

Deep Brain Stimulation

In the last edition of *The Parkinsonian* we produced a factsheet on Deep Brain Stimulation. As a follow up here are three people's experiences of undergoing this procedure.

RICHARD

Richard was diagnosed with Parkinson's in 2002 aged 50. He had his DBS operations in mid 2011. In an interview with the local newspaper some months later he described the surgery as "better than winning Lotto". For Richard, the assessment to see if he was eligible for DBS was really tough, but not as tough as the gap between the first and second operations. "After the first operation you come out nice and steady, then you have to wait six weeks for the second operation. I was really hammering on their door to get the second stage done as I'd reverted back to where I was feeling lousy after the initial period of feeling really good."

Richard says DBS has made a huge difference to him. "I can go out socially now. Before the operation I'd have to go home at about 8.30 as my medication would no longer be working. Now I go to a pub quiz night and as far as I know the people there have no idea I've had this operation. That is how good it is."

Since the DBS operation Richard has only had to have his DBS adjusted twice. For the first 18 months he stopped taking all medication, although he is back on madopar now to control his dystonia. There has also been some deterioration in his walking. "I've not got the Parkinson's shuffle, but my walking isn't as free as it was."

"My advice to anyone eligible for the operation is to go for it!"

PAM

Pam was diagnosed with Parkinson's in 1978 at the age of 39. It was 8 years before poor movement and slight tremors meant she required light medication. With time, increased periods of 'freezing' required her to take more medication and ultimately Pam vacillated between intense movement (sometimes for up to 6 hours) and complete non-movement.

In 2001 Pam went to Sydney and was the second New Zealander to have the DBS operation. Her husband Bill described seeing her after the operation "I was astounded when I walked into Intensive Care and saw this lovely lady, half asleep, lying serenely and completely calm. If there had ever been a time when I believed in God I think it was then. I remember touching Pam's face and it felt as smooth as a baby's bottom. It was amazing- ALL the Parkinsonian symptoms had disappeared". Pam and Bill flew back to New Zealand a few days after the second operation.

Pam returned to her part-time teaching job after a few weeks off and retired 8 years later. Pam enjoyed a virtually Parkinson-

free life for the next ten years. However the Parkinson's has continued to progress and although she doesn't have the dyskinesia she had before the operation, she is weaker and now walks with the aid of a frame. Bill says that for Pam the operation was a life saver and although her Parkinson's has progressed life is easier for Pam because of the DBS.

GORDON

Gordon underwent DBS at the end of 2010. He had been diagnosed with Parkinson's 11 years earlier when he was 50. As he had a history of depression he had the DBS probes inserted into the Globus Pallidus interna which carries less risk of exacerbating depression.

The change in Gordon's condition after the DBS was switched on wasn't dramatic. "I didn't have a bad tremor before the operation, my problem was mainly mobility issues, and being able to use my hands, it was like they didn't belong to me."

A few weeks after Gordon had the second operation to fit the Implanted Pulse Generator (IPG) he got an infection. "I was feeling depressed so I did nothing about it. When my wife came home after a trip away she got me to the doctor. I was lucky that the infection was only at the IPG site and didn't go into my brain, but I still had to have the DBS completely removed."

"It was difficult to decide to have the DBS done again as I was concerned about getting another infection. But my son was getting married and I wanted my dyskinesia under control."

"DBS was certainly worth having. Although it has made my speech worse, my mobility and the control I have over my hands is much better. My family are happy I had the procedure. I've not had a reduction in my medication however if I'm late taking my pills or miss a dose it doesn't affect me like it would have before."

Auckland member Andrew Johnson's blog youngandshaky.com details his assessment for DBS and his experience of undergoing the operation. Andrew also posted a video on YouTube showing the difference DBS makes to him as he switches the impulse generator off. This video has since gone 'viral' having had 1.2 million views. There is a link to the video on Andrew's blog.

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