



Judy – Parkinson’s disease

At age 36, Judy had a narrow escape from a nasty car accident. Her parked car began to roll forward, and when she went to jump back in to put on the brake she slipped and fell under the front wheels. Miraculously, she walked away unharmed. Shortly after, however, she began to experience strange changes in her movement. She started to get a bad tremor, as well as dystonia in her leg. Naturally enough, she put this down to the effects of the accident, as did the many GPs she consulted.

“No-one considered Parkinson’s disease. It was very frustrating. I knew there was something wrong but I couldn’t tell what it was. The doctors all wanted to put me on anti-depressants.”

Judy’s symptoms deteriorated dramatically over the next 12 months. This is unusual for Parkinson’s, which generally has a slow progression.

“The tremor was getting really bad. The dystonia was so bad I could hardly walk.”

Finally, the eleventh GP she consulted told her the news that she had Parkinson’s disease.

“I didn’t have a clue what it was. I thought, well, I’ll go home and start reading about it, and it was quite scary to read about.

“I went back to my GP and said: ‘So I have this disease, what are we going to do about it? How are we going to solve this problem?’ He really argued with me – saying I needed to go home and just accept that I have this disease. I was so frustrated because I’m the kind of person that thinks ‘well let’s just get on with it’. He made me feel so stupid. I think he was saying it because he had no idea of what to do with me.”

Judy’s GP referred her to a neurologist she had seen previously when trying to uncover the cause of her symptoms.

“I went up to see him and I think that was just the worst day of my life.

“He told me to go home and get my financial affairs in order because in five years’ time I was going to be in a wheelchair in a nursing home. I thought my life was over.”

But Judy didn’t give up. She visited a second neurologist who had a more positive attitude.

“He said: ‘There is something we can do to help you.’”

Judy was finally on the way to managing her Parkinson’s.

Her neurologist prescribed a levodopa drug which controlled the tremors. She was able to return to her work with a car parts manufacturer, which she’d been forced to give up because of the severity of her symptoms.

After a number of years however, the drugs were becoming less effective at controlling Judy’s tremors. While she had originally been taking 7 tablets daily, she was now up to 15. She also began to experience disturbing side effects such as paranoia, delusions and hallucinations.

In 1997, Judy became the sixth person in Queensland to have a pallidotomy, an operation where a lesion is burnt in the damaged brain cells to relieve the tremor.

The effects were immediate and the tremor did not return. She dropped back to four tablets of her drug daily. However, over the next four to five years, Judy became more and more affected by rigidity and slowness of movement. Her level of medication began to creep up again – to the point where she was taking 22 tablets a day. Not surprisingly, she began to experience paranoia and delusions again.

Her neurologist suggested she was an ideal candidate for Deep Brain Stimulation (DBS), a reversible therapy using small implanted programmable electrodes to block the brain signals that caused her disabling symptoms.

“I was a bit worried about it, but I knew that I had nowhere else to go with the meds. I was on too many and they were over for me as far as I was concerned.”

Judy made the decision to go ahead with the procedure – despite some reservations about having her head shaved – and she was admitted for surgery on her birthday in 2003.

The surgery is done in two stages. In the first, leads are positioned in the brain and their placement tested with an external high frequency generator. If this is successful in controlling the symptoms, a few days later the neurostimulator (similar to a pacemaker) is implanted.

“I went off the meds virtually straight after the trial. Three days later I had the neurostimulators put in. You are awake for part of the operation, but that didn’t really worry me.”

The DBS was a success and her rigidity and slowness difficulties improved. She was back down to five of her tablets per day. However, about three weeks after the procedure, Judy began to feel down, a common experience after DBS.

“You’ve got to realise you are on a real high after the operation. But you do come down and you’ve got to be prepared. You have to realise that it’s not the end of the earth, because you will come back up again.”

This down phase lasted about three weeks for Judy, during which time she fell a number of times, damaging her hand. She says that increased susceptibility to falls is common after DBS, and patients need to become more aware of their movements to make sure they don’t cause themselves any harm. It can take up to six months for everything to settle down.

“Take your time at doing things, don’t rush.”

Since then things have been “excellent” and her medication dosages remain low.

“The neurologist keeps an eye on your progression and adjusts the neurostimulators as he thinks is necessary, that’s the great thing about it. Mine’s currently set very low, so I have a long way to go.

“And I’m not having paranoia, delusions or hallucinations, so I’m having a better quality of life.

“I want people to know that Parkinson’s is about more than just a tremor, and also that there are treatments that can help.”