STANDBYME

OFFICIAL PARKINSON'S NSW MAGAZINE

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IN THIS ISSUE

IN THIS TOGETHER
parkinson's NSW

In this issue…

There is something for everyone in this Spring issue of *Stand by Me.* Articles range from research to social well-being and exercise. Exercise is very much to the fore now that we are enjoying the warmer weather of spring.

There's a story on setting and tracking exercise goals for maximum benefits plus – on a different but related note – a first-person story on how Madeleine found her Parkinson's family through an exercise class. You can also learn about a new education module that has been launched to help exercise professionals upskill to better work with clients who have Parkinson's.

Then read about a research breakthrough. It may now be possible to diagnose Parkinson's disease years before it becomes untreatable, by scanning people's brains with functional magnetic resonance imaging (fMRI). Another study has found that orthostatic hypotension may serve as an early clinical marker of the body-first subtype of Parkinson's.

There is a useful how-to article on practical ways of managing tremors. Then, to cap off this issue, an inspiring Parkinson's love story. For more than 50 years, Debbie and Bill have shared a life filled with music, laughter, and unwavering love. Then, just before turning 50, Bill was diagnosed with Parkinson's disease.

As Bill's condition progressed, Debbie became Bill's fiercest advocate, learning everything she could, managing his care with intelligence and heart.

Debbie credits Parkinson's NSW with making a tangible difference – especially for their daughter Danielle, who was also diagnosed with young onset Parkinson's in her 40s. "She's thriving because of the information, support groups, and connections she's found through Parkinson's NSW. It's given her confidence and hope."

This family's moving story is at the heart of our spring appeal.

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

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Parkinson's NSW launches new online education module for exercise professionals

Parkinson's NSW has launched Module 3 of its Parkinson's online education series.

Module 3 – Exercise is designed to help exercise professionals to explain the evidence and benefits of exercise for someone living with Parkinson's.

It will educate trainers, physiotherapists and exercise physiologists on planning and supporting the implementation of quality, balanced exercise regimes tailored to each person with Parkinson's goals, impairments and personal motivations.

The professionals who complete this module will then be able to discuss the impact of motor and non-motor impairments and activity limitations with their clients – along with co-morbidities, personal goals and preferences, disease stage, fall history, and medications.

The module was developed with the guidance of the Education Advisory Subgroup which includes physiotherapists Associate Professor Natalie Allen, Emeritus Professor Colleen Canning and Andrew Han, along with Nate Lum, an exercise physiologist.

The first of the education modules in this series was launched in 2022. **Module 1** is an Introduction to Parkinson's which provides a greater understanding of the nature of Parkinson's, its symptoms, and some of the ways you can help to improve the quality of life of a person living with Parkinson's.

Module 2 was launched in 2023. It is about Best Care Practices for Parkinson's for health professionals – particularly those working in the Aged Care sector.

> *"Each of these modules addresses key management strategies for Parkinson's disease," said Mary Kay Walker, CEO of Parkinson's NSW. "This includes being familiar with the full range of physical and cognitive symptoms, understanding the importance of administering medication on time and every time, and that correctly prescribing vigorous, tailored exercise is also a form of medication for this degenerative condition."*

The learning modules were developed by Cognition Evolve which has expertise in innovative digital learning solutions. The modules are published on the Litmos platform – thus making them accessible to health professionals.

Find out more about Parkinson's NSW online learning modules on our website

https://www.parkinsonsnsw.org.au/education/

New brain imaging method shows promise for early diagnosis of Parkinson's disease

An international team, led by researchers at the Champalimaud Foundation (CF), has shown – for the first time in a realistic way – that it may be possible to diagnose Parkinson's disease years before it becomes untreatable, by scanning people's brains with functional magnetic resonance imaging (fMRI).

Their results were published in the Journal of Cerebral Blood Flow and Metabolism.

It has been known for some time that otherwise symptom-free people who are slowly developing Parkinson’s complain about the loss of their sense of smell. This can happen five to 10 years before they get really sick and experience the full symptoms of the disease: slowness of movement, resting tremor, rigidity, and postural instability.

The significance of this type of sensory impairment in Parkinson’s has not been the object of much research. Moreover, although a lot of people report loss of the sense of smell, only some of them will develop Parkinson’s, which means smell impairment by itself is not a specific biomarker for the disease.

But what also happens is that people developing Parkinson’s and related disorders may also suffer from visual deficits and even hallucinations – and it is here that there may be room for more reliable biomarkers.

Now, for the first time, Noam Shemesh (leader of the Preclinical MRI lab at CF) and his team – together with Tiago Outeiro, a neuroscientist and Parkinson's specialist at the University Medical Center Gottingen – have joined efforts and demonstrated that evaluating these two (and maybe other) sensory impairments in the brain, at the same time, could provide robust biomarkers for early Parkinson's. And the earlier the diagnosis, the better the chances of developing effective treatments for PD patients.

Ultra-high resolution functional MRI

Using an ultra-high field experimental MRI scanner installed in Shemesh's lab, the researchers submitted a mouse model of Parkinson's to a technique called functional magnetic resonance imaging (fMRI). To give an idea of the power of the experimental machine, it generates a magnetic field of 9.4 Tesla (whereas medical machines typically only go up to 3 Tesla). This substantially improves the images and enables a clear view of brain structures in the small mouse brain.

The transgenic mice used here were widely used in Outeiro's Lab and carried increased levels of a human protein called alpha-synuclein. This protein is thought to play a major role in disease, as it tends to accumulate and form inclusions, also in the substantia nigra – the brain region that produces dopamine and whose progressive degeneration is responsible for the motor impairments in Parkinson’s.

> *"The aggregates then spread to other regions in the brain, and affect motor areas", explains Ruxanda Lungu, co-first author of the study.*

Moreover, the behaviour of the mice denotes an impaired sense of smell – and it is also thought that these animals experience visual impairment.

Functional MRI is used to see which areas of the animal (or human) brain are activated – when they are exposed to odours or to visual stimuli. In the whole-brain images obtained, areas ‘light up’ in response to stimulation due to changes in blood flow and oxygenation, which are driven by the neural activity.

The researchers started by comparing, using fMRI scans, activity in the brains of living mice that produced tangles of alpha-synuclein to those of siblings that did not. The mice were around nine months old, analogous to an intermediate stage of development of Parkinson’s.

And indeed, the main analyses, conducted by Francisca Fernandes (co-first author on the study), showed that the control mice had normal activity in the corresponding brain areas, while in the Parkinsonian mice, there was much less activity.

Untangling the neural from the vascular

However, the problem with MRI is that "...it doesn't detect neural activity per se", says Shemesh. "Since it relies on interactions between ongoing neural activity and vascular properties, it detects a complicated combination of both effects."

And in the present study, it was paramount to ‘untangle’ these two components to visualize the purely neural effects of the disease. "It is very, very difficult to do that with fMRI", Shemesh points out.

So they had to use other approaches as well. Co-author Sara Monteiro assessed the vascular properties with a method called ‘cerebral blood flow mapping’ and showed that the vascular effects were indeed weaker in the Parkinson’s mice when compared to the controls.

In parallel, Lungu measured neural contributions using a protein called C-FOS, which is released when a neuron is activated. And when she quantified how much of this protein was present in the PD mice's brain (post-mortem), she found that the reduction of neuronal activity was even more pronounced than that of vascular flow.

> *"We concluded that while both the neuronal and the vascular effects exist, the changes we saw in the fMRI scans were mainly driven by neuronal effects," says Shemesh. "The mice neurons were just firing less."*

Source:
Champalimaud Centre for the Unknown

Setting achievable exercise goals and the power of tracking them

Setting personal exercise goals is one of the most effective ways to stay motivated, achieve fitness results, and maintain a healthy lifestyle.

Whether you're a seasoned athlete or just starting your fitness journey, setting clear, achievable goals can make a significant difference in your progress. However, the true power of goal setting lies not only in creating them but also in tracking them.

Monitoring your progress can boost motivation, provide insights into your performance, and help you make necessary adjustments to stay on track.

Why setting achievable exercise goals is important

Setting goals gives you direction. Without a clear objective, your workouts might lack purpose, and it could be easy to lose interest or get discouraged. However, when you set achievable goals, you create a roadmap for success that encourages consistent effort.

The importance of achievable goals

- **Focus:** Goals help you prioritize what matters most in your fitness routine. It could be improving strength, increasing endurance, or enhancing flexibility. Knowing what you want to accomplish allows you to tailor your exercises accordingly.
- **Motivation:** Success breeds motivation. When you set goals that are realistic and measurable, you'll feel more driven as you hit milestones. These wins, even if small, will keep you motivated to continue working toward bigger goals.
- **Progress:** Tracking your progress allows you to see tangible improvements, whether it's a personal best on the treadmill or an increase in weight lifted during strength training. This progress reinforces the value of your efforts.

How to set achievable exercise goals

When setting personal exercise goals make sure they are specific, measurable, attainable, relevant and time-bound (SMART).

- Specific: Avoid vague goals like "I want to get fit." Instead, break it down into concrete objectives, such as "I want to run 5 kilometres without stopping" or "I want to improve my flexibility by being able to touch my toes."
- **Measurable:** Your goal should have clear metrics that allow you to track your progress. For example, instead of saying "I want to get stronger," set a goal like "I want to increase the amount of weight I can bench press by 5 kilos."
- **Achievable:** It's important to set goals that are challenging yet attainable. Don't plan to run a marathon in a month if you're just beginning to exercise. A goal like "I want to run 5 kilometres within three months" is more reasonable for a beginner.
- **Relevant:** Your goals should align with your overall fitness aspirations. If you want to focus on weight loss, your goals might include fat loss or increasing daily physical activity. Make sure your goals are meaningful to you and fit within your lifestyle.
- **Time-Bound:** A deadline helps create a sense of urgency and prevents procrastination. Set a specific time frame for achieving your goal, such as "I want to do 10 push-ups in a row within 4 weeks" or "I want to lose 3 kilos in the next 6 weeks."

Benefits of tracking exercise goals:

- **Boosts Motivation:** Seeing your progress, for example more steps, distance, or strength, helps you stay inspired.
- **Builds Accountability:** Tracking your workouts keeps you consistent and helps spot areas for improvement.
- **Sharpens Focus:** Patterns in your results show where to adjust or increase intensity.
- **Encourages Reflection:** Reviewing your progress lets you celebrate wins, learn from setbacks, and refine your goals.
- **Reveals Body Insights:** Monitoring how you feel, your heart rate, or energy helps prevent burnout and injuries.

Tools to track your goals

Choose what works best for you:

- Apps like MyFitnessPal, Strava, or Fitbit log steps, workouts, and heart rate.
- Wearables such as Apple Watch or Garmin provide instant performance feedback.
- Journals or Spreadsheets help you record workouts, set targets, and see progress over time.

Staying Flexible

Goals should guide you, not stress you. If life, illness, or injury gets in the way, adjust and keep going.

Tracking and reflecting on your goals keeps you motivated, accountable, and focused helping you build a sustainable routine that leads to lasting results.

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Low blood pressure on standing a likely body-first Parkinson's marker

In body-first subtype, disease may start in the digestive tract and then spread

People with Parkinson's disease who have orthostatic hypotension – that's where the blood pressure drops suddenly upon standing up from a sitting or lying position – appear more likely to develop heart and digestive problems, act out their dreams, and go through motor fluctuations, a study has found.

These clinical features are consistent with the body-first subtype of Parkinson's, where the disease is thought to start in the digestive tract and spread to the brain and then the body. This causes non-motor symptoms that may appear years before motor symptoms manifest.

The findings suggest orthostatic hypotension may serve as a "...clinical marker of the body-first subtype of [Parkinson's]," researchers wrote in Orthostatic Hypotension: a clinical marker for the body-first subtype of patients with Parkinson's Disease, which was published in the npj Parkinson's Disease journal.

In Parkinson's, the alpha-synuclein protein takes on an abnormal shape that makes it prone to clumping into so-called Lewy bodies, which are toxic to nerve cells. These can spread rapidly across the brain, leading to nerve cell degeneration and affecting how fast the disease progresses.

Researchers have proposed dividing Parkinson's into brain-first and body-first subtypes depending on where Lewy bodies first form.

Brain-first and body-first subtypes

In the brain-first subtype, it's thought that certain toxic chemicals are breathed in through the nose and rapidly travel to the brain, where they trigger Lewy bodies to form, causing motor symptoms early in the disease's course.

In the body-first subtype, Lewy bodies are believed to form in the digestive tract and travel to the brain via the vagus nerve – the longest nerve in the body. They then spread to other parts of the body, leading first to non-motor symptoms and later to the hallmark motor symptoms.

A common non-motor symptom is orthostatic hypotension, which can happen spontaneously or be triggered by medications such as levodopa, the mainstay treatment for Parkinson's.

In this study, researchers evaluated whether orthostatic hypotension could help identify the body-first subtype of Parkinson's. Their study included **928** patients, mean age **62.4,** who had Parkinson's for an average of **7.9** years.

More than half **(57.2%)** were on stage **2.5** or lower in the modified Hoehn and Yahr scale, indicating motor symptoms in one or both sides of the body without impairment of balance.

About as many **(57.4%)** had motor fluctuations, which occur when the effects of levodopa wear off before the next dose is due, causing 'off' periods when symptoms return or worsen. Almost **25%** had dyskinesia, a side effect of levodopa that produces involuntary muscle movements.

How patients were tested

The patients were tested while off their medications and after a levodopa challenge where they took a morning dose of it **50%** higher than their usual one to watch for changes in their blood pressure when asked to move from a lying to a standing position.

Based on the results of this, the patients were divided into those without orthostatic hypotension **(41.3%)**, with spontaneous orthostatic hypotension **(24.1%)**, and orthostatic hypotension triggered by a higher levodopa dose **(34.6%)**.

Those with orthostatic hypotension were older than those without it and up to twice as likely to have motor fluctuations. They also generally showed more severe symptoms and had more limitations in daily activities.

They also were up to nearly three times as likely to have probable rapid eye movement sleep behaviour disorder, where a person acts out dreams by making noises and often violent movements.

Acting out dreams occurs frequently even when motor symptoms haven't yet developed and may help identify Parkinson's in its early stages. This was especially true in those with the spontaneous type, who were also more likely to develop hallucinations and cognitive impairment.

Patients with orthostatic hypotension were also more likely to develop problems with their autonomic nervous system, which is responsible for controlling involuntary bodily processes such as heartbeat and digestion, "...consistent with the body-first subtype of [Parkinson's]," the researchers wrote.

While future studies should include patients with earlier-stage disease and objective tests such as imaging, the findings suggest orthostatic hypotension is a "...potential clinical marker" that can be confirmed with a levodopa challenge test, they said.

Sources:

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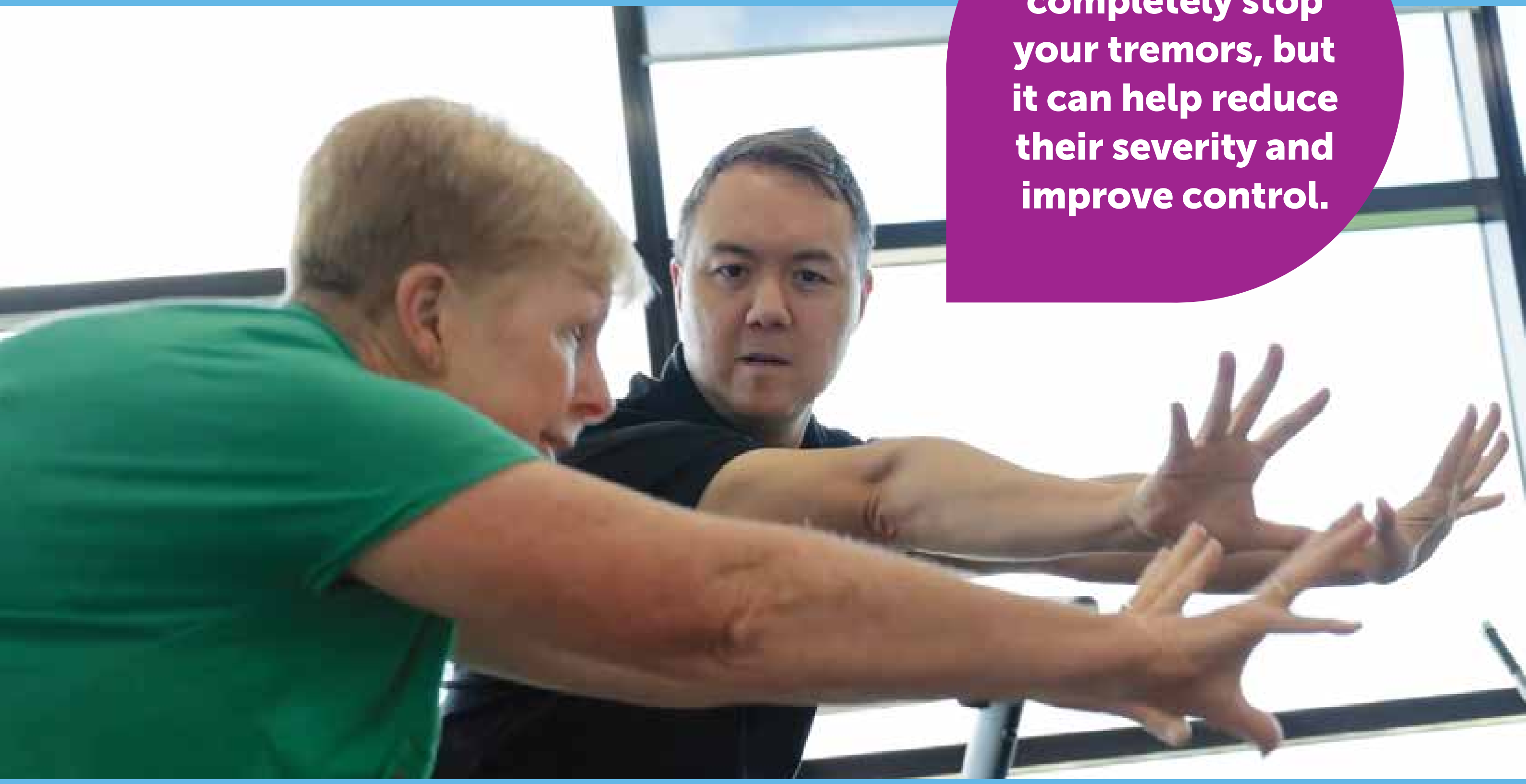
Tackling Tremors



Exercise won't completely stop your tremors, but it can help reduce their severity and improve control.

Tremors are a common symptom of Parkinson's disease. While medication helps, it doesn't always do the trick, so it's important to have other ways to assist symptoms like tremors.

Exercise won't completely stop your tremors, but it can help reduce their severity and improve control.

Picture yourself feeling more confident in social settings, eating out in public, or enjoying family events and sports games. These simple strategies can help reduce tremors, so you can relax and enjoy life more!

Hand Flicks – This one involves using a full range of motion with your hands, like you're tossing your tremors away with a lot of energy. Close your hands tightly, then throw them open as wide as you can. You can do this with just your hands or get your whole arms involved.

Punching – Squeeze your hands into fists, then throw a few punches with all your force, speed and power. Make fists, raise your arms, straighten your elbows, and punch forward. Do this with both arms.

Grounding – This is all about using pressure and deep breathing. This can be done sitting or standing. Push your open hands into your knees and push your legs into the ground as you take a deep breath. Keep the pressure on for a count of ten and repeat ten times.

Go Big – Take a break when you need it. If you're struggling with something like putting on earrings or eating, take a pause. Have a loud conversation, go for a walk using big strides, or throw a soft ball into the wall or floor half a dozen times. Then come back and tackle your task again.

Finger Tapping - Tap each finger to your thumb in order. Try to pick up speed gradually. Do this ten times on each hand.

Wrist Flexion and Extension – Rest your forearm on a table with your hand hanging off the edge. Slowly bend your wrist up and down. Do this 10 times per hand.

Deep Breathing Exercises – Inhale through your nose for a count of four, hold for six, then exhale slowly through your mouth for eight. Repeat this ten times.

Progressive Muscle Relaxation – Start with your toes and work your way up to your face. Tense each muscle group, hold for five seconds, then relax and breathe before moving to the next muscle area then repeat.

Give these exercises a go and see if any (or all!) of them can make a real difference to your tremors in how you move, feel, and go about your daily life.

Whether it's improving your mobility, boosting your safety, or just making you feel more confident in your routine, these simple strategies could have a big impact on your overall quality of life.

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My [Parkinson's] Family

By Madeleine Pizzuti

Our eyes met momentarily as we stretched our arms out wide clutching the coloured bands in front of us, whilst counting backwards from three. Again and again our eyes would meet as if it were meant to be part of the exercise.

Already I was out of breath, and this was only the first exercise of the designated hour-long program. It was my 'look forward to' exercise twice a week – an hour each time.

I had never liked exercise, yet here I was at the age of 70 enjoying every minute of it. I had no option really – this was essential if I were to maintain some normality in my life.

"Are you OK Maddy?" the instructor's voice brought me back to the present moment. The name 'Maddy' would have annoyed me years ago, but now, in my senior years I seemed to be more accepting of variations to my name.

"Yes, I'm OK thanks." I replied, bringing myself back to the task at hand.

"Good. We're now going to do our stretches."

The instructor's voice seemed to fade into the distance as I was brought back to those eyes again. It was hard to look elsewhere as we were sitting directly opposite each other with other participants around us forming a circle.

As our eyes met again, I wondered about this person. His past: his occupation when he was younger; his family; had he been married; did he have children?

He glanced at me again. What might he be thinking of me? Probably he's saying to himself, "she doesn't look like she's got it. I've watched her walk, and she seems quite balanced. She doesn't shake. She's not even as old as me."

Whatever he was thinking, or come to think of it, what I was thinking, the reality was that we both suffered the same demise.

I dropped down into my chair whilst letting out a deep sigh and waited for the instructor to direct us to our first exercise station. The staff and students at the Exercise Lifestyle Clinic had been fantastic.

This was the one place in my now 'changed' world where I felt accepted and cared for. My safe haven. A place where each participant bore an invisible label on their chest that read 'I have Parkinson's.'

I remember vividly the day I received my diagnosis. It was April 2021.

The first sign of the disease was a tremor in my left hand, and I was referred to a neurologist who sent me for the necessary tests. It was the day I was to receive the test results, and as I sat in the patient chair opposite the doctor waiting for some words of reassurance, my eyes scanned the wall behind him that displayed his framed qualifications and a large photo of a younger version of himself with what seemed to be his medical colleagues.

On his extremely neat desk sat a 3D dissected model of a brain. I watched the doctor as he stared at his computer screen, carefully guiding his hand over the computer mouse. Then he spoke these words .... "Well, it's all pointing to Parkinsons's Disease."

It took me a few seconds to process his words. I had expected a less significant diagnosis – one which could be fixed with medication of some sort.

However, all I could think of was... 'can I live with this?' I answered his statement with '...isn't that life-threatening?' He replied, 'well we all have to die someday.'

I froze at his apathetic response. I knew nothing about Parkinson's disease apart from the fact that Michael J Fox had it. I had never given any thought (before that day) to the disease. However, that was soon to change.

After being prescribed some medication for the tremor, I set to investigating as much as possible the effect of Parkinson's and how to live with it.

I discovered that Parkinson's is not just about tremors, and that there are numerous symptoms that may present themselves. Some of which are age-related issues and not brought on by Parkinson's Disease. One of the first things I did after receiving my diagnosis was to read Michael J Fox's book No Time Like the Future.

This was a stepping stone towards my own future and how it might change. The book gave me hope and the realization that I was not alone in this.

After much research I joined a support group and received counselling through Parkinson's NSW.

The mere ability to talk with someone who understood what I was experiencing was invaluable and so important for my mental health. I had learnt that exercise was one of the most important activities to undertake and was known to slow the progress of the disease. Hence my enrolment in this exercise program. Yes, I have had to make some changes in my daily life.

The crazy thing about Parkinson's disease is that a lot of the symptoms are not visible to the outsider. They are feelings from within – the effort it takes to merely put one foot in front of the other, and the simple things that we once took for granted but we're now not able to do, such as rolling over in bed or getting up from an armchair.

Thankfully though, with the aid of these exercise classes I know that I am doing something positive towards making my life as normal as it can be.

I grab my water bottle and wave to everyone, grateful for the support and encouragement that I've been given.

Until next time bless them all – my Parkinson's family.

You can still keep living your life – just differently”

Debbie & Bill’s Story

For more than 50 years, Debbie and Bill have shared a life filled with music, laughter, and love. They met as teenagers when Bill was playing at a rock’n’roll gig, fell in love, and built a life together – raising three daughters and navigating all of life’s ups and downs, side by side.

Then, just before turning 50, Bill was diagnosed with Parkinson’s disease. At first, the signs were subtle: a tiredness in his legs, a slight tremor, or an occasional moment of disorientation.

> ***“Back then we didn’t know much about Parkinson’s,” Debbie recalls. “You were referred to a specialist every six months, given some tablets and off you go.”***

In those early days, support felt limited and the medical world offered little guidance, with Debbie and Bill left to work it out themselves. Today, Parkinson’s NSW helps fill that gap.

As Bill’s condition progressed, Debbie became Bill’s fiercest advocate, learning everything she could, managing his care with intelligence and heart. When Bill’s health took a sharp turn last year, and doctors prepared Debbie for the worst, she simply refused to accept it.

> ***“He was in a coma for six days. They told me to prepare for the end. I just yelled at him; ‘Don’t you dare die.’”***

He didn’t. Thanks to Bill’s resilience, Debbie’s determination, and relentless care and rehabilitation, he beat the odds. “After five weeks, he walked again.”

Now 77, Bill is still exercising regularly, singing along to his music and playing chess with carers. He works on his stamp collection while Debbie keeps the household running. “He might not get the words out the same, but he knows everything,” she says. “He's still him. And I’m still me.”

Debbie credits Parkinson’s NSW with making a tangible difference – especially for their daughter Danielle, who was also diagnosed with young onset Parkinson’s in her 40s. “She’s thriving because of the information, support groups, and connections she’s found through Parkinson’s NSW. It’s given her confidence and hope.”

The family now attends Parkinson’s NSW support groups regularly, where they find advice, community, and shared experience. “It’s not just for the person with Parkinson’s,” says Debbie. “It’s for carers too. Not everyone knows how to problem-solve or what questions to ask. Parkinson’s NSW is there for them.”

Your support helps ensure no one faces Parkinson’s alone

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Thank you – your generosity helps fund counselling, the Parkinson’s NSW InfoLine health service and Support Groups across NSW.

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