

## 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**

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!

***Nerissa, diagnosed 2006, age 29***



## A new perspective: **Personal stories** *continued*

### **Peter**

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. And 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 wriggly 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.

## A new perspective: Personal stories *continued*

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.

*Peter, diagnosed 2001, age 52.*

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### **Marion**

My husband Ken and I both retired from full time work around 2003, but Ken continued to enjoy part time work as a Parish Assistant at Murrumbena Uniting Church. Ken was diagnosed in early 2004, and while we had both heard of Parkinson's, we didn't know anyone who had it.

Ken's initial response was, "Don't tell anyone yet. They might think I can't do my job. Or play bowls. Or preside at meetings. Or continue preaching. We won't be able to travel overseas! What if I can't drive?" (*This was an attitude that Ken maintained for at least 12 months after diagnosis.*)

But the diagnosis completely stopped me in my tracks. I felt in limbo in those early days. It was Ken who had Parkinson's, but here was I evaluating **my** "independent living", my and our lifestyles...how would this change? Just how much would *I* have to change *my* way of life? Selfish? Probably yes.

I realised that of course things would change and made the decision to do all I could to support Ken and share this new journey. We read Michael J. Fox's autobiography, **Lucky Man**. It was all we knew to do.

Our children meanwhile were glad that "something" had finally been diagnosed. Our daughter had noticed Ken's right foot tremor and urged him to tell the doctor – but I had noticed it too and simply said, "Your Mum used to do that!" They too had no idea what having Parkinson's meant – but they wanted to help.

After the initial diagnosis, a million questions were running through our minds, like "How did it develop?" And "How quickly does it progress?" We knew we needed more information and I called Parkinson's Victoria. Our most immediate questions were answered and the team continues to be supportive, providing information and direction, especially to credible, relevant resources.

During our initial contact with the organisation, it was suggested we get in touch with the local Support Group. It was one of the best things we could have done. At last Ken had someone he could relate to and who could relate to him and everything he was going through.

Joining a support group was also an enlightening experience for me. During our first meeting, someone asked if I was the person with Parkinson's or a carer? I was taken aback. I hadn't thought of myself as *anything* – I was just there with Ken.

## A new perspective: Personal stories *continued*

We've since found the support group meetings to be a valuable and encouraging environment. There is a wealth of information about Parkinson's-related news and information and there is always time for members to share their own news, experiences, concerns and personal advice.

It's only natural I guess to see group members experiencing different symptoms to Ken's – or at a different stage of the condition's progression - and wonder, "Will Ken be like that?" But members continue to inspire me. I am continuously amazed at how people LIVE with Parkinson's.

It was difficult not sharing this new dimension in our lives (although we began to see it as simply a new way of living), but this remained Ken's choice and I had to respect that. Eventually, however, he realised that for his own wellbeing and in fairness to his workplace, he should at least speak to the Minister of the church where he was working.

In his own words, Ken "came out" to his peers during a lay preacher's conference, revealing that a book titled "**Hope**" had given him the confidence to share his Parkinson's diagnosis. There were beautifully supportive outcomes and a sense of freedom for us.

Today, Ken participates in Physiotherapy, Occupational Therapy, handwriting and speech programs which are tailored to his needs and these give him great support. The "men's group" is also eagerly attended. His abilities and self esteem have been boosted by his involvement, led by encouraging and skilled staff.

I have learnt, and continue to learn, many things from our journey with Parkinson's and I strive to live them everyday. These are some of the lessons I have found valuable – some are purely practical and others are from the heart:

- Being open - and ongoing communication - is the key to comfortable living.
- Be patient when tasks are in progress and allow extra time to meet schedules.
- It is extremely valuable for both the person with Parkinson's and their carer or partner to attend neurology appointments.
- Note those "every day" difficulties that you can assist with when required.
- Travelling is still possible but seek advice and tips from professionals.
- Be supportive when 'let downs' arise and pride is bruised.
- Encourage initiatives shown to maintain independence and self esteem.
- Keep in mind that as a carer, you may now need to train someone who was once your driver to be a navigator.
- Laughter is an excellent tonic.

With our faith, the love of our family and friends, and the support and unexpected friendship of the Parkinson's groups I mentioned, we will continue to search for the silver lining in every cloud that looms. I don't want to drown in Parkinson's. I want to LIVE **with** it. I will try not to lose myself, but **be** myself.

*"I. We. They. Us"* Words used in our wedding toast more than 44 years ago are recalled with deeper meaning now. **I** = me. **WE** = Ken and I. **THEY** = family and friends, support groups all. **US** = people with Parkinson's and carers together. Reality is simply where we are living right now. I don't feel alone on this road - as uncertain as it is. Let us all "look for the silver linings", and go forward in hope together.