



Kay – Parkinson’s disease

Kay’s first memory of experiencing the symptoms of Parkinson’s was when she made a telephone call at the age of 33. At the time, she didn’t think much of it.

“I felt a tremor in the top part of my arm. I could see it as well as feel it.

“I thought it was a pinched nerve. If I had 10 cents for every time that someone thought it was a pinched nerve I’d be a rich woman by now! I visited chiropractors and physiotherapists trying to get help but nothing worked.”

Within months, what had started as a tremor had developed into a radical swing and Kay realised that she needed to get to the bottom of what was happening.

“I went to a specialist on Macquarie Street (Sydney) and he told me that it looked like Parkinson’s, but that he couldn’t give me a formal diagnosis. He told me to go away and live my life as normally as possible. I was three months pregnant with my first son at the time.”

After the doctor’s comments, Kay spent a lot of time researching Parkinson’s disease and the treatment options.

“I rang Parkinson’s NSW and had some of their information sent to me; I soon realised that I definitely had Parkinson’s. Interestingly enough, it was more of a relief than anything to find out what was wrong. Of course there were still times when I was scared. I’d be crazy if I wasn’t.

“I knew I wasn’t going to go on medication. That’s one of the reasons why I didn’t go back to the doctor for so long. I’d read about the medication and I knew that I wasn’t going there.”

Kay lived with the symptoms of her condition, all the while managing life as a busy mum to two young boys.

“It wasn’t easy. I went through the kids’ early years using cloth nappies with the big pins! So when I look back I did it the hard way. And this tremor was really something.”

When her youngest son was 18 months old Kay made the decision to go back to the doctor.

“Until that time I was managing without medication, which wasn’t always fun. I remember saying to a girlfriend ‘I think I’m almost ready for the medication’ and she said ‘I thought you were ready 12 months ago, Kay’. It’s interesting how other people have a different perspective.

“I went on a drug that was the big new thing at the time. The doctor said that it would be effective for a year, and pretty much exactly a year later it began to lose effect. I’ve found that with doctors – they do tend to be right, for better or worse!

“We had booked a trip to Europe with the kids and we decided to go earlier rather than later in case I couldn’t do it then. I was getting to the end of my tether with the tremors so I decided it was time to go on the big drugs.

“I went onto levodopa and it was great. Within the hour – the hour – the tremor had stopped completely. I had so much energy. I thought ‘what do normal people complain about if this is how they feel?’

“We had a great trip. It was really about the little things. I remember putting makeup on. I wanted to look good again.”

Over time, the levodopa became less and less effective at treating the symptoms and Kay had to keep increasing her dosage. A friend who also had Parkinson’s told her about surgery known as a pallidotomy and she decided to go for it.

“I had the pallidotomy in 2000. I was only in hospital for one night. I remember one of the nurses saying to me ‘its amazing, people are in here for problems with their livers and so on and they’re in here for weeks. You’re in here for brain surgery and you’re only in for a night.’”

Balance issues meant that Kay only had the pallidotomy on her right side. Over time, the balance issues on her left side worsened.

“I was falling left right and centre. I’d be going down and holding onto the kitchen bench and even that wouldn’t help me. I was lurching all over the place. I was really in a mess.”

Eventually, Kay investigated the possibility of deep brain stimulation, and decided to go ahead with the procedure. She had no fear of the surgery.

“Even the drill didn’t scare me. To me what is terrifying is the thought of being stuck in my body for the next 25 years. I had my hip replaced this year and that was much scarier. I’m a bionic woman now – spare parts everywhere!”

Kay no longer has her balance problems following the deep brain stimulation and has had great improvement in her gross motor movements. Unfortunately, her fine motor movements are not as improved, and she has difficulty with activities such as typing.

Kay recognises the importance of being able to talk to someone who has been through a similar experience.

“I remember talking to friends about surgery and that sort of thing and they would all say ‘don’t do that’ and I remember thinking at the time that I just wanted them there as a sounding board – my mind was already made up.

“I didn’t necessarily want them to say anything; I just wanted them to listen.”