



Neil – Parkinson's disease

For 66 year old Neil, deep brain stimulation (DBS) means being able to do the things that other people take for granted.

"I'm sitting here holding a phone in my hand – I couldn't do that before. I can hold a book on my lap and read it. I can sit with my grandchildren on my knee and read a story to them."

Neil first started noticing some unusual symptoms about 15 years ago while going about his normal day at work.

"I'd spent 25 years building trucks and after that I went back to where I'd originally started my apprenticeship to work as a Quality Manager. I made that change when I was 48 years of age.

"Not long after that the signs started to show up, not that we knew what they were.

"I was walking down into the moulding shops down at the plant and I just froze. I was having trouble taking that next step.

"Things like that kept happening. I found that I was veering off to the left when I was walking. I'd be going into my office and my left shoulder would hit the door frame as I walked through the door.

"Then my wife said to me 'your mouth is going funny'. My doctor said 'well you have to go to the dentist.' I went to the dentist and he said 'there's nothing wrong with your teeth, I don't know why your doctor sent you to me.' So these were all the little signs that were going on over the years."

Neil's GP was baffled by the symptoms and couldn't offer an explanation. It would take another health crisis for the diagnosis to be made.

"During the same period of time I had a heart attack. I saw my physician and I was telling him these problems and he did a test and told me 'you've got parkinsonism symptoms.' I didn't know anything about it.

"He gave me some medication. I took the script home and showed it to my wife. A friend of hers had a big book that told you what all the medicines were. They looked it up in that and they were more concerned than I was from what they had read in this book."

At that point, Neil made the decision to continue with the medication given to him by his heart doctor rather than visiting a neurologist.

"I let my physician treat it for the first couple of years but it was getting to the stage where I wanted confirmation. I guess also for a period of time there was denial in my mind.

"I went to a specialist and he confirmed that it was Parkinson's disease. I was about 53 years old."

Neil's symptoms were for the most part, adequately managed by medication during the early years of his disease. As the medications became less effective, he tried new drugs, not always successfully.

"Several years ago my specialist tried me on one drug and that just sent me off the planet. I became compulsive and I couldn't sleep. I used to go fishing at two o'clock in the morning and not come home until nine o'clock at night. It was a terrible period and I was probably on that drug for two years. Finally I came off it and that was one of the best things that happened."

Like many people with Parkinson's, over time, Neil began to find that his medication was becoming less effective.

"The last five years that I'd been on medication I'd been going backwards. I was taking more medication but the dyskensias were getting worse. I was taking 150ml every hour.

"I'd sit all day and rock and roll on the chair. I had a family and grandchildren and I couldn't do much with them.

"My specialist mentioned that he knew a neurosurgeon who was now doing DBS and suggested that I might want to go and have a talk to him. It's the best thing I've ever done.

"I wasn't intimidated by the surgery. I was ready to grasp anything at that stage. The neurosurgeon suggested that I was a prime candidate for it. He came across as very confident. I had two visits with him to talk about the surgery and each time I'd go home excited for the future."

Neil underwent the deep brain stimulation procedure in November 2005. The improvement was immediate.

"I went to see the surgeon about two weeks after the operation and I said to him 'I feel so good I reckon I could drive around Australia'. He said 'you'd better not, you're not meant to drive for three months after brain surgery!'"

For Neil there have been few negatives about DBS. The only downside is uncertainty about how long the treatment will be effective. But for now, it has enabled him to do the activities he had been forced to abandon.

"I was doing some bowling before the operation but that was all. Everything else just fell by the wayside. The only thing I had left was bowling and that was a struggle. Now I go for walks. My bowling has improved. I can tie a knot in a fishing line and I haven't been able to do that for several years.

"I had virtually no quality of life before the surgery. I won't say this works for everybody, but I only need 15 percent of the medicine I was on before and I feel terrific.

"I have 95 percent of my life back."