

information

A NEW PERSPECTIVE: PERSONAL STORIES

Hearing the personal stories of others who are living with Parkinson's can be reassuring, enlightening, inspiring and helpful, especially for those recently diagnosed and their families.

Nerissa's Story

Diagnosed 2006, age 29

It all started with a fall on the netball court. I tripped over a stray leg and fell on my arm. My hand was badly bruised and took a long time to heal. Once the bruising subsided, my typing skills didn't return, but I was convinced it would get better with time.

After a while, people began to comment on how slow I was. My moves on the dance floor became limited to a single motion that my friends nicknamed 'the shoulder', and I became famous for my 'disco' or afternoon naps.

Eventually, other aspects of my life became increasingly difficult and annoying. Simple things, like negotiating a knife and fork or trying on clothes in a store change room became a constant source of frustration and embarrassment.

It's funny how as a young person, these things really didn't concern me, and I never questioned my body's ability to heal itself. I wasn't concerned when my GP referred me to a neurologist or when the neurologist recommended a set of MRIs.

But it all happened fairly quickly from that point: The shock diagnosis, the dexterity and medication response tests, telling my family and friends.

In the first few months after I began taking medication, the nausea was like being hit by a truck.

My appetite disappeared and I had to force myself to eat. I lost a heap of weight, which is sometimes difficult to explain to friends and family. Even today, although my nausea has eased off, thanks to better medication management, I struggle to put some 'healthy weight' back on. But, I do have more control over my body and have returned to both the dance floor and change room with a vengeance!

I've found having Parkinson's is like being a member of a secret society. It seems people with Parkinson's don't talk about "it", often not telling friends, family or work colleagues for years, if ever. But I seem to have missed the unspoken ban on communication, though I'll admit it isn't easy to tell people. I find the main problem with telling people is that it sounds so dramatic, yet I am not a dramatic person.

Added to this is the fact that most people don't know much about Parkinson's, and this lack of knowledge either makes it sound more serious than it is, or as though I have just told them I have a common cold.

2006 was the most challenging year of my life. But I'm pleased to report I've achieved some great things in that time - despite having undergone counselling for depression. I completed the first year of a post graduate qualification, received a pay rise, a bonus and a promotion, and founded POP - Perspectives on Parkinson's to raise awareness and funds to help find a cure for the disease in my lifetime. And, I'm still playing netball!

For further information contact
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IN THIS TOGETHER
parkinson's
VICTORIA

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Peter's Story

Diagnosed 2001, age 52

When I was diagnosed, my wife and I had to deal not only with our own preconceptions about the condition, but also our children's. For our son, those three words "I have Parkinson's" suddenly transformed me from the fit, healthy, active, indestructible father he knew, to being a mere mortal.

In many ways I disagreed. I understood Parkinson's was a degenerative disease, but it wasn't fatal. After my diagnosis, I continued to see myself as fit and well. "My symptoms were not so obvious. No one will notice any difference".

But in the lead up to diagnosis, the little changes were starting. Over the past decade, I noticed a marked deterioration in strength on my right side, accompanied by persistent shoulder and neck soreness. I could only throw a cricket ball 20 or 30 metres, and could no longer even underarm a cricket ball accurately back to the bowler.

Some days I felt extremely weary and carried my feet like leaden weights. My balance was not quite as sound and I stumbled occasionally, albeit ever so slightly. My hand writing at times became so bad even I could not decipher the spider-like scrawl. I cradled my right arm when I ran and didn't swing it when I walked. The top button of my shirt was a pain to do up, as was the button on my left cuff. I purchased an electric toothbrush because cleaning my teeth manually had become an exercise requiring greater dexterity than I could muster. I even began to shave left-handed.

All these changes were subtle and, at the time, of no consequence. I was simply getting older. That's what older people do. They slow down. My self-diagnosis was tennis elbow, but eventually after weeks of ineffective physiotherapy, my GP made the correct diagnosis in less than a minute. "I think you've got Parkinson's" he said. "Let's get you off to a neurologist and find out." And that was that.

After diagnosis, my perception of what Parkinson's was, how it affects you, what the future holds, became very personal. Which is why, when my wife and I attended a Parkinson's Victoria seminar, we asked ourselves, "Where are all the trembling old people?" In fact, we found it difficult to distinguish the people living with Parkinson's from their carers!

Since then, I've realised that Parkinson's is a multi-faceted condition, and that while there are a number of common symptoms, no two journeys are alike. Needless to say, any idea that Parkinson's instantly means a life half-lived is out the window.

Since that period of discovery and initial fear, nothing much has changed for my wife and I, in our approach to life and the way we live. I retired at 55, which I was going to do anyway, but still work as a management and training consultant. My wife and I travel overseas as often as we can afford and I am planning to play my 40th season of cricket in a few weeks.

On a weekly basis I play basketball, soccer, run, stretch and lift weights. But, I struggle to lift and hold my beautiful but wiggly 18-month-old grandson. I fiddle painfully with small change and know my right arm and hand are becoming weaker and weaker. Mishandling cutlery means cold soup. I have become more left-handed in everything I do.

Sometimes I wake at night burning like a furnace. I've developed adult acne. I know the location of every public toilet in Melbourne. I have had to add more fibre to my diet. My calf muscles cramp. I never go to bed before midnight and turn in bed like the Queen Mary! I cry more spontaneously and gulp the occasional word when speaking.

The medication I was first prescribed precipitated out-of-character, compulsive and addictive behaviours requiring counselling and personal determination to overcome. But, otherwise, I'm actually really fine, and I wait expectantly for what lies around the corner. Not fearfully expectantly. I just love a challenge and am determined to grow old with my friends and family – and I mean really old.

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