STANDBYME

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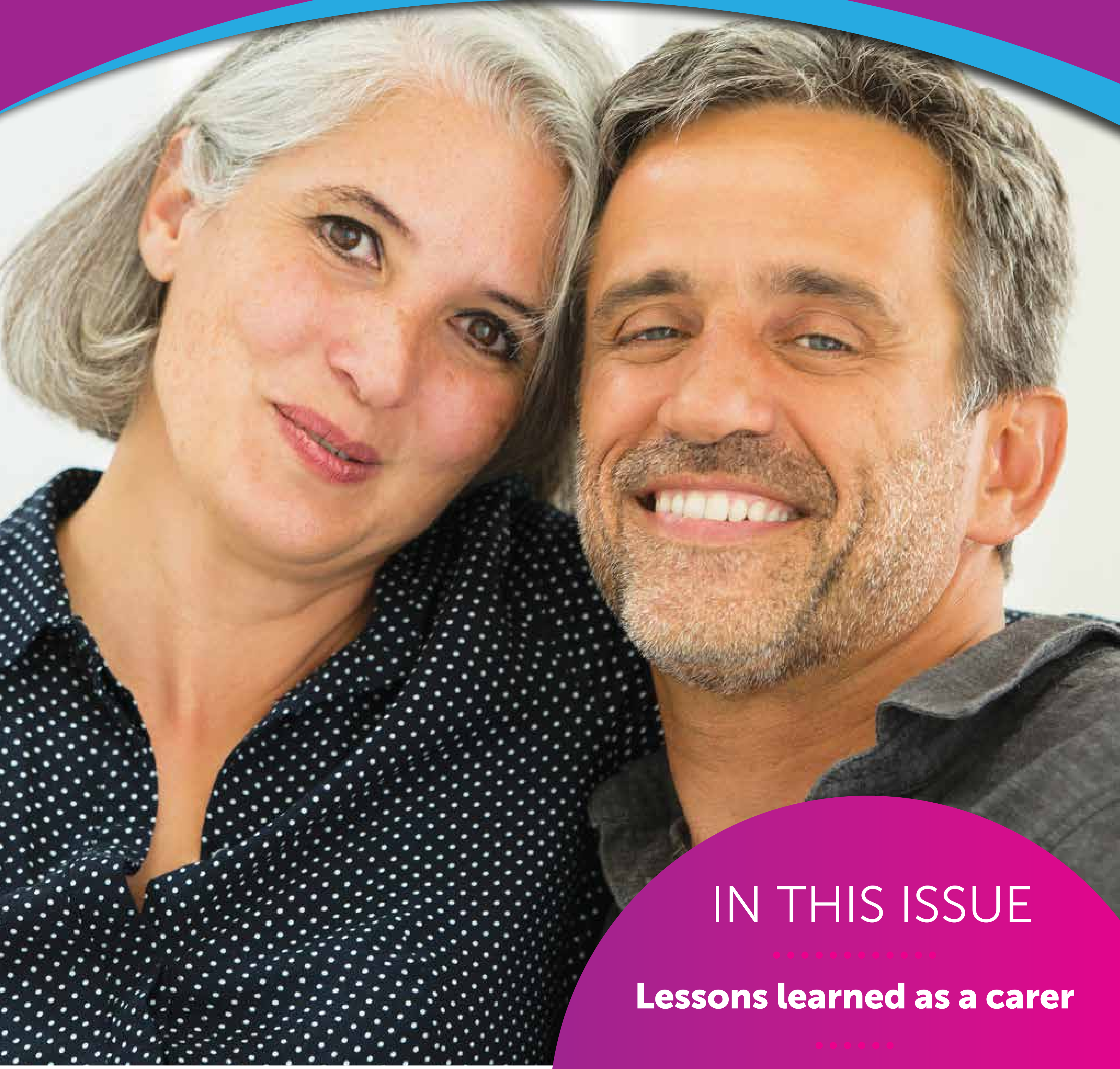

IN THIS ISSUE

Lessons learned as a carer

Brain in motion technology

My [Parkinson's Life]
Danielle McCarthy

IN THIS TOGETHER
parkinson's
NSW

In this issue…

As days shorten and temperatures drop, this Winter issue of *Stand by Me* will keep you warm with practical tips and updates on living with Parkinson's and caring for someone who does.

There's a story on adapting your sports and hobbies to Parkinson's, plus another exercise article on working out with friends – which is both fun and beneficial.

You can also read about a breakthrough in brain in motion imaging technology and what this could mean for diagnosing and treating Parkinson's.

Be inspired by a moving first-person article by a dedicated caregiver for her husband who is living with Parkinson's. She writes: "Caring for someone is one of the purest acts of love you can do".

There's also an update on Danielle (Dani) McCarthy's Parkinson's story of motivation and adaptation as her symptoms progressed. Among Dani's mottos as her journey unfolds is this: *Nothing is impossible, you just must find your own path to achieve your goals.*

Our tax time fundraising appeal is also underway, so read about Jeni who was a fit, active 67-year-old retired nurse. She had a growing sense that something wasn't right, then came her Parkinson's diagnosis. Now Jeni is supported by Parkinson's NSW which she says "...is so important for people like me, when you don't really know where to start. And I'm learning how to keep going."

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

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How to adapt your hobbies to Parkinson's

Art, craft & music

Keep small items in trays or baskets so they're less likely to be knocked onto the floor. Or use non-slip mats to keep things in place while you're working on them.

> *"Now I create digital art. I've had to give up the majority of my painting, but it hasn't stopped me being creative. Adapting to the digital realm of art has been a lifesaver. There are no rules in art. You can't make bad art. Everyone's an amateur."* Alex

> *"I get bad cramps in my right hand. The first time it happened I couldn't hold my guitar plectrum properly as my hand had curled up. But I chatted to the crowd until it passed, and I've since found plectrums that you can attach to your finger."* Laz

Sport

> *"I have been an avid weight trainer for over 30 years. I can highly recommend the use of figure-of-8 lifting straps. They're simple to put on and off and allow me to keep exercising pretty much as before, despite my tremor."* Richard

> *"I can no longer play golf, as I can't maintain the same swing with my tremor. Instead, I've taken up ten-pin bowling. The weight of the ball means my hand doesn't shake."* Karl

> *"In walking tennis, the ball doesn't move as fast or need to be hit as hard. I've just taken up pickleball as well, which is a combination of badminton, table tennis and normal tennis, and is great fun!"* Sharon

> *"I bought a table tennis trainer, which is a ping pong ball on a swing-ball that you can use at home. It meant I could still practise and keep my skills up, like maintaining a good swing with my arm. It helped keep my motor skills going."* Paul

Writing

Use pens and pencils with a thick or padded cover to help you get a better grip.

If you have a tremor, a weighted cuff may give you more control. This is a heavy padded strap that you wear around your wrist.

Use a clipboard or a non-slip mat to stop your paper slipping.

Write on lined paper, so it's easier to keep your writing straight.

Take your time to write, or dictate into a smartphone or voice recorder.

Cooking

If chopping food is difficult, a mini food processor can help you chop things like garlic, ginger and spring onions finely. Then you can freeze the ingredients until you need them.

If you have difficulty gripping things, a curved-handled or rocking-action knife can be used for chopping food.

A kettle tipper lets you pour boiling water out of the kettle without lifting it up. This reduces the risk of spills and burns.

You can place a non-slip mat under a plate or bowl to stop it from moving around. This can be useful if you have limited mobility in one arm and find yourself chasing plates and bowls across the table.

Source:
Parkinson's UK

When Parkinson's strikes, it can feel like you're all alone

Just 18 months ago, Jeni was a fit, active 67-year-old retired nurse. She walked daily, practised yoga, and loved spending time with her dog. Then her body began to change - fatigue, sadness, and a growing sense that something wasn't right.

After a series of medical visits, she heard the words she never expected, not in her wildest nightmares - **"You have Parkinson's."**

"It felt like the rug was pulled out from under me," she says.

Jeni's first symptoms were subtle. Her walking slowed. She couldn't keep up with friends. She started avoiding social situations. And without close family nearby, she felt overwhelmed and isolated.

Then she reached out to Parkinson's NSW. We invited her to attend a Newly Diagnosed Seminar and offered counselling. There, Jeni met others like her. She started to understand Parkinson's and herself.

"Parkinson's NSW is so important for people like me, when you don't really know where to start. And I'm learning how to keep going."

Every person living with Parkinson's has the right to live with dignity and that means making sure they have the care and support they need, from the start. Nobody should have to face this alone.

What to expect at a Newly Diagnosed Seminar

Our Newly Diagnosed Seminars are an intimate, welcoming space to learn and ask questions. Each session may include:

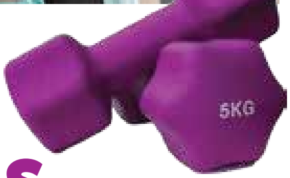
- **What is Parkinson's** - an overview with our Parkinson's Nurse Specialist about how Parkinson's affects people differently, the role of medications, and why timing matters.
- **Taking care of the body** - learn from qualified speech and exercise therapists about the importance of early assessments and exercising with effort.
- **Living well with Parkinson's** - our Specialist Counsellor talks through the emotional impact of Parkinson's, answers your questions, and shares practical tips for day-to-day living.

To find out more call

(02) 8051 1900

Find out more

With your help, people like Jeni won't be alone.



Exercising with friends

We know that exercise is great for our minds and bodies, but sometimes it's challenging to maintain interest.

Have you ever exercised with a friend or group and found how much more fun and rewarding exercising is when it's done with others? Whether with family or friends, in a team or in a class, in person or online, exercising together has many benefits.

There are lots of extra benefits from exercising with a friend or group, such as:

1. It's more fun exercising with a friend.

While you're catching up, having a laugh, and encouraging each other, you're also getting healthier. It's a win-win. You'll also have more exercise/activity options, such as a game of pickleball, tennis or squash.

2. Build new friendships.

Joining an exercise class or group can be a great way to meet new people, and an easy way to know them better and make new friends.

3. It's more likely you'll stick to your commitment.

If you've arranged to meet a friend for a walk or booked an exercise class, you're more likely to keep that commitment. As your exercise becomes a routine habit you'll both find it easier and will be more likely stick to your commitment. On the days you don't want to exercise, a talk from your workout buddy might just help you get there. This way you can support each other.

4. You're more likely to succeed in your goal.

Having someone to motivate you can make all the difference to achieving your goal. In fact, research has shown that people who exercise together are more likely to get healthier as their friend or group gets healthier.

5. Many people work harder when exercising someone else.

When you exercise with a friend, you're more likely to encourage each other and to push a little harder than you might do on your own. It may also bring out your competitive side and spur you on.

6. It can be more cost-effective exercising with a friend.

If you hire a personal trainer or hire a court or equipment, splitting the cost will save you money. You can also save on travel costs by car-pooling to get to the park, gym, pool, or sports venue.

7. Your friend or group may suggest new exercise ideas or skills that you may not know.

You may refine your running style, golf swing, or riding technique for example. Or you could try a whole new exercise, sport, or activity. Variety and changing exercise routine will help you not get bored, offer more fun and give you less reasons to quit.

8. It's safer to exercise with someone else.

Having someone to walk or run with, or assist you when you're lifting weights, means you have help at hand if anything goes wrong.

There are plenty of ways to find an exercise partner.

Here are a few suggestions:

- Start with friends and family who live nearby, or maybe your neighbour or a work colleague. Suggest a daily or weekly workout date, and make the commitment, helping each other along the way to achieve goals.
- Exercise groups are easy to find, or to start one yourself. You can talk to your council, gym, or other groups about how they got started. You can look for a group through web sites or Facebook – or what about starting up a lunchtime exercise or walking group at work, your local senior citizens centre, church, or club?
- Exercise classes are a fun and affordable way to exercise with others. Many personal trainers offer discounted classes at local parks and recreation centres. Search online for classes in your area. You can search for your local AUSactive registered professional or AUSactive registered business for sound advice and ongoing support.
- Look at charities like Parkinson's NSW for fundraising teams. You can exercise and become more active while doing a good deed at the same time. Many charities host walks, runs and triathlons to raise money and awareness for their causes.

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What new ‘brain in motion’ technology can reveal about Parkinson’s

How ground-breaking medical imaging is helping EU-funded researchers monitor brain activity during movement – and what this could mean for diagnosing and treating Parkinson’s

Neuroimaging has made huge strides in trying to demystify the human brain, but there’s still so much to discover. While most studies have been conducted under stationary conditions – usually with the participants lying down – a three-year research initiative is taking a more dynamic approach.

The EU-funded TwinBrain – ‘Twinning the brain with machine learning for neuro-muscular efficiency’ – project, coordinated by Slovenian scientists, has developed game-changing technology to monitor a patient’s brain activity while they move around their environment.

The brain is a powerful multitasker, working hard behind the scenes while we all get on with our daily lives. But it’s exactly this type of day-to-day brain activity which TwinBrain is keen to explore further.

Investigating what is going on in the brain as we walk, balance or run has been a big challenge for neuroscientists. However, innovative new technology developed by the TwinBrain project now makes it possible to monitor new areas of the brain while in movement.

The brain in motion

Led by Dr Uroš Marušič, senior research associate at the Science and Research Centre in Koper, Slovenia, and head of the Slovenian Mobile Brain/Body Imaging Lab – SloMoBIL, the TwinBrain research has been studying the brain during everyday activities, with the hope of picking up the early signs of disorders that affect brain-to-body coordination, like Parkinson’s.

The initiative has been a global collaboration, bringing together researchers from the Technical University of Berlin in Germany, the University of Trieste in Italy and the University of Geneva in Switzerland.

Together they have developed cutting-edge technology called mobile brain/body imaging (MoBI). This advanced imaging allows specialists to monitor the brain and body movement simultaneously, making it possible to spot any signs of neurological issues and – crucially – start treatments earlier.

The MoBI technology, developed in 2021 in Berlin, combines electroencephalogram (EEG) technology, a test that measures electrical activity in the brain, with electromyography (EMG) which measures muscle response or electrical activity in response to a nerve’s stimulation of the muscle.

Simply put by Dr Marušič, “We can now measure what is going on in the brain while you are walking, running, or doing other types of physical or mental activity.”

What this means for Parkinson’s

The TwinBrain initiative is focused on making strides in the diagnosis and treatment of complex neurological conditions that affect movement, including Parkinson’s.

Speaking to Horizon – the EU research and innovation magazine – Dr. Marušič explains: “In early-stage Parkinson’s, behind the scenes, the brain is compensating for balance and movement deficiencies. This can lead to a person tripping or falling.”

The hope is that MoBI will offer a more comprehensive look at exactly what is going on in the brain during this ‘multi-task’.

Paolo Manganotti, a professor of neurology at the University of Trieste, was involved in the recruitment and testing of volunteers for the TwinBrain study, with 57 participants taking part in MoBI testing since 2021. Manganotti found that participants were very willing to take part to “...help improve outcomes not only for themselves, but also for future patients.”

Speaking to Horizon magazine, Paolo Manganotti said: “TwinBrain offers groundbreaking insights for clinical practice. By integrating the latest technology, we can revolutionise the diagnosis and monitoring of Parkinson’s disease within a few years, increasing patient satisfaction and their quality of life.”

Looking to the future

Ultimately, the aim is for the TwinBrain initiative to result in earlier and more advanced treatment with people living with Parkinson’s and other neurological disorders.

For Dr Marušič this is all about personalised healthcare. Speaking to Horizon magazine, he said, “I want patients to be able to come to one place to address all issues at the same time. Personalised centres offering diagnostics and treatments tailored to your needs – one place that does it all.”

To find out more about TwinBrain visit

www.twinbrain.si/?page_id=18699

Sources:
Original article by Sarah Dawson
Parkinson's Europe
Horizon magazine

Lessons I've learned while being a Parkinson's caregiver

by Jill Hammergren

Caring for someone is one of the purest acts of love you can do

Caregiving for a loved one is one of the most challenging, demanding, and often frustrating jobs that I can think of. My husband, Eric, and I never anticipated that I'd be his caregiver, but Parkinson's disease changed our reality. I've learned that caring for someone is one of the purest acts of love you can do.

As I reflect on what we've been through since his Parkinson's diagnosis in 2014, I realise that I've learned several lessons from caregiving that I'd like to share with you.

Community-mindedness: I'm more community-minded now that I'm a caregiver. The proverb "It takes a village" comes to mind, as villagers impart expertise, knowledge, and wisdom while maintaining traditions. While the saying is frequently associated with raising a child, the same principles apply when dealing with Parkinson's disease. I rely heavily on our village, which includes members of our immediate family, friends who are like family, those in my writing group, our church family, neighbours, and others in the tremendous Parkinson's community. These people boost our spirits, offer support, impart wisdom, provide guidance, create understanding, and share their love.

Creative and critical thinking: I'm a naturally creative person and think critically about our world. These skills and life lessons suit me as a caregiver. When facing difficult situations while caring for Eric, I lean on my creativity to manage everything. I must think critically about what best serves him and what I should let others handle.

Mental health awareness: Parkinson's drains both of us mentally. As his caregiver, I think I'm more aware of our mental health needs. I've incorporated counselling, journaling, meditation, and other self-care practices into my routines. I also recently added positive messaging, lessons, and actions to our daily lives. I push, prod, and promote Eric's mental well-being with exercise, acknowledgments of joy and gratitude, and being present in the moment.

Patience and grace: These are the two things I most struggle with, both in terms of Eric and myself. It's a work in progress.

Perseverance and bravery: Caregiving teaches me to persevere through every adversity Parkinson's throws at us. For 34 years, I've volunteered for Special Olympics. I'm awed by the athletes' abilities and perseverance. Before every competition, they take an oath: "Let me win. But if I cannot win, let me be brave in the attempt."

Resilience: Caregiving teaches resilience. Parkinson's has robbed us of everything we knew about ourselves, including our personalities and our relationships with each other and with family and friends. Yet, we are resilient. I'm happy to announce that, in June, Eric and I will celebrate 30 years of marriage.

Resourcefulness: Resourcefulness is required when caring for a loved one with a debilitating disease, raising children, or caring for aging parents, grandparents, siblings, or other family members. I'm resourceful in connecting with people, places, and available resources. As Eric's caregiver, I've become more vigilant in finding what we need to help us navigate the challenges. I've also learned to ask for help and to say yes when assistance is offered.

Strength: Caregiving teaches, builds, and requires mental, physical, and spiritual strength. I've sometimes felt broken in all of these areas. Eric's experiences with Parkinson's have been brutal when rigidity and bradykinesia appeared, forcing him to drag his right leg and foot when he walked, which affected his overall gait and balance. While Eric's Parkinson's is not tremor-dominated, he had a slight twitch in his thumb in the early stages of this neurodegenerative disease.

I often call myself Eric's Sherpa. I'm neither a Tibetan nor a guide on mountainous treks in Nepal, but I do carry everything for Eric. My load includes his medications, the liquids he needs every three hours to stay hydrated, and his boxing gear.

Although we might not always win, we'll continue the long fight against Parkinson's by persevering and being brave when we encounter this journey's unknowns.

Source:
Original story published in Parkinson's News Today

My [Parkinson's] Life

Danielle McCarthy

Danielle's (Dani's) Parkinson's journey began in 2022 with a workplace injury.

"I tripped over the rubbish bin in the classroom!" she laughed. But it turns out this injury was the least of the challenges awaiting her this particular year, and the next few to follow.

The knee injury she sustained forced Dani to stop doing some of the work roles she loves; coaching teams, teaching PE, playground duty, and teaching lessons.

This didn't stop her continuing to have an impact in the school community and with her students, who always greeted her the next day with questions about the progress of her rehabilitation. Dani encouraged her students to tell her to "Sit down Miss" if she spent more than a few minutes standing to teach. Dani felt well and stayed fit by swimming, lifting weights, and riding the stationary bike, and by August was well enough to coach and teach PE again.

When Dani's father was 50, his family had noticed an uncontrollable tremor in his left pinkie finger.

"Just like Michael J Fox," Dani said. Soon, he had a diagnosis of Parkinson's.

But when Dani started experiencing her own symptoms a couple of decades later, it took her a long time to put the pieces of the puzzle together.

In June of 2022 something sinister had crept into her life: anxiety and depression.

Masking this from workmates and students, she sought help from her GP and was put on a Mental Health Plan with a regular psychologist. Medication came next, but it did not change the brain fog, sense of dread, apathy and the 'going through the motions' feeling of daily life. As symptoms worsened, Dani retreated from social events, including even using the staffroom at school.

"I was just going through the motions of going to work and coming home. I stopped going to the gym. I stopped seeing friends."

She lost a lot of weight, went for test after test, and was developing phobias of doing everyday tasks, but the GP could not work out why she was so ill. By September, Dani needed more help so made the tough decision to take a term off teaching to get better, with the help of specialists at the Bronte Clinic.

At first, her sudden onset of severe anxiety and depression was put down to psychological factors. In 2023 she returned to full-time work, still suffering, but focusing on teaching gave her some joy. She also went back to the gym and was ready to umpire AFL when the season began.

Physical symptoms began

"My school was great – they reduced my duties to help me readjust to work for the first term." But it wasn't long before other, more obvious physical symptoms began.

A strong swimmer, Dani found her right arm would no longer swing, and her right leg wouldn't kick. She was finding it hard to lift her feet to climb the stairs to her classroom, was fighting off phobias of working, driving, cycling and exercising by taking the 'opposite action' as she had learnt at the Clinic – but her severe anxiety and depression was becoming a lot to cope with while teaching.

Talking helped, but didn't stop the cloud of hopelessness she felt, nor the pains developing in her body, including severe peripheral neuropathy.

Eventually, after months in limbo, she got a midday appointment, to visit a neurologist who gave her the devastating news.

"Before I even sat down for the consultation, he said, 'You know what you've got?' And I said, 'I've got Parkinson's'."

All the clinical tests were done, and she found her toes didn't even wiggle. That was a surprise. Finally there was an answer to the turmoil and hopelessness of the past two years. She even remembers smiling about the diagnosis. But she was utterly drained by work and her ill-health.

Finding Parkinson's NSW was a turning point. Even though Dani had some experience of Parkinson's because of her dad, there was a lot she didn't know. From the first call to the Parkinson's NSW InfoLine, Dani found knowledgeable friends who could guide and support her to get the help she needed.

Illnesses don't define me

"The combination of chronic illnesses I have is long, but they don't define me," she reports. "If anything they push me to keep on going, stay strong, and help others when they ask for advice or what services to reach out to."

Dani believes that when you have a disease like Parkinson's, strong relationships and support are the most important things you can have. Parkinson's NSW believes that too. She recently got married in February to her partner of 16 years.

Dani's mottos and mantras in life include:

Not just a diagnosis: Strength in Every Step.

My full-time job is my health.

Nothing is impossible, you just must find your own path to achieve your goals.

I am most inspired by the stories of others who have Parkinson's. They know.

IN THIS TOGETHER
parkinson's
NSW

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."