \$1million I pledged to the Alzheimer's Research Trust was just to make them talk louder for a while.

It is a strange life when you 'come out'. People get embarrassed, lower their voices, get lost for words. Fifty per cent of Britons think there is a stigma surrounding dementia but only 25% think there is still a stigma associated with cancer. It seems that when you have cancer you are a brave battler against the disease, but when you have Alzheimer's you are an old fart. That's how people see you. It makes you feel quite alone. It seems to me there's hardly one family in this country that is not touched by the disease somehow. But people don't talk about it because it is so frightening. I swear that people think that if they say the word they're summoning the demon. It used to be the same with cancer.

Journalists, on the other hand – I appreciate that other people living with the disease don't get so much of this – find it hard to talk to me about

anything else, and it dominates every interview: Yes, I said I had PCA ten months ago, yes, I still have it, yes, I wish I didn't, no, there is no cure.

I can't really object to all this, but it is strange that a disease that attracts so much attention, awe, fear and superstition is so underfunded in treatment and research. We don't know what causes it, and as far as we know the only way to be sure of not developing it is to die young. Regular exercise and eating sensibly are a good idea, but they don't come with any guarantees. There is no cure. Researchers are talking about the possibility of a whole palette of treatments or regimes to help those people with dementia to live active and satisfying lives, with the disease kept in reasonably permanent check in very much the same way as treatments now exist for HIV. Not so much a cure therefore as – we hope – a permanent reprieve. We hope it will come quickly, and be affordable.

When my father was in his terminal year, I discussed death with him. I recall very clearly his relief that the cancer that was taking him was at least allowing him 'all his marbles'. Dementia in its varied forms is not like cancer. Dad saw the cancer in his pancreas as an invader. But Alzheimer's is me unwinding, losing trust in myself, a butt of my own jokes and on bad days capable of playing hunt the slipper by myself and losing.

You can't battle it, you can't be a plucky 'survivor'. It just steals you from yourself. And I'm 60; that's supposed to be the new 40. The baby boomers are getting older, and will stay older for longer. And they will run right into the dementia firing range. How will a society cope? Especially a society that can't so readily rely on those stable family relationships that traditionally provided the backbone of care?

What is needed is will and determination. The first step is to talk openly about dementia because it's a fact, well enshrined in folklore, that if we are to kill the demon then first we have to say its name. Once we have recognized the demon, without secrecy or shame, we can find its weaknesses. Regrettably one of the best swords for killing demons like this is made of gold – lots of gold. These days we call it funding. I believe the D-day battle on Alzheimer's will be engaged shortly and a lot of things I've heard from experts, not always formally, strengthen that belief. It's a physical disease, not some mystic curse; therefore it will fall to a physical cure. There's time to kill the demon before it grows.

Summary

This is a personal account by an acclaimed and accomplished author who, at the time of writing, had just been diagnosed with Alzheimer's disease.

We are proud that he has given us permission to use his writing as the first chapter in our collection about long-term conditions. This chapter emphasizes the importance of listening to the people who have long-term conditions. What they have to say is always important, but it may not be what health and social care professionals were expecting.

Further reading

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