



## Richard - Parkinson's disease

When Richard Moir's good friend Esben Storm asked him how he was feeling one day, he was greeted with the following reply:

*"I can't work, my marriage is a failure and I've got a disease that's eating my brain.*

*"But apart from that I feel great."*

Richard finds that when you've got Parkinson's it pays to have a sense of humour.

Richard is an actor. He is well known to Australians through roles in films such as *Indecent Obsession*, *The Odd Angry Shot* and *Welcome to Woop Woop*. He also played the pivotal role as the father, Mr Twist, in the critically acclaimed series *Round the Twist*, considered by many to be the most successful Australian children's television series ever made.

Richard was around 40 when he began to notice that something wasn't quite right. His left arm would no longer swing as he walked.

"I went to the doctor about another matter, a cold or something, and I said 'by the way my left arm isn't swinging when I walk'. The doctor said 'well what it might be is Parkinson's disease'. It sort of blew me out of the water a bit.

"When you are an actor, your body is a tool. If your tool is broken, you can't work. You can't earn a living and you can't express yourself."

At the time, Richard was appearing as Mr Twist. He relished the role, as it gave him the chance to do comedy for the first time. But the lack of movement in his arm soon became a problem, and he found himself concentrating more on disguising the symptoms of his disease than on portraying his character.

"My left arm wouldn't cooperate, so I'd put it in my pocket, or hold it. Sometimes it would just dangle there. The comedy I had been enjoying so much wasn't so fun anymore.

"For the third series they found another actor to play my part. That wasn't funny at all."

Richard's last major role was in television series *Law of the Land* playing Police Sergeant Clive O'Connor. The writers wrote in that Clive had a heart attack to cover for the symptoms of Parkinson's becoming obvious in Richard's performance. Then the show was axed.

The next time Richard went in front of the camera was for a series of tests.

"I went off all the drugs so the doctors could get a true reading of what I was really like. I could barely walk, barely move my hands. I could hardly speak.

"Most acting roles require a slightly broader range of expressions and a little more control.

"Some don't of course."

For Richard, the main symptom of Parkinson's was freezing, which rendered him quite immobile.

He was prescribed apomorphine to control his symptoms. He self-administered the drug intravenously using a syringe pump to maintain the drip continuously throughout the day. This treatment allowed him to respond to the down times and evened out his day, but it became increasingly inefficient and burdensome.

Every morning it took an hour or more just to inch his body out of bed. Then there'd be the dystonia in the form of a locked jaw which would make it impossible to eat or drink. Finally he'd get to the first drugs which would enable him to prepare the drugs to get him through the day. He hoped for a better way.

"I was always going to another doctor, going to another specialist, having another test or procedure. It felt like all I did was live in waiting rooms and walk down endless corridors without ever getting anywhere.

"I had investigated some kind of brain operation years ago. One operation actually removed some part of your brain. I didn't want to do that. I wanted to leave everything there – even if it was dead."

Eventually, his research led him to deep brain stimulation and he decided to go ahead.

"I'd made up my mind; done all the tests, had the haircut and passed the audition."

The day of the operation wasn't easy for Richard.

"I couldn't get to sleep for hours and I had to get up really early. Plus I didn't have any drug relief because they didn't want it masking the symptoms, so I had about the worst dystonia I'd ever had. My mouth was wide open and it was going to stay like that until after the operation.

"Then when they turned the stimulator on the stiffness disappeared. The effect was immediate."

While the operation was a success, a few weeks later, Richard went through a period of depression, which is not uncommon for DBS patients.

"The ordeal of the operation was so profound that a sense of anticlimax began to hover over me.

"Back home in the suburbs you're a normal bloke, but you feel like you've been to another planet.

"It's been a slow process – well, slow compared to my expectations of it. I'd seen these documentaries where the patient jumps off the operating table, runs down the corridor and streaks home, you know. It's not like that. It's a much more careful and conservative project than that.

"It was like I had to unwind from the years of anxiety built up before the operation. I was so caught up in where I was at now that I'd forgotten how far I'd come.

"Now I stand up with ease, where once it had been an almighty struggle. I cross the room like any normal person going for a stroll."

Richard viewed the operation as a major turning point in his life. When he made the decision to go ahead, he enlisted the help of his good friend and long-time collaborator filmmaker Esben Storm to capture his journey pre and post deep brain stimulation. Richard's story has now been made into an hour-long documentary titled *The Bridge at Midnight Trembles*, which will screen on SBS TV in 2006.

Richard is having to write now rather than act, because he's suffering from a side-effect of the operation known as dysarthria or slurred speech. He finds that his speech therapy is like going back to acting classes – think loud and speak slow.

It is now nearly two years since Richard's operation. Refinements in the programming of his DBS system have lead to further improvements in his condition and he has been able to reduce the amount of medication he uses.

"You've got to keep fighting this disease. I believe I have to take treatment to the limit of what is available. I owe it to myself and everyone around me. Especially my children.

"I also realise that I have to accept this condition as an irrevocable reality of life. The disease is a challenge and if I fail to see the whole Parkinsonian experience as a vehicle for growth, then I am lost.

"And I am *not* lost."