Dementia: the person living with the disease

We talk to Keith Oliver about what it's like living day-to-day with dementia.

At first Keith Oliver's doctor thought he'd had a minor stroke. It would have explained Keith's symptoms of loss of balance and mobility and the forgetfulness.

But a series of tests, including MRI and CT scans, revealed the truth. Keith had Alzheimer's Disease, the most common form of dementia.

'It was a shock,' recalls Keith nine months on. 'I thought of dementia as something that affected very old people sitting in nursing homes.

'I feel fortunate in that it took only seven months to get a firm diagnosis, because the uncertainty is more draining than knowing what you are dealing with. It was very hard on my wife Rosemary.

Giving up work

'Yes, I know it's going to get worse, but I can make the most of what I can do today. Probably the hardest thing was giving up my job as a primary school head teacher. But I have been invited by a local school to go in and listen to the children read each week. I love it.'

Talking to Keith, who is currently in his mid-50s, you'd be pushed to know anything is wrong. Articulate and intelligent, he prepares for our meeting. In advance of our chat he wrote down the three broad areas we would talk about and reminders of what he wanted to say. This is a good day, he tells me. 'On a bad day I can't talk and listen. I go into a monologue. But I will get very tired.

'When I look back at the person I was, the job I did, the things I was able to do, it feels like a different person rather than 'me before'. Now, when I'm in an unfamiliar place on my own, I can get disorientated and feel panic. I'm not good near kerbs because of my balance, which puts me at risk. And I have to be careful when I eat because it can be difficult for me to swallow.

Beating the stigma of dementia

'We thought long and hard about whether I should carry a card explaining I have dementia because it makes me vulnerable. In the end we decided the benefits outweigh the risk of being exploited in some way.

'At present I'm putting a lot of effort into doing anything that will help get rid of the stigma attached to the word dementia or will help improve services for people diagnosed with it. I find that stimulating.'

This he acknowledges adds to Rosemary’s stress. ‘Whereas I want to do more and more about Alzheimer’s she prefers having opportunities to not think or talk about it. I have to remember that.

All the same, when the local mental health team wanted to call him a ‘service user’ Keith quickly voiced his opinion. ‘That is far too impersonal. Nor am I a "sufferer". As far as I’m concerned "I’m living well with Alzheimer’s".’

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