

Living with Dementia



Terry Pratchett, OBE

Terry Pratchett is one of the most popular authors writing today and is the acclaimed creator of the bestselling Discworld series. The first Discworld novel, *The Colour of Magic*, was published in 1985 and there are now 36 books in the series. The first Discworld novel for children, *The Amazing Maurice and his Educated Rodents*, was published in 2001 and was awarded the 2001 Carnegie Medal.

Long regarded as a significant satirist, Pratchett has won numerous literary awards, was appointed OBE in 1998 and has received four honorary doctorates.

Terry Pratchett featured in New Year Honours

Author Terry Pratchett was awarded a knighthood for services to literature in the New Year Honours list. The best-selling fantasy writer has sold almost 60 million books worldwide.

Neil Hunt, Chief Executive of Alzheimer's Society, says, "I would like to congratulate Terry on this fantastic and well-deserved achievement. Terry is not only a successful author and well-loved public figure; he is also playing a key role in fighting the misunderstanding and stigma surrounding dementia."

Seven hundred thousand 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. This report goes some way to redressing that situation and allows others to tell you all about dementia. I regarded finding I had a form of Alzheimer's as an insult and I decided to do my best to marshal any kind of forces that 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 have always 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.

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 is capable of diagnosis. 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 recognise what I came to call Clapham Junction days when the demands of the office just grew too much to deal with. I was initially diagnosed not with Alzheimer's but with an ischaemic 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 that I knew there was something more going on.

Fortunately, she knew well enough not to bother with the frankly pathetic MMSE test and sent me to Addenbrookes Hospital, Cambridge when, after examination of my MRI scan and an afternoon of complex testing, I was diagnosed with PCA – an uncommon variant which had escaped the eagle eyes of the original diagnostician.

When Milton's Satan stood in the pit of hell and raged at heaven, he was merely a trifle miffed compared to how I felt on that day. I felt totally alone with the world receding away 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 were

able to give 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 (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 not help me and the other would only take on patients over 65 – 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 having 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 that 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 days, now understood and dealt with. I have written 47 novels in the past 25 years, but now I have to check 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 asks 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 extreme problems handling the physical world but we 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 the 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 that 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 a bit louder for a while.

It is a strange life, when you 'come out' people get embarrassed, lower their voices, get lost for words. 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 strange that a disease that attracts so much attention, awe, fear and superstition is so under-funded 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 sensible eating habits are a good idea but they don't come with any guarantees. There is no cure. So we hope – more hope than would fit in Pandora's box, where it was the last thing.

We hope very carefully, that a half-way cure will arrive. 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 dis-

ease 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.

In the meantime we hope for Aricept, which is not a cure but acts as a line of sandbags against the rising tide of unknowing. However, it is available free only to those in the moderate stages of the disease: others must pay \$1,000 a year, which I do. Eligibility is determined by the MMSE test, and it would be so easy for a patient in the mild stage to cheat their score into the free zone that I take my hat off to those too proud or responsible to do so. I cough up. NICE says the change it makes at my stage is minimal, but we don't think so in our house, where those little changes make the difference between a dull day and a fine day. The disease is, after all about small changes, and it may be that individuals may indeed be individual.

And that is nearly it for hope at the moment. 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 – will expect to stay younger 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 back-

bone of care in previous generations?

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 recognised 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 and lots of gold. These days we call it funding.

I believe that the D-day battle on Alzheimer's will be engaged quite shortly and a lot of things I've heard from experts in the field, not always formally, strengthen that belief. It is 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.

I want to thank the Alzheimer's Society for publishing this report and bringing closer the day when the funding we need is made available. This report is part of the Society's Living With Dementia programme, which I'm pleased to see has the support of Comic Relief. A member of the Society once said at a conference: 'I am not dying of dementia – I am living with dementia'. And so the programme was born; to help those with dementia tell it like it is to the rest of the world and help influence for the better the lives of all of us with this 'embuggerance'. ♦

Terry Prachett's comments came at the launch of *Dementia - Out of the Shadows*, a new report into the impact stigma has on the lives of people with dementia.

The report and videos featuring four people with dementia sharing their views on stigma and diagnosis can be viewed at www.alzheimers.org.uk/outoftheshadows.



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