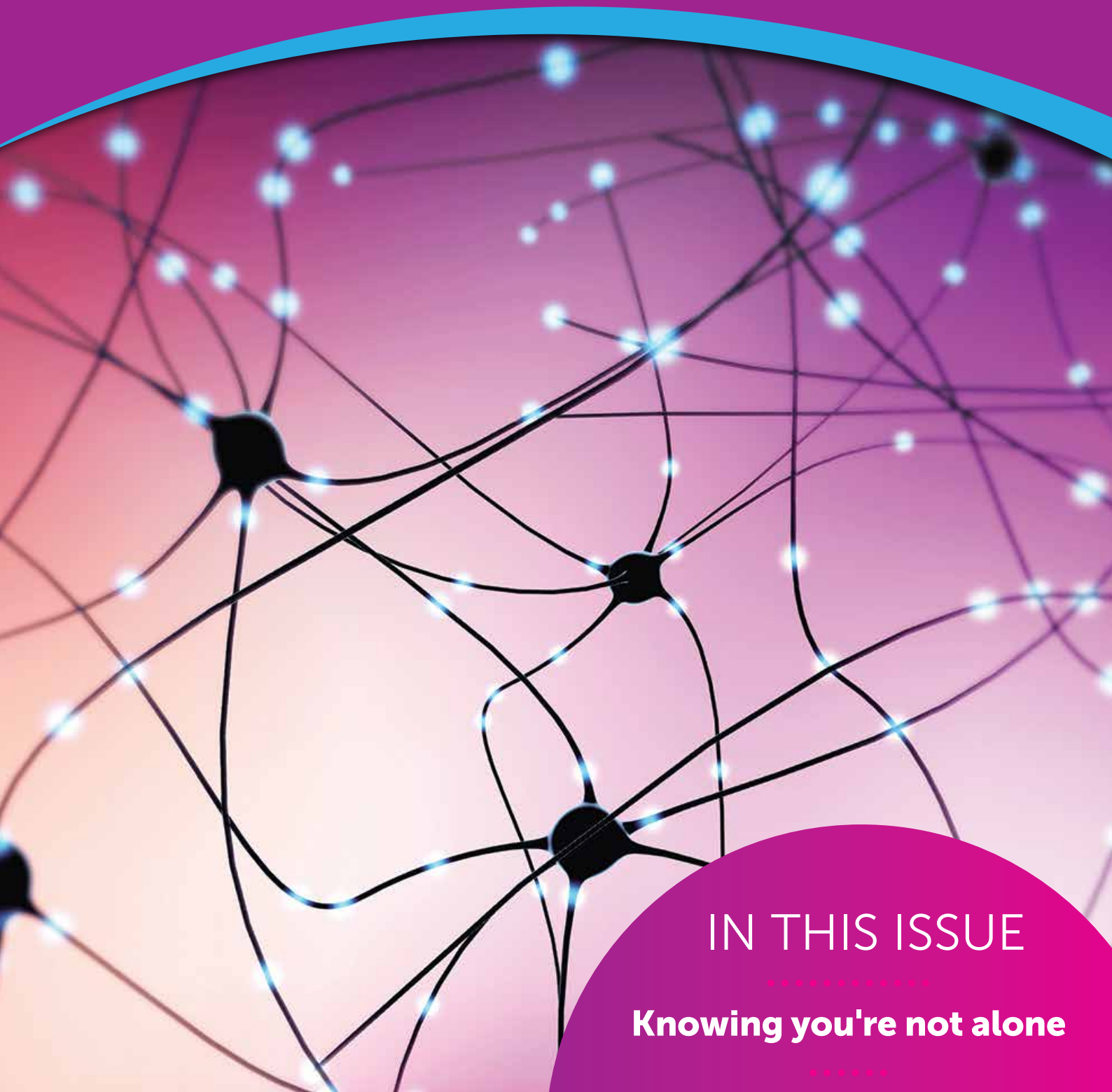


STANDBYME

OFFICIAL PARKINSON'S NSW MAGAZINE

Issue 157 SUMMER 2024
ISSN 1839-0269



IN THIS ISSUE

.....
Knowing you're not alone

.....
**Life factors affecting
cognitive ability**

.....
Nurses In Action

IN THIS TOGETHER
parkinson's
NSW

In this issue...

It is widely reported that the non-motor symptoms of Parkinson's are often more troubling than motor symptoms. Two stories in this edition attest to that.

Read about a free, digital phone application that tracks your symptoms. It allows you to complete daily check-ins and reports on your condition. Reports generated by the application have revealed that fatigue, mood and sleeping issues are among the top symptoms experienced.

It's also worth reading our story on how lifestyle factors affect your cognitive abilities, as well as an article on helping someone through a panic attack.

We haven't forgotten the importance of exercise either. Take a look at the highly informative article titled Exercise: One size can't fit all. It provides a detailed and practical guide to tailoring your exercises to address specific Parkinson's symptoms. This article is a must-read guide to getting active.

And join us in recognising the quiet achievers who so work hard as part of the wider Parkinson's care team, delivering practical support and advice with great compassion – our wonderful Parkinson's Specialist Nurses. This issue includes the latest in our Nurses in Action series.

Enjoy the Festive Season and we wish you safe and happy holidays.

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



Fatigue most common Parkinson's symptom reported

Fatigue is the most common complaint among people with Parkinson's disease, according to anecdotal data from a free digital phone application (app) that allows patients or caregivers to complete daily check-ins and rate how they feel.

In the nine months since the launch of Parkinson's On, more than 2,500 patients and caregivers have shared their experiences through the app, with more than 160,000 symptom reports that provide insights of what life is like with Parkinson's, according to the app's developer, Kuhan Pushparatnam.

"I really hope these insights can help not only our community and their healthcare teams, but also researchers grappling with their understanding of this degenerative condition," Pushparatnam said.

Problems with mood and sleep came second and third in the top symptoms, suggesting that non-motor symptoms may have the greatest effect on patients' quality of life.

Motor symptoms, a hallmark of Parkinson's, were reported less frequently, with tremors coming fourth. An analysis of the daily check-ins revealed that the more physically active patients were, the better their day was, suggesting that staying active may help manage the disease.

Painting the 'big picture'

Pushparatnam received a Parkinson's diagnosis in 2013 at age 38. With a background in mobile technology, he wanted to develop an app that would help other patients manage their symptoms on a day-to-day basis and feel more in control of their lives.

"I also wanted people to better understand their Parkinson's. I wanted both the big picture and the individual portrait. The anonymised data gleaned from Parkinson's ON app is starting to paint that big picture," said Pushparatnam, who co-hosts a podcast called '2 Parkies in a Pod.'

"I've always believed tech, when done right, can be a great enabler in daily life," Pushparatnam said. "So, I set out to build a simple, 'Parky-friendly' app that would not only empower those of us living with the condition, but ultimately allow for a better, more informed quality of care."

Pushparatnam self-funded the app's launch last year. Since then, with funding from Parkinson's UK, the app has been updated and expanded. Parkinson's UK is a member organisation of Parkinson's Europe.

Users can stay on time with their medication through simple setup, reminders for what medication to take and when, and one-click logging to track when the medication is taken. They can also stay on track by completing daily check-ins to rate their symptoms and log daily activities.

A personalised dashboard shows trends in treatment adherence, symptoms, and daily activities, along with access to special content like a 'Yoga for Parkinson's' series, strategies to help with anxiety and sleep problems, and bonus episodes of the '2 Parkies in a Pod' podcast.

Features include a diary, a shareable medication card, and an audio format for news and research. The app also helps users plan mealtimes around their medication and track off periods, which are times when medication stops working well and symptoms return.

Parkinson's On is free to download from both Google Play and the Apple App Store.

Sources: Original article by Margarida Maia, PhD Parkinson's News Today, Parkinson's Europe, Parkinson's UK

Knowing you're not alone is a huge gift

When Dani's father was 50, his family noticed an uncontrollable tremor in his left pinkie finger. 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. At first, her sudden onset of severe anxiety and depression were put down to psychological factors. But it wasn't long before other, more obvious physical symptoms began.

Eventually, after months in limbo, she got an appointment with 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."

A diagnosis of Parkinson's is terrible at any age but increasingly, we're seeing it develop in younger people like Dani. Learning you have a complex, lifelong neurological condition that will worsen over time can feel heartbreakingly lonely.

Dani said the months she went undiagnosed were some of the hardest of her whole life. As someone



who is naturally resilient and hardworking, she refused to let her symptoms consume her and kept working as a schoolteacher every day. But she was utterly drained.

These debilitating, confusing months were traumatising for her whole family – including her partner and teenage daughter, who was studying for her HSC. 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 our InfoLine, Dani found friends who could guide and support her to get the help she needed.

Our counsellors provide compassionate support and guidance for:

- coping with Parkinson's
- discussions on disclosing a diagnosis to family, friends or work
- changes to work roles or activities and interests
- mood management and the treatment of depression or anxiety.

Our Impact

Thanks to generous donors like you.



InfoLine:

3,491 InfoLine calls were answered



Counselling:

1,300 Counselling sessions delivered



Support Groups:

2,520 participants in **75** support groups across the state



Education & Training:

44 Information & Education sessions delivered



Parkinsons Specialist Nurses:

Had **2,563** patients on their lists, coordinated **237** Telehealth sessions and covered **17,916 km** of travel to support their communities.



Please help Parkinson's NSW to deliver the support that people like Dani and many others like her need.



Helping someone through a panic attack

There are many ways to help someone experiencing a panic attack, but the most important things are to remain calm and help in the ways that they ask for.

A panic attack is a brief but intense rush of fear. These attacks involve symptoms similar to those experienced when facing a threat, including:

- Intense fear • A sense of doom • Sweating or chills
- Shaking • Pounding heart • Difficulty breathing
- Head and chest pain

Panic attacks differ from a typical fear response because there's no actual threat involved. Panic attack triggers aren't always easy to identify, so people who have one attack often worry about having more, especially in public.

Panic attacks usually feel very uncomfortable and cause significant distress. Many people believe they're experiencing a heart attack or other life-threatening issue.

If you know someone who experiences panic attacks, there are several things you can do (and avoid doing) to help them in the moment.

Remain calm

Keeping your cool is one of the best ways you can help.

Even if you feel a little afraid yourself, stay calm. If your voice seems to help (and they haven't asked you to keep quiet), talk with them in a calm voice.

What to say:

- Reassure them you won't leave or judge them
- Remind them the attack won't last long
- Tell them they're safe • Ask how you can help

Most people who experience panic attacks or live with other types of anxiety have their own go-to coping methods. When offering support, keep in mind your loved one knows best when it comes to what will help most.

During an attack, however, they might find it harder to communicate this. Consider asking in advance how you can offer assistance if they experience an attack around you.

What if they want me to leave?

As long as they're not in immediate danger, take a few

steps back and give them some space. Stay nearby so you can still keep an eye on things and let them know that should they change their mind, you'll come right back.

Learn the warning signs

If you haven't already, take some time to familiarise yourself with the early signs of a potential panic attack. Panic attacks commonly begin with:

- A feeling of terror or dread • Hyperventilation or shortness of breath • Feelings of choking
- A pounding heart • Dizziness and shaking

Not everyone experiences panic attacks in the same way, so it's best to ask what signs they tend to experience.

Focus on action over words

A soothing, familiar voice helps some people but try to avoid repeatedly saying things like "don't worry" or asking them if they're alright over and over. Of course you mean well, but your words may not have much benefit in the moment.

Take action with your words by:

- Asking if they want to leave the room and go somewhere else • Reminding them to keep breathing
- Engaging them in light conversation, unless they say they don't want to talk

When to get help

It can be frightening to watch someone have a panic attack, but at what point should you bring in additional help? It's hard to say.

Simply sticking around and seeing them through the experience might not feel like much to you, but it can make a significant difference for the person having the attack.

That said, reach out for emergency help if:

- Chest pain feels like squeezing (not stabbing) and moves to their arms or shoulders
- Symptoms persist for longer than 20 minutes and get worse, not better
- Shortness of breath doesn't improve
- Pressure in the chest lasts more than a minute or two

Sources: Original article by Crystal Raypole
Healthline.com

Lifestyle factors affecting cognitive abilities



'Cognitive' is a term used in psychology to describe anything related to thinking, learning, and understanding. So when we talk about cognitive skills or processes, it refers to different aspects of how the brain works – including things like remembering information, learning new things, paying attention, and processing information.

Exercise can improve your cognitive abilities, but there are also some daily lifestyle habits that can also help.

Reducing your stress

Anyone with high amounts of stress is more likely to suffer from cognitive problems than those who are free of stress. While medications can reduce the symptoms of stress, they don't cure the problem or help you understand the cause of the stress.

Often medications can require ever-increasing dosages to be effective, and many have side-effects. It is also important to consider reducing stress in more natural ways, such as exercise, naps, counselling, meditation, relaxing hobbies, spiritual growth and other means.

Here are some ways you can enhance cognitive function, keep your memory sharp and improve mental clarity.

Adopt a growth mindset

Adopt a growth mindset, which is believing that you can improve your abilities and create successes through continuous learning, practice and persistence. Openness to new experiences through traveling, learning a new skill or taking on something that is unfamiliar and mentally challenging has been shown to improve cognitive function. To develop a growth mindset, it's important to get out of our comfort zone and try something new.

Manage stress, anxiety and depression

Our emotional well-being influences our health in many ways, including our brain health. Prolonged stress, anxiety, and depression impacts cognitive functioning, leading to impaired memory and cognitive decline.

Neuroscientists found that elevated levels of the 'stress hormone' cortisol damage the brain, which changes brain structure and function, and leads to mental problems such as anxiety and mood disorders.

To help minimize the negative implications of prolonged stress, the key is to identify the root cause and situations where stress is likely to occur. Then develop effective strategies to help cope.

10 Learn effective ways to relieve stress such as physical activity, breathing techniques and proper sleep. Choose one to practice and note how you feel. Then try another technique until you find one that works for you.

There are many online stress management tools, which use cognitive behavioural therapy to help you de-stress and learn strategies to combat negative thoughts

17 Eat for brain health

You can also eat for brain health. Foods rich in nutrients such as omega-3 fatty acids, antioxidants and B vitamins have all been shown to support brain health. Foods particularly rich in these healthful compounds include leafy green vegetables, fatty fish, berries, tea and coffee.

As a bonus, research has shown that these same foods which are linked to better brain function have also been shown to protect our hearts. Adding these foods into your diet on a regular basis may improve the health of your brain, leading to enhanced mental function and overall health.

Try to emphasise plant foods in your diet. Research shows that eating more plant foods may help slow cognitive decline. Incorporate fish in your diet twice a week. Remember to choose varieties that are low in mercury, such as salmon and canned light tuna. Try handful of walnuts as a snack or on a salad. A recent study from the University of California Los Angeles linked higher walnut consumption to improved cognitive test scores.

Focus on quality of sleep

Few things feel better than waking up after a good night's sleep. Quality sleep puts us in a better mood and gives us energy to keep up with our busy lives. Sleeping is important for storing memories, while also restoring us both mentally and physically. Lack of sleep can contribute to difficulties problem-solving, reasoning and concentrating.

Getting a good night's sleep is one of the most difficult challenges for people living with Parkinson's but don't give up and keep working on ways to improve your sleep quality.

Exercise your brain

Join in thoughtful conversations with family or friends. This allows you to practice speaking, critical thinking and many other cognitive aspects which stimulate and refresh your mind. This is especially important for people living with Parkinson's who often withdraw from social interaction.

One of the best brain exercises for your brain is meditation. Meditation allows you to relax and focus on your thoughts and emotions. There are many free applications available that provide guided meditation for those unfamiliar with how to meditate.

Sources:

<https://www.medicalnewstoday.com/articles/cognitive-functioning>"<https://www.medicalnewstoday.com/articles/cognitive-functioning#>:

<https://thinkhealth.priorityhealth.com/brain-health-5-tips-to-improve-memory-and-cognitive-function/>

Exercise: One Size Can't Fit All



There is a large amount of research happening around the benefits of exercise for people with Parkinson's. Most people want an easy answer. Unfortunately, there isn't one.

Below is a list of common Parkinson's symptoms. Each symptom is improved by a different type or style of exercise.

SYMPTOM	BENEFICIAL EXERCISE TYPE	EXERCISE EXAMPLES
Tremor or shaking at rest	Aerobic – moderate to intense – puffing	Running, fast walking, bike riding, boxing
Loss of muscle strength	Strength training moderate to intense	Weightlifting, body weight, rock climbing
Muscle stiffness (rigidity) affecting posture, mobility, and movement	Flexibility, stretching	Yoga, stretching exercises
Slowness of movement	Speed and agility training	Sprinting, obstacle course, boxing
Fatigue	Aerobic and strength	As above
Depression/anxiety	Exercise you enjoy	Team sports, dancing, painting
Restlessness	Rhythmic/repetitive activity	Boxing, dancing, cooking, yoga,
Localised muscle pain	Flexibility, stretching	Massage, heat, stretching
Balance difficulties	Balancing exercises	Yoga, Pilates, Tai Chi
Speech changes – slower/quieter	Speech therapy, vocal exercises	Singing, loud speaking
Eating and swallowing difficulties – increased saliva production	Speech therapy, vocal exercises, medication	Singing, loud speaking, throat exercises
Sleep problems	All and any exercise.	More intense exercise increases fatigue
Handwriting – small and messy	Occupational therapy, writing exercises	Writing, drawing, painting
Constipation	Aerobic – moderate to intense exercise AND 2-3 litres of water per day	Running, fast walking, bike riding, boxing, all sports
Cognitive changes – memory difficulties, slowness of thought	Cognitive exercises, problem solving	Games i.e. crosswords, sudoku, puzzles, learning something new.

The above table is a simplistic, brief overview of what types of exercise benefits some of the common symptoms of Parkinson's.

However, please keep in mind that no two people living with Parkinson's will have the exact same combination of symptoms, nor will those symptoms progress at the same rate for everyone.

Many other factors will affect Parkinson's symptoms daily including how busy or how stressed you are, and how

well you've slept – along with the food and water you've consumed and even the weather will have an effect.

Sources:
https://exerciseismedicine.org.au/wp-content/uploads/2021/01/EIM-FactSheet_Parkinsons_Professional-2020.pdf

Prepared by Professor Graham Kerr (Queensland University of Technology) Updated by Dr Natalie Allen and Prof Colleen Canning (The University of Sydney).

Nurses in Action

Stephen Gee and Nurse Jody Lloyd, Port Macquarie

A few years ago, Stephen Gee noticed that he was having more trouble with the physical aspects of his work as a refrigeration mechanic in Sydney.

"I had to climb up a lot of ladders and onto roofs and I was finding it hard," recalls Stephen, now 64. "I had also started to shuffle. I kept telling myself to walk properly and step out, but I couldn't. Even doing things like putting a shampoo bottle back on a bathroom shelf was in 'slow-mo'. I was moving like I'd had half a dozen beers, but without the fun."

Stephen had been to see a heart specialist in early 2019 who put him on statins to manage cholesterol issues. He had also been taking blood pressure tablets for many years. The onset of his symptoms had coincided with the use of statins.

"We started noticing small physical and mental changes as the doctor had put him on a very high dosage," says Suzanne, Stephen's wife. "We had many months going back and forth to the local GP and heart specialist who continued to adjust the medication. However, nothing helped and his clinical changes were slowly getting worse."

"By November that year we had decided to take a holiday, believing it would help Steve to have some relaxation – but his symptoms of shuffling and depression (which Steve had never suffered with) were at an all-time high,"

Suzanne did not know what to do.

"Steve was not coping in any way and watching his decline was heartbreaking," she recalls. "I had never seen Steve so sad, crying, and not thinking clearly."

"We decided to see another Sydney heart specialist who at least had the fortitude to admit that statins were not tolerable for a percentage of the population, and it was extremely obvious that Steve was in that category."

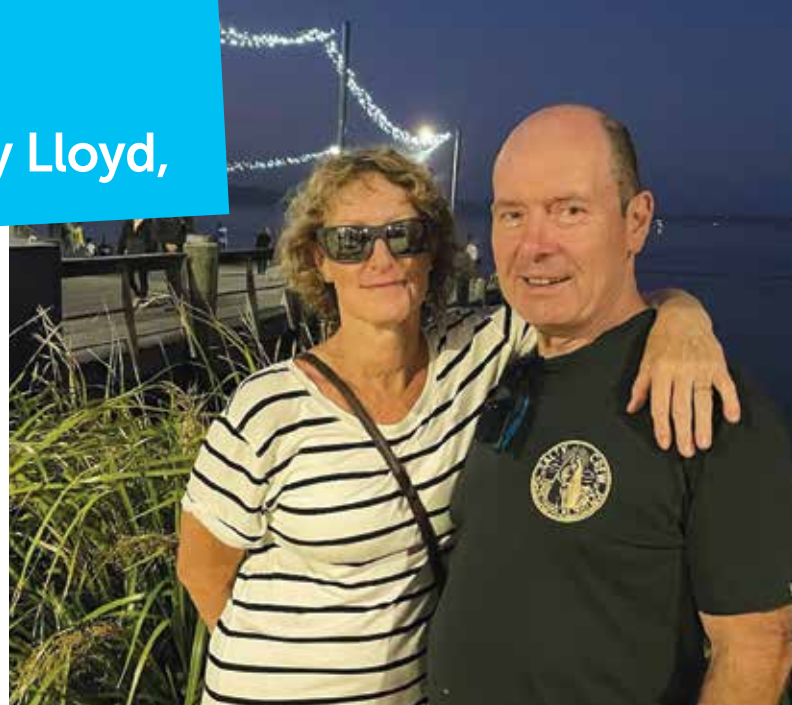
"It was decided to discontinue the statins, blood pressure tablets and aspirin and to look at other options. His blood pressure returned to normal, and his cholesterol began to drop with changes to diet and exercise. He also took vitamins and supplements such as Bergamot and Coenzyme Q10 and K2 – all suggested by a highly-regarded heart specialist who was recommended to us by a friend."

After coming off those medications, Steve started to feel somewhat better but the lingering effects left him with brain fog, and the slow and shuffling movements continued.

Steve saw neurologist Dr Chung in late 2020, had tests and was then diagnosed with a form of Parkinsons.

"He prescribed the medication Madopar," says Suzanne. "The problem was Steve got worse on that medication. He began to suffer with the depression again, shuffling and the very slow movements. Steve persevered with that medication for some time before we both decided that he was not getting any better, there were no improvements at all and it was better he come off that medication."

"By the time we had packed up and moved to Port Macquarie in May 2022, we had decided to look for help. That is when we found an apothecarist, who was a wonderful help. She recommended Jody Lloyd the



Parkinson's nurse, and life began to change for Steve for the better from then on."

"If it wasn't for Jody I'd be a mess now," Stephen says.

"Jody, God bless her, went through all my medication and my blood pressure tablets were combining with my other medications and making my blood pressure way too low. She sorted it all out for me and it's so much better now."

In fact, Stephen is now well enough to enjoy the coastal lifestyle and is making the most of retirement.

"I go fishing about once week, which was much harder to do where we lived in Sydney," he says. "I also do archery, which was something I'd started in Sydney. Suzanne and I go out for coffees and a meal or with friends we're making up here. I also help Suzanne with things she likes to do around the house and in the garden."

Stephen also goes to an exercise therapist and sees a speech therapist to strengthen his voice.

"I also go to Loud Crowd (a Parkinson's program which assists with speech and swallowing issues)," says Stephen. "I want to make the most of things for as long as possible and be helpful to my wife because one day she will be doing more for me."

Stephen says that living in a regional area would have been so much harder for him without the assistance provided by Jody.

"Jody has arranged my specialist appointments, and I wouldn't have known who to see or where to start," says Stephen. "We have a fly-in, fly-out specialist who visits every six months as well as being able to do telehealth video hook-ups with Jody's assistance."

"The latest thing Jody has been helping me with is getting me accepted for NDIS. I was reluctant to start the process until Jody explained that while there might not be much I need now, further down the track I could need more help. And you can't apply once you're over 65."

"Jody has been so helpful in so many ways, and not just in answering my questions. She's so knowledgeable and goes out of her way to arrange things. It would have been hell if we'd had to try and arrange things ourselves."

"Jody is worth her weight in gold. While Port Macquarie has good facilities and infrastructure, it's still a rural area. Parkinson's nurses are a godsend."

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."

