STANDBYME

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IN THIS TOGETHER
parkinson's
NSW

IN THIS ISSUE

Parkinson's Nurses In Action

Life Changing Surgery

Eye scans may spot Parkinson's early

In this issue…

Spring is with us at last. The warmer weather is a great incentive to become more active and get out and about in our communities.

Exercise is a must for maximising wellbeing while living with Parkinson's, but sometimes more serious medical interventions are required – such as Deep Brain Stimulation (DBS) surgery. This edition includes an article about a couple's shared DBS journey.

Speaking of shared journeys, our occasional series My [Parkinson's] Life highlights the individual experiences of people being diagnosed then coming to terms with living with Parkinson's. Read all about the journey of Donald Conolly in his own words.

There's also a useful article on the causes and prevention of falls, and an interesting research story about how eye scans may become a pre-screening tool to identify people at risk of developing Parkinson's.

The important role of nurses is also back in the spotlight in this issue. We look at how Parkinson's Specialist Nurse Vince Carroll provides indispensable support for a dedicated carer who is trying to keep her husband out of a nursing home for as long as possible.

It's all here in the Spring edition of *Stand by Me.*

Nurses in Action **Vince Carroll & carer Robyn Armstrong**

Two decades ago when Robyn and Glen Armstrong bought their home in Sapphire Beach near Coffs Harbour, it was the first house they hadn't built together.

Glen was a builder and they'd built a number of houses, while Robyn was a nurse. Both really wanted to be close to the beach and with no land to buy, they settled on the two-story house where they still live.

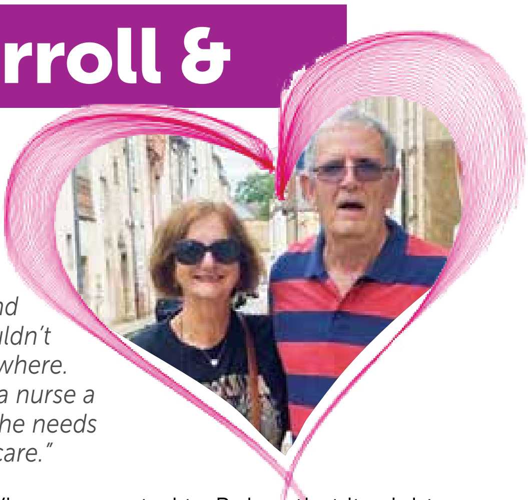
Now that house is for sale and the plan is that once that's sold, Robyn and Glen will move to Wollongong on the South Coast to be nearer family and friends.

They had enjoyed their beach lifestyle for many years, but things began to change four years ago when Glen, then 72, had a serious reaction to the anaesthesia following knee-replacement surgery.

> *"Problems started straight after the knee surgery," said Robyn, who is now 74.*
>
> *"The surgery was routine, and I'd just said 'see you this afternoon' but when I got there, he was acting really erratically and weird. We hadn't seen serious issues before, though there were a few small mental issues when I look back. People would ask 'is Glen OK?'. I think I didn't want to believe anything was wrong.*
>
> *"But as things evolved his GP said he thought Glen might have Parkinson's. He'd never had a tremor, but he was started on medication. He couldn't go back to work as a builder, but he was able to join an exercise program and used to drive himself there and back home.*

Meeting Nurse Vince Carroll

> *"The PD Warrior program (specifically designed for Parkinson's patients) was where Glen first met Vince Carroll, the Parkinson's Specialist Nurse who has been so helpful to us both. I had already met Vince through working in the hospital and I'd thought then he seemed like a nice person.*



> *"Unfortunately, Glen's symptoms became worse and eventually he couldn't drive himself anywhere. I quit working as a nurse a few years ago as he needs me for full-time care."*

In October 2023, Vince suggested to Robyn that it might be helpful if Glen saw a movement disorder specialist who was visiting the Coffs Harbour area.

> *"Through this specialist, Glen had a checkup which included an MRI," said Robyn.*
>
> *"We discovered Glen's Parkinson's symptoms were a result of a fistula on the surface his brain that caused an embolism. Unfortunately because it took so long to diagnose, Glen's gait had been seriously affected and he had started to develop dementia.*

While Robyn has a lot of nursing experience, she relies on being able to call Vince to discuss any issues with Glen.

> *"I knew nothing really about Parkinson's before Glen was diagnosed with it," says Robyn. "Vince is a wonderful person to consult, and someone to talk things through with.*
>
> *"Just having the opportunity to hear Vince's voice seems to calm Glen down. It is not unusual for Glen to say to me 'why don't we ask Vince?' about something.*
>
> *"I cope by just dealing with one day at a time. If there is a problem I try and sort it out with a doctor or I call Vince. It's great to have him to talk to because he knows so much about Parkinson's, dementia and caring for patients with complex illnesses as well as supporting the carers like me.*

“Everything we do is about helping to improve the quality of life for a person with Parkinson’s.”

Receiving a diagnosis of Parkinson’s is a huge shock. The first neurologist’s appointment can feel like a blur, there’s just so much to process. This is when many people turn to our Information Line (InfoLine) for help.

That conversation can be one of the most important they will ever have.

Our InfoLine Officers, Mel and Margaret are trained to help people find solutions to manage their Parkinson’s, including connecting them to other services, like Support Groups, allied health professionals, or counselling.

They will talk to thousands of people over the course of the year. Many of the callers have been newly diagnosed. Every single one of them is looking for support – support which is incredibly hard to get anywhere else.

Gathering the right information is a skilled task. Some people need lots of help to come out of their shell and talk confidentially about their problems. Others are desperate to offload because of their anxiety and really need someone to just listen.

Mel and Margaret are there for every caller, whatever they need.

This kind of service is absolutely essential for a condition like Parkinson’s. As one of the fastest growing conditions in Australia, it has a bewildering number of symptoms that change over time. Most people will live with Parkinson’s for many, many years, which puts a huge burden on our already overstretched health services.

Yet the government provides just three percent of our funding. It’s not nearly enough.

A conversation with Margaret or Mel can also be life-changing for carers or family members struggling to make sense of what’s happening to someone they love.

> *“People are so very grateful that our service is here for them. You really do feel like you’ve helped – that’s truly rewarding.” – Mel*

Mel and Margaret take the time to listen, really listen. For many people with Parkinson’s, it’s often the one thing most other health professionals they will encounter just can’t give.

> *“Whilst a Parkinsons diagnosis can be overwhelming at any age, Young onset Parkinsons for people in their late 30s or 40s has its own challenges. People are still of working age, they may be juggling a young family, caring for older family members and worries about future finances all play a part. It’s great they can reach out to us for advice and support, so we can connect them to services that our organisation provides, such as counselling, peer support groups and NDIS advocacy and to link them to external allied health. Having somewhere to turn, after they walk out the door of a neurologist’s office can be comforting and less isolating”*
> *- Margaret*

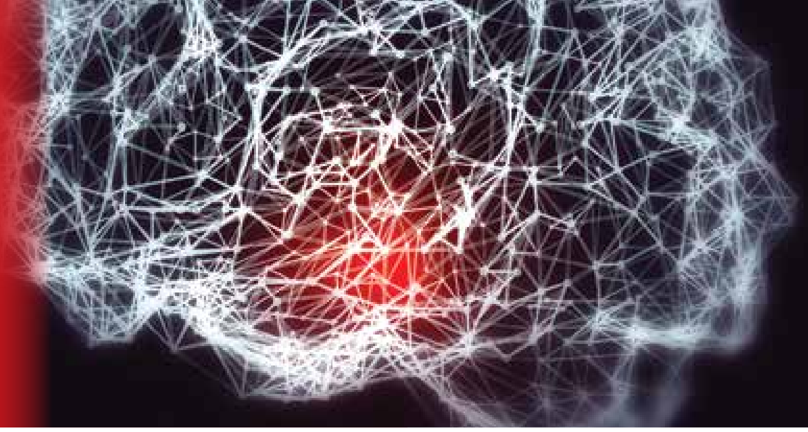
Our InfoLine staff provide essential information and support including:

- **Newly-diagnosed support**
- **Managing medication regimens and potential side effects**
- **Connection to Support Groups in the caller's local area**
- **Referrals to Parkinson's Specialist Counsellors**
- **Support to apply for an NDIS package**

Find out more

Can you support us to keep people like Margaret and Mel on the line to make sure that when people need them, they are there to take the call?

Deep Brain Stimulation surgery was life-changing for my husband



DBS helped Eric find relief from his most debilitating Parkinson's symptoms

By Jill Hammergren

I've often heard people scoff "It's not rocket science" or "It's not brain surgery" when expecting someone to accomplish an easy task.

But as I tried to calm my jangling nerves, an important clarification ran through my mind: "This is brain surgery."

I was alone with my thoughts in the hospital waiting room after my husband, Eric, had been taken back for Deep Brain Stimulation (DBS) surgery. He'd been prepped by his neurologist, neurosurgeon, surgical team, and a representative from Boston Scientific – a medical device manufacturing company.

I'd sent him off with a quick kiss, and then he was wheeled into the operating room for the first of two DBS surgeries to treat his advancing Parkinson's symptoms.

That was two years ago, but I remember it like it was yesterday.

A neurologist diagnosed Eric with Parkinson's in 2014. Over the next eight years, the disease progressed, but Eric's symptoms were never tremor-dominant like so many other people with Parkinson's.

His version of the disease manifested as extreme joint stiffness, muscle rigidity bradykinesia (slow movements), and dystonia – which presented as a constant, painful writhing and cramping of Eric's feet that made his toes curl and twist. He also complained that the pressure on his shoulders felt like an anvil pressing down on him.

Reduced to crawling

Medications helped with various symptoms, but his off times had become horrendous – especially the crawling.

Tears quickly fill my eyes when I recall those horrific images permanently seared in my memory. When Eric couldn't get his dopamine-depleted brain to move his body, he dropped to all fours and crawled.

Seeing the hopeful strides of babies exploring independently on their hands and knees may be awe-inspiring. When a man in his 60s is forced to crawl by the stranglehold of a neurodegenerative disease, it's demoralizing and dehumanizing.

As the woman who loves him, experiencing these excruciating moments left me devastated and helpless.

Eric's neurologist was confident that bilateral DBS would improve Eric's long-term quality of life with Parkinson's. We were more than ready to try it.

Preparing for and undergoing DBS surgery was a process. Psychologists gave Eric several cognitive tests to determine his tolerance for surgery.

First step

During an office visit a week before the first operation, the neurosurgeon drilled four anchors into Eric's skull and then sent him for an MRI. This would help the team map the size and shape of Eric's brain and the anchor locations so a halo brace could be customized and anchored for surgery.

Imagine something similar to a round locking anchor on ready-to-assemble furniture. The anchors didn't protrude like the bolts on Frankenstein's monster, but they were visible in Eric's head for a week.

Eric had to stop taking his Parkinson's medications 24 hours before the first surgery. He was miserable and couldn't function well.

In total, Eric went 36 hours without his meds. We then struggled to have them administered on a rigid schedule in the hospital. As a caregiver, I had to relentlessly advocate for Eric's needs.

Awake for surgery

Here's a remarkable note: The surgical team kept Eric awake during the four-hour surgery so he could help them determine which placement would be most effective in alleviating some of his Parkinson's symptoms.

I thought I was prepared to see the big, curved incisions across the top and side of Eric's bald head, but it was still shocking. However, his smile was wonderful.

During the second surgery a week later, the neurosurgeon tucked the wire leads behind Eric's right ear and down through his neck, and then hooked them to the neurostimulator he implanted in Eric's upper right chest, just below his shoulder. The stimulator is akin to a pacemaker, but this device keeps Eric's brain stimulated night and day.

A month later, the neurologist used a portable tablet to access and program Eric's DBS system, and it can now be adjusted as needed. Eric uses a remote to change the settings, and he charges the device weekly by sitting with a sleeve that holds the charger atop the stimulator in his chest.

DBS has been a life-changing experience for us. It alleviated some of Eric's most bothersome Parkinson's symptoms and enabled him to eliminate three medications. Eric still struggles with the roller coaster of off times and some gait freezing, but we are thankful for advancements

Source: US Parkinson's News Today

Balance Impairment Leading to Falls in Parkinson's

One of the most challenging symptoms of Parkinson's disease that fundamentally affects quality of life is balance impairment that can lead to falls.

Falls are one of the major causes of emergency room visits and hospitalisations for people living with Parkinson's, so finding ways to prevent as many falls as possible is a high priority. Thankfully there are things you can do to improve your stability and decrease the likelihood of falling, and we'll share some helpful tips and advice below.

Causes of falls in people with Parkinson's

The most important first step to prevent falls is to identify the cause or causes of the falls.

- *Postural instability* – this is often referred to as one of the four cardinal features of Parkinson's (along with resting tremor, bradykinesia or slowness of movements, and rigidity or stiffness). Postural instability refers to the inability to right oneself after being thrown off balance. It is typically tested in the doctor's office when the neurologist tugs backward on your shoulders to see if you are able to prevent yourself from falling. A person living with Parkinson's with postural instability may fall if they are jostled. This symptom is not typically present early in the disease and tends to develop as the disease progresses.
- *Freezing of gait* – This is an abnormal gait pattern that can accompany Parkinson's in which you experience sudden, short, and temporary episodes during which you cannot move your feet forward despite the intention to walk. In a sense, you're stuck. This results in the characteristic appearance of the feet making quick-stepping movements in place. However, while the feet remain in place, the torso still has forward momentum which makes falls common in the context of freezing of gait.
- *Festinating gait* – this is another abnormal pattern of walking that can occur in some people living with Parkinson's. In this gait, the person takes short steps which get smaller and faster, until it looks like they are almost running. The person may not be able to stop this pattern of walking and may end up hitting up against barriers in order to stop. Festination can lead to falls.
- *Dyskinesias* – These are extra, involuntary movements that occur in some people as a side effect of Levodopa ingestion. When severe, dyskinesias can throw a person off-balance and cause falls.
- *Visuospatial dysfunction* – One of the typical cognitive challenges that can affect people living with Parkinson's is deficits in visuospatial thinking. Deficits in this cognitive area lead to an inability to navigate oneself in three dimensions. A person may have difficulty manoeuvring around obstacles in a room or backing up to sit down in a chair. This difficulty can also lead to falls.
- *Orthostatic hypotension* – A common non-motor feature of Parkinson's is drops in blood pressure upon changing head position. This can lead to dizziness and even passing out, which can be interpreted by the bystander as a fall.
- *Posture problems* – Parkinson's can be associated with stooped or tilted posture which can contribute to imbalance.

Falls prevention

Understanding which factors are contributing to falls is important since each is treated in a different way:

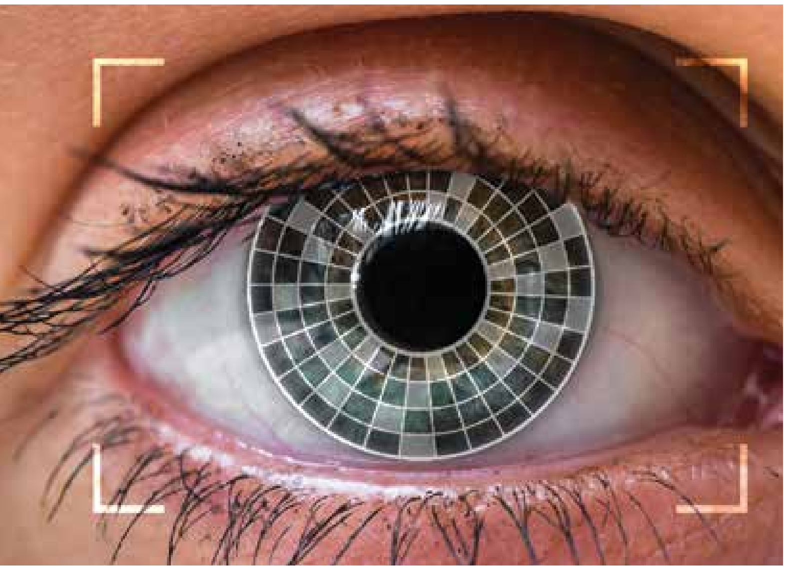
- Postural instability may be responsive to increases in Parkinson's medications.
- Sometimes episodes of freezing of gait and gait festination can be reduced with increases in medication as well.
- Bothersome dyskinesias can be treated by adjusting Parkinson's medications.
- A number of strategies can be used to manage orthostatic hypotension including increased fluids and dietary salt as well as compression stockings. If necessary, medications to increase blood pressure can also be considered.

Another important step in falls prevention is modification of the home environment, such as:

- Remove rugs and potential obstacles.
- Install grab bars in key areas in which falls are more likely, such as the bathroom.
- Choose the right shoes for you. Some people like rubber soles and some do better with leather soles. Check that shoes are not loose-fitting and provide support. Wear shoes with a slight heel to reduce falling in the backward direction, but no high heels.
- Wear a medical alert bracelet or pendant in case a fall does occur.

A very important part of managing someone who tends to fall, which is often overlooked, is assessing bone density. If thinning of the bones or osteoporosis is detected, medications can be prescribed to improve this, which can prevent a fracture should a fall occur. Your GP can arrange for bone density testing, which is done via a quick and painless x-ray scan.

Eye scans may spot Parkinson’s years before diagnosis



Researchers are hopeful eye scans will become a pre-screening tool for at-risk people

Eye scans may help identify who’s at risk of developing Parkinson’s several years before symptoms first become apparent and doctors can make a diagnosis of the disease, a study suggests.

Researchers observed that two specific structures in the retina – a light-sensitive layer of tissue at the back of the eye – were thinner than normal in people with Parkinson’s, as well as in those who went on to develop the disease up to seven years later.

While it’s still early to know if these measures can be accurate predictors, the findings may be a step forward toward a more rapid diagnosis. For people with Parkinson’s, this could create a better chance of receiving timely intervention.

> *“I continue to be amazed by what we can discover through eye scans,” said Siegfried Wagner, MD, a researcher at the U.K.’s University College London (UCL) Institute of Ophthalmology and the study’s first author.*
>
> *“While we are not yet ready to predict whether an individual will develop Parkinson’s, we hope that this method could soon become a pre-screening tool for people at risk of disease,” added Wagner, who also is a clinical research fellow at Moorfields Eye Hospital in London.*

The study, Retinal Optical Coherence Tomography Features Associated With Incident and Prevalent Parkinson Disease was published in the journal Neurology.

Diagnosing Parkinson’s can be challenging because its symptoms emerge gradually, sometimes taking years to become noticeable. It would be important to identify signs of the disease early on when intervention would be most effective.

> *“Finding signs of a number of diseases before symptoms emerge means that, in the future, people could have the time to make lifestyle changes to prevent some conditions arising,” Wagner said.*

The researchers already knew that one the retina’s layers, called the ganglion cell–inner plexiform layer (GCIPL), is thinner in people with Parkinson’s than in those without the disease.

Eye scans culled from two databases

Now, they used eye scans available from two large databases, the AlzEye and the UK Biobank, to find other signs that may lead to earlier diagnosis of Parkinson’s. All eye scans were taken using optical coherence tomography (OCT), a technique that offers detailed pictures of the retina.

To make measurements faster and more accurate, the researchers used a software tool for automated segmentation. This refers to a process whereby area boundaries are assigned automatically by a computer program.

Of the 154,830 people with eye scans available from AlzEye, 700 (0.45%) had Parkinson’s. Compared with control individuals who did not have Parkinson’s, those with the disease were older, more likely to be men, and have high blood pressure (hypertension) or diabetes.

After accounting for these factors, the researchers observed that people with Parkinson’s had a GCIPL that was on average 2.12 micrometers (mcm) thinner than that of people without the disease.

Inner nuclear layer also thinner

Another layer known as inner nuclear layer (INL) was also on average 0.99 mcm thinner compared to that of people without Parkinson’s. The researchers noted that the cell bodies of dopaminergic neurons – those that are lost gradually throughout the course of Parkinson’s – sit at the border of the INL.

In the UK Biobank, eye scans were available from 50,405 people, mean age 56.1 years. Of these, 53 (0.1%) went on to develop Parkinson’s at a mean of 7.3 years, after their eye scans.

Both thinner GCIPL and thinner INL were linked to higher chances of developing Parkinson’s in the future.

> *“Individuals with [Parkinson’s] have reduced thickness of the INL and GCIPL of the retina,” the researchers wrote. “Involvement of these layers several years before clinical presentation highlight a potential role for retinal imaging for at-risk stratification of [Parkinson’s].”*
>
> *“This work demonstrates the potential for eye data, harnessed by the technology to pick up signs and changes too subtle for humans to see,” said Alastair Denniston, MD, PhD, a consultant ophthalmologist at University Hospitals Birmingham in the U.K. and a study author.*
>
> *“We can now detect very early signs of Parkinson’s, opening up new possibilities for treatment,” Denniston added.*

Sources: Original article by Margarida Maia, PhD
Parkinson’s News Today Neurology

My [Parkinson's] Life Update

Donald Conolly

I have long had a personal connection with Santa Cruz, California. It came about entirely through a happy accident – a chance encounter with a lady who hailed from there. We met each other on Sydney Harbor in 1987, immediately fell deeply in love and in five years would marry.

During the 30 years we were together we would visit Santa Cruz multiple times, with it becoming like a second home to me. My latest visit in June this year was coincidentally the sixth anniversary of my Parkinson's diagnosis.

Funnily enough, I also believe that my Parkinson's story starts in 2003 at a Santa Cruz watering hole by the name of The Poet & the Patriot.

After settling in to imbibe some restorative beverages, I made my order. The server came back with my drink and when reaching out my left hand to secure the glass, my hand promptly went berserk!

Strangely – or should I say fortunately – the progress of my condition remained glacially slow for the next few years. It wasn't until late in the first decade of this century when other symptoms made their presence known.

Around 2008 my sense of smell all but left me. A computerised tomography (CT) scan of my sinuses and an eye-watering nasal endoscopy revealed nothing out of the ordinary.

Then came the random drooling, usually at an awkward moment. (But then, drooling at any moment automatically renders it awkward).

After this came the mumbling. I work in the medical records department of a hospital. One of my duties was then working in the enquiries section.

I was one of those people who managed to always sound chirpy and upbeat on the phone. Now, at times, it seemed like I had a mouthful of marbles when I spoke, usually in a dull monotone. When asked to repeat myself, I could only respond with a slightly louder mumble, frustrating communication all the more.

By this stage I had a fair idea of what was wrong, as my mother had Parkinson's and I was displaying all the same symptoms. However, I didn't want to know about it. I was very much in denial.

I was also distracted as I had become a caregiver for my wife who had Pick's Disease – a type of frontotemporal dementia – and was rapidly deteriorating. She would pass in 2017.

My Parkinson's confirmation came in the form of a chance meeting on the hospital grounds with a neurology professor the following year. I recognized him as the one that had diagnosed my wife.

After striking up a conversation I noticed he was studying me. At a pause he said: "Do this" (foot stamping), "Now do this" (finger tapping).

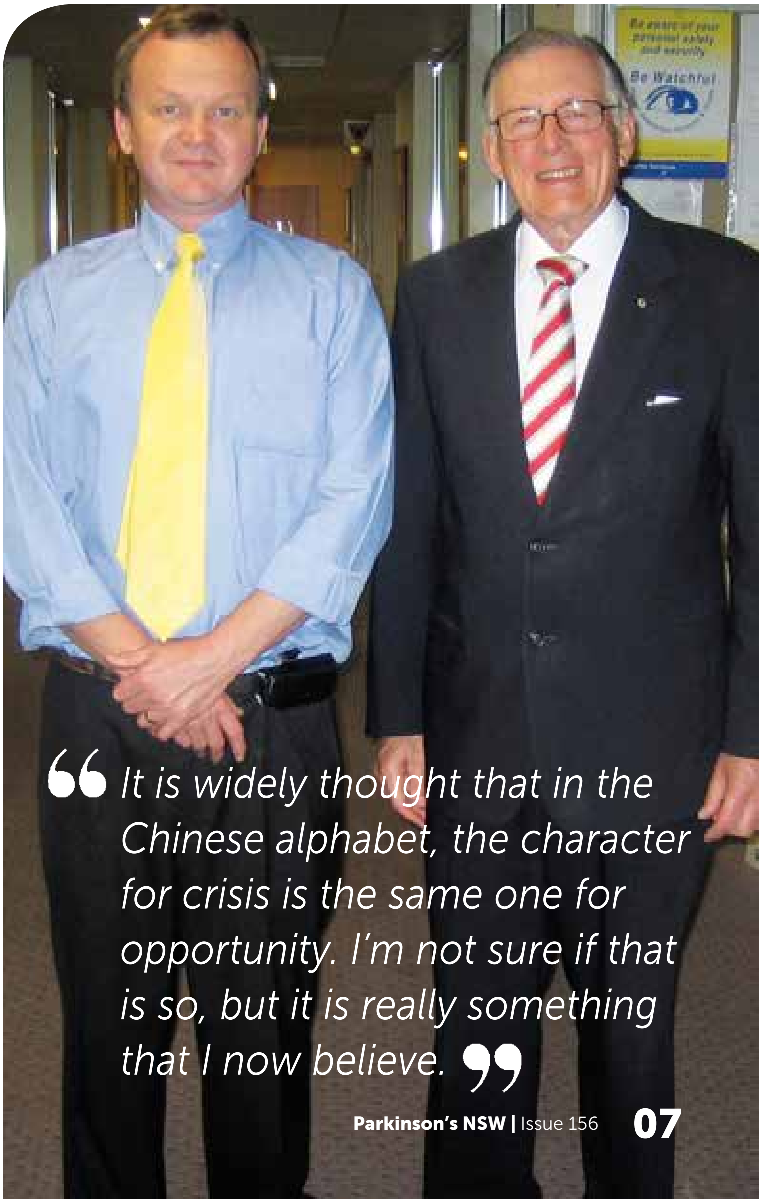
After several seconds of compliance, and feeling like a total twit, he stopped me with: "Not good. Go to the front desk and make an appointment to see me. Tell them it's urgent."

In a way, I was relieved at my diagnosis as, in its early stages this disease is very similar to much worse conditions such as Multiple System Atrophy or Motor Neuron Disease. Parkinson's? Now, THAT I can deal with!

I've heard Parkinson's cynically described as 'the gift that keeps on giving'. For me, it's been one that's kept on taking – taking my fine motor control, my sense of balance and sense of smell.

But one sense it couldn't take was my sense of humour, and that's what's kept me going these past six years. Also, while I initially found my diagnosis daunting, I realise now that without it I would not be promoting Parkinson's awareness.

It seems that Fate has steered me in this direction, whether I liked it or not, and I'm OK with that. In addition to my daily work at the hospital, building awareness around Parkinson's helps me feel that I can continue to make a meaningful contribution to others.



> *"It is widely thought that in the Chinese alphabet, the character for crisis is the same one for opportunity. I'm not sure if that is so, but it is really something that I now believe."*

IN THIS TOGETHER
parkinson's
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Be part of a future

where no-one has to face Parkinson's alone.

By leaving a gift in your Will, you can give people living with Parkinson's a better future.

Without access to specialist information and supports, the Parkinson's journey can be a lonely one. It can be filled with fear, grief – and misinformation.

But through your legacy, people with Parkinson's – and their carers and loved ones – don't have to feel they're going it alone. You can empower them every step of the way.

You'll be making sure people can always access expert, specialist supports and information that helps them be part of life in their community and make the most of every moment.

Your legacy Your kindness will impact the lives of countless people into the future, giving them expert, specialist support so they don't have to face Parkinson's alone.

Our shared vision You'll be part of the greater mission to empower people through knowledge, information, education and advocacy.

Their future Your gift gives people living with Parkinson's a better future – a future where they have more chance to make the most of every precious moment and a future where they will have access to expert and quality services whenever needed, and wherever they live.

A legacy that lives on: John's story

John decided to leave a gift in his Will to Parkinson's NSW to honour his late mother Patricia, who had Parkinson's for 20 years.

> *"She was only 59 when she was diagnosed, just when she was looking forward to retirement. I saw what she went through.*
>
> *I also donate to Parkinson's NSW every year, and I know exactly what they do with my money because they tell me about the difference I'm making. They have such a personal approach. They make me feel like my gift is really valuable.*
>
> *I know I'm helping employ nurses in regional areas to help people with Parkinson's. Their services are really hands-on. This is stuff that really, really helps people."*

We welcome the opportunity to discuss how you can be part of a future where no-one has to face Parkinson's alone. We are happy to help with any questions you may have about leaving a gift in your Will. Please call our Donor Development team on 1800 644 189.

"Thank you for thinking of people living with Parkinson's now and into the future."