

Lack of proper assessment

Younger Onset Dementia Summit

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Today I am going to tell you about my long journey to diagnosis. My story is simple, my wife knew better than the doctors but it took a long time for them to listen.

After 12 months of my memory slowly getting worse, I was persuaded by my wife, who is an Occupational Therapist, to see the doctors. After some paper tests the doctor said there was nothing to worry about, he decided to send me for a blood test. This test showed that my blood glucose level was high and after a fasting glucose test I was told that I was borderline diabetic and that this could cause my memory decline. I was told that I was slightly overweight and needed to lose 10 kilograms in six months and then to come back to the doctors. I had lost the weight in three months but my memory continued to cause me problems. I went to a different doctor, who gave me further paper tests and I was sent away again and told nothing was wrong, but I continued to struggle, especially at work. My job as a forklift technician presented many challenges and I had to work harder to keep afloat.

My wife was not convinced. She wanted my blood glucose checked again and wanted me to tell the doctor my memory continued to be an issue. I was given paper tests again and my blood glucose checked. This time my blood glucose levels were ok and I still did well in the paper tests so I was sent away again.

My wife saw many changes in me. I would come home from work exhausted. After work I would fall asleep and wouldn't engage in conversation. We planned a new kitchen and I did not help with any decisions leaving it all to her. She felt so strongly that something was wrong that on a routine visit to the doctor for herself she told him all that she was seeing and that I needed more thorough investigations.

My wife saw many things doctors did not and they were slow to listen. We had a new kitchen and I couldn't find anything in the cupboards for many weeks. When I was painting the room I couldn't remember which walls had been painted. When driving I could not react quickly to red lights and I got confused over right of way. My wife was upset and said she didn't feel safe when I was driving. She had also started getting phone calls from my work saying that they had noticed trouble with my memory and I couldn't solve problems.

We decided I should have a brain scan, but it showed nothing and the doctor wanted to send me away. My wife insisted on further investigation because by this time she was becoming more convinced that I had dementia. We were then sent for a SPECT scan. The conclusion was that there was no definite scan evidence of neurodegeneration, however these findings can occur early on in dementia of the Alzheimer's type. Therefore, it was clinically appropriate for a repeat study in 6-12 months to assess progress. The physician at this point again wanted to send me away with no follow up but my wife said that was not good enough. It was now December and a year since I first went to the doctor.

Our memory clinic appointment came through for May but by this time my wife was very concerned about the rapid deterioration in my memory, initiation and planning of tasks and my ability to problem solve and do the same functional handy man tasks around the home.

On my first appointment I felt that at long last I was being taken seriously and even though I scored well on the Mini Mental State Examination because of what my wife was telling them they sent me for a MRI scan. Results came back and I was told that I had Alzheimer's. I was given 5mgs Aricept and as I responded to it well it was increased to 10 mgs. I felt better, the fuzziness of my thoughts cleared a little but I continued to have issues with my memory and my ability to manage at work. I had to give up work in September of last year.

I go to the hospital every six months. I keep being told about clinical trials but nothing happens. I am left feeling let down and out of control. The assessment process was lengthy and I am left with the following questions:

- Why did no one take my concerns seriously until my wife became involved?
- Why is diagnosis based on paper exercises which do not highlight the cognitive issues that I experience?
- If I had been diagnosed and received treatment earlier would I still have been at work?
- And now, what next?