

The Fight Goes On

I was diagnosed with FTD (frontotemporal dementia) eight years ago. It was hard for me to accept, and the way I got my diagnosis made it so much harder to accept.

I had never thought about dementia. The view that I had of this disease was that of an old person sitting in a chair, with grey hair, wrapped up in a blanket, maybe dribbling, looking out a window, not knowing where they were and unable to remember people or occasions. I thought dementia was an old person's disease and that they were waiting to die.

How wrong was! After diagnosis, I went into denial. The day I got my diagnosis there was myself, my wife and my daughter. The psychiatrist told me that my dementia is progressive, there was no cure or medication. All I could do was go home and get my affairs in order. He then asked me to leave the room so that he could talk to my wife and my daughter.

While sitting in the waiting room, I felt like a second-class citizen, I wasn't even worth talking to. After all, I had dementia and was incapable of understanding. I realized what the black people in South Africa in the 1970s and '80s must have felt like with the way that the whites treated them: second class citizens.

A couple of months later, the Admiral nurse contacted my wife and told her about a course that they had set up. It was once a month and it was in the evening, which was a lot better for my wife. She decided to go and I went with her just to get to keep face. The meeting was in two parts; the first hour everyone was together, then we split. I went with the people that had a diagnosis of dementia. It wasn't until one man shared about his emotions that it hit me in the face. I thought I had been hit with a shovel. What the man was saying, I was going through the same things and had been doing for the past few months.

The day after the meeting, it was as though a switch flicked in my head and I knew that I had to make a choice between sitting in the chair feeling 'Poor me', or I could educate myself about dementia. That was the Turning Point for me. The best thing I ever did was to go to the support group. I have never looked back since. I became an ambassador for Living well with dementia. I am also a KMPT (Kent and Medway Partnership Trust) envoy. I am one of the steering group for the Three Nations Dementia Working Group. I also work with Alzheimer's Society's Dementia Voices. I now go all over the county talking to students, doctors and I was very fortunate to be invited to talk to over 100 MPs in the House of Commons.

My main objective is to pull the stigma of dementia down and I want everyone to know that we are not cabbages, we can still live a good life and I enjoy educating people. I have a saying: I have dementia, but I won't let dementia have me. After all, I'm still the same person I have always been. Okay, sometimes I forget things like a word or a birthday and sometimes I may be a little bit slower at doing things, but I won't stop fighting. I have a voice and I intend to use it to make a difference for new people who have just had their diagnosis.

Dementia is not Madness, there is life after a diagnosis and I will keep fighting and talking until people hear the truth and realize that we are the same people. When they realize this, the stigma will be pulled down.