Issue 4 Summer 2024

InMotion

A magazine for the Parkinson's community

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Fight Parkinson's™
Together we can

In this issue:

CEO update

As we look ahead to 2025, we are energised by the incredible leaders and advocates who inspire and support our mission.

Our Annual General Meeting honoured two exceptional individuals whose dedication embodies the spirit of our community. John Eren received the Sir Zelman Cowen Award and Betty Suggett was honoured with the Harold Waldron Carer's Award. Their contributions, alongside the tireless efforts of so many, remind us that our work is driven by the strength of the Parkinson's community.

The year ahead holds exciting opportunities to expand services, elevate your voice and deepen our commitment to research. Fight Parkinson's is preparing to launch a community seminar program in April 2025, delivering 16 face-to-face seminars across Victoria over the next two years. These seminars are designed to help you navigate the complex pathways of care and support while managing the challenges of Parkinson's. Recognising the importance of accessibility, we are also working to bring these seminars online, ensuring everyone can benefit from this program.

Details of confirmed seminar locations are available in the events calendar and additional events will be announced soon.

With the support of $268,000 in NDIA funding, we are developing a two-part program aimed at raising awareness of available services and building knowledge for individuals living with Parkinson's and their carers. This program will provide tools to better understand symptoms, rights and responsibilities while empowering participants to navigate feedback channels and improve their service experiences. Designed with community input, this initiative will cater to those both within and outside the NDIS. It will address the unique challenges of managing Parkinson's symptoms while navigating complex health, disability and community support systems.

Mark your calendars for April 27, 2025, as we gear up for our much-anticipated A Walk in the Park. It's a wonderful opportunity for our community to come together, raise awareness and celebrate our collective strength. I am already forming my family team, and I encourage you to do the same and help make this event a highlight of the year.

In other exciting developments, Fight Parkinson's is launching a redesigned website this year, informed by consultations with 40 diverse community members. With improved navigation and optimised content, the new website will make accessing information easier and more intuitive than ever.

Our commitment to research continues to grow, with plans to invest $120,000 in 2025—which is set to double the following year. We are thrilled to announce applications are now open for our 2025 Seed Funding Grants, with $30,000 allocated to both clinical and basic science research projects. These grants will support innovative approaches to Parkinson's prevention, care and finding a cure.

To further our mission, we're bringing back Fight Parkinson's Research Symposium on April 4, 2025. This free event will feature national and international experts sharing the latest breakthroughs in Parkinson's research, followed by a Young@Park dinner to connect and inspire our community.

Perhaps the most transformative development this year is the launch of the National Parkinson's Action Plan, made possible by $0.8 million in federal funding. For too long, Parkinson's has been under-served compared to other chronic conditions. This groundbreaking initiative focuses on early detection, prevention and improved management, signalling a new era for the Parkinson's community. Fight Parkinson's is proud to have played a pivotal role in this historic achievement and we invite you to join us in bringing this plan to life.

In these pages, you'll find valuable information and stories from our vibrant community - each a testament to the unique experience of living with Parkinson's, Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) or Corticobasal Syndrome (CBS).

Fight Parkinson's CEO Emma Collin

We are privileged to share the stories of Mark McAuley, Peter Brown, Vanessa Lynne and Cheryl Barnes, whose personal journeys have inspired them to become community advocates. To everyone who has shared their time, insights and expertise throughout this edition, we extend our deepest gratitude.

This is a year of opportunity and action. Together, we can reshape the future of Parkinson's care, advocacy and research. Thank you for your unwavering support and commitment to building a stronger, more equitable community for all. Let's make 2025 a year to remember.

Emma Collin
CEO
Fight Parkinson's

News & highlights

Peninsula Community Seminar

The Fight Parkinson's Health Team is proud to continue delivering community seminars across Victoria, providing essential resources and support for individuals impacted by Parkinson's.

These seminars not only raise awareness about Parkinson's, but also offer a valuable opportunity for individuals to learn more about the condition, share experiences and connect with others in their local area.

The team recently hosted a successful Community Seminar on the Peninsula. The event featured expert Dr Arthur Thevathasan, who shared invaluable insights on current symptom management techniques and explored advanced treatment options, such as Deep Brain Stimulation (DBS).

Additionally, community member Ken Wall bravely shared his personal journey of living with Parkinson's, highlighting the positive impact of Fight Parkinson's Peer Support Groups. These groups offer a unique platform for connection and support, creating a sense of community for those navigating the challenges of Parkinson's.

As always, members of the Fight Parkinson's Health Team were available throughout the seminar to address frequently asked questions and dispel common myths about Parkinson's, ensuring attendees left with a better understanding of the condition and available resources.

New online course for PSP care

We have launched our latest initiative to support the Atypical Parkinson's community – an online PSP course for health care professionals.

Fight Parkinson's "Introduction to Progressive Supranuclear Palsy" course, available on our Health Professionals Learning Hub, equips health care teams with practical strategies to enhance care for people living with PSP.

Made possible through the generous contributions of John and Peta Seymour, the course helps health care professionals understand PSP and improve quality of life for people living with the condition. The course covers everything from early management strategies to palliative care, ensuring health care professionals can better support individuals throughout their PSP journey.

With plans to develop courses for other Atypical Parkinson's conditions, such as MSA and CBS, we continue our commitment to improving care and support for everyone in the community.

Sheenagh Bottrell named World Parkinson Congress Ambassador

We are thrilled to celebrate the selection of Board Member Sheenagh Bottrell as an Ambassador for the World Parkinson Congress (WPC) 2026 in Phoenix, Arizona.

Sheenagh, who is also a member of our Consumer Engagement and Advisory Committee, will proudly represent Australia as the country's sole Parkinson's Ambassador for this triennial event. "It's a privilege to represent people living with Parkinson's, especially as a woman living with Young Onset Parkinson's," she said.

The WPC provides a global platform for scientists, researchers, health professionals, carers and people living with Parkinson's to come together and exchange knowledge and inspiration.

WPC Ambassadors are chosen for their lived experience and deep understanding of Parkinson's. In her role, Sheenagh will help promote the Congress, give talks and share insights into living with a condition that is both challenging and often misunderstood.

Sheenagh, who attended and presented a poster at the WPC 2023 in Barcelona, looks forward to representing the community, further educating herself and bringing back valuable information for others.

Parkinson's Victoria re-branded to Fight Parkinson's in December 2021

Managing symptoms

Mood and mental health

As we begin 2025, many of us are thinking about building positive habits for the year ahead. For people living with Parkinson's, managing your emotional wellbeing is especially important.

Mood changes, such as depression and anxiety, are common Parkinson's symptoms. These can result from changes in Dopamine and other substances or neurotransmitters in the brain. The emotional impact of living with Parkinson's – whether you're adapting to a new diagnosis or managing changing symptoms – can also affect how you feel.

Understanding emotional responses

Living with Parkinson's brings a range of emotions that may shift over time. If you are recently diagnosed, you might still be coming to terms with the initial shock. If you've been living with Parkinson's for a while, you may be adjusting to changes in your symptoms or lifestyle. It's common to feel a mix of grief, anger, frustration or uncertainty. You might find yourself asking, "Why me?" or feeling anxious about the future. These emotions can fluctuate and often don't follow a predictable pattern.

Recognising and understanding your emotional responses is a crucial step toward living well with Parkinson's.

Mood and motivation

While many people are familiar with the physical symptoms of Parkinson's, changes in mood, anxiety levels and motivation can be less visible but equally important. These symptoms, which sometimes appear even before physical changes, can significantly impact daily life.

Being open with your health team about these experiences is crucial – they're a normal part of Parkinson's and can often be helped with medication adjustments, counselling or other treatments.

Depression and anxiety

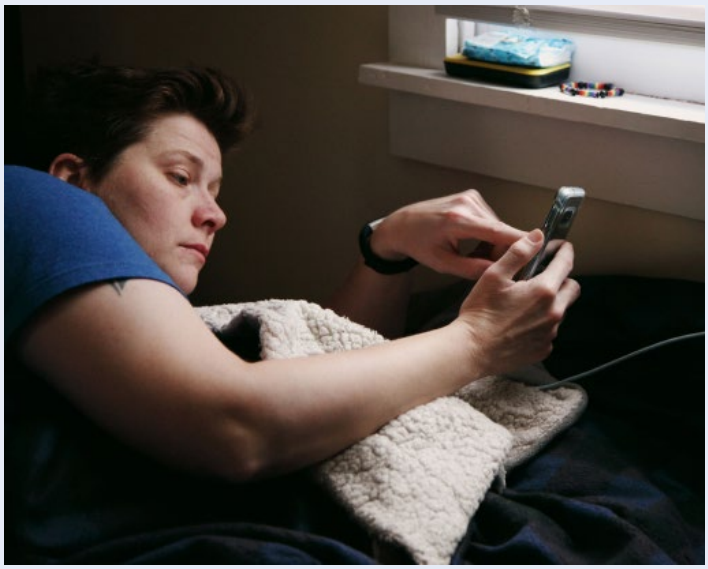
Research shows that up to 50% of people with Parkinson's experience depression and about 40% experience anxiety. While feeling low occasionally is normal, clinical depression is more persistent and affects daily life.

If you notice ongoing feelings of sadness, moodiness, irritability, or a lack of interest in activities that once brought you joy, this may indicate clinical depression. Anxiety might show up as uncontrollable worry, phobias, panic attacks or physical symptoms like a racing heart or hot flashes.

Both depression and anxiety can fluctuate with your medication cycle, often dipping when medication is wearing off. It's important to remember that treatments are available and it's important to seek help if these symptoms persist.

Apathy

Apathy, or a lack of motivation, enthusiasm and emotion, is another common symptom of Parkinson's. Unlike depression, apathy is not linked to sadness but stems from changes in brain chemistry. This symptom can be particularly frustrating for you and for your carers and family members supporting you. As we move into the new year, setting achievable goals, scheduling enjoyable activities and incorporating regular exercise can help combat apathy.



Managing your mood and mental wellbeing

Medical support

If you're experiencing depression, anxiety or apathy, start by discussing this with your treating doctor. They can assess your mood, adjust your medications and refer you to a counsellor, psychologist or psychiatrist who understands Parkinson's.

Antidepressants may be helpful but should be discussed with your treating doctor to understand potential side effects. Parkinson's medications can also improve mood symptoms, and timing your doses effectively may help stabilise mood fluctuations.

Psychological support

Counselling or psychological therapies can provide valuable tools for managing emotions and building resilience. You may be able to access subsidised sessions through a Mental Health Treatment Plan via Medicare or through private health insurance.

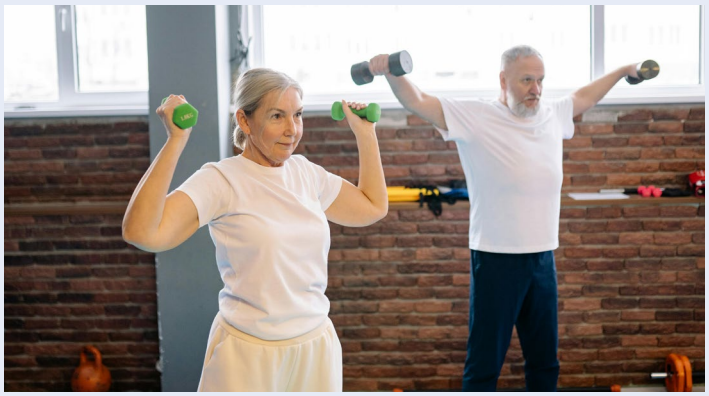
Lifestyle strategies

These practical approaches can support your mental wellbeing throughout the year:

- **Stay connected:** Maintain social ties and engage in activities that bring you joy.
- **Exercise regularly:** Aim for a mix of aerobic, strength and balance exercises three to four times a week for 45 minutes. A physiotherapist or an exercise physiologist can help you build an exercise routine.
- **Eat well:** While there's no specific Parkinson's diet, a balanced diet supports gut health and overall energy levels, positively affecting mood. Eating well can also assist in managing symptoms such as constipation which can affect medication absorption and mood.
- **Understand and listen:** Depression is a common symptom of Parkinson's; it is not a sign of weakness. Those around you may notice mood changes and there is value in listening to them.
- **Practice mindfulness:** Meditation, progressive muscle relaxation or guided breathing can help calm the mind and reduce stress.

Self-care tips

- **Pace yourself:** Avoid overloading your schedule. Allow for breaks and balance activities with rest.
- **Stay positive:** Focus on what brings you joy.
- **Plan:** Schedule outings and activities for when you feel your best and when your medications are most effective.
- **Learn about Parkinson's:** Understanding your condition and treatments can empower you and help you manage symptoms.



Peer support and connection

Connecting with others who understand your experience can provide comfort and practical advice. Fight Parkinson's Peer Support Groups welcome people with Parkinson's, their families and carers. Groups are available for specific interests or needs, such as Young Onset or Atypical Parkinson's. Other non-Parkinson's-specific groups, like craft or book clubs, also offer opportunities for connection.

When joining a Parkinson's support group, remember that everyone's Parkinson's journey is unique. Symptoms and progression vary widely, so avoid direct comparisons.

Managing fatigue

Fatigue can be a major challenge, particularly over the summer months. Speak with your health team to explore medication adjustments or other solutions. Incorporating regular exercise, maintaining a consistent sleep schedule and pacing your activities with breaks can help conserve energy and reduce fatigue.

Remember, supporting your mental health is just as important as managing physical symptoms. Take advantage of the fresh start this year brings to focus on what matters to you. Whether you're starting a gentle exercise routine, joining a Peer Support Group or checking in with your health team, each step forward contributes to your overall wellbeing. Know that support is always available and with the right tools and resources, you can continue to lead a fulfilling life.

Ask the Expert

Navigating insurances and superannuation

A diagnosis of Parkinson's can be life-changing, especially if you are still in the workforce or nearing retirement. Handling a diagnosis while you are still working often involves balancing work, life and medical expenses.

In an Ask the Expert Session, Hayriye Uluca, Head of Superannuation & Insurance Litigation in Victoria at Maurice Blackburn Lawyers, explored the entitlements, insurances and benefits that may be available in your superannuation policy.

Understanding your insurance benefits and maximising them ensures that you can access necessary financial support if you are unable to work. Moreover, knowing how to access these resources can alleviate the stress of managing financial uncertainties, allowing you to focus more on your health and well-being.

Understanding insurance through superannuation

When you're employed, your employer contributes to your superannuation account, making you a member of a superannuation fund. Most of these funds include automatic default insurance cover, which acts as a financial safety net if you're unable to work due to injury or illness. Typical insurance policies include Income Protection and lump sum benefits for Total and Permanent Disability (TPD), Terminal Illness and Death.

Types of insurance explained

Income protection: This insurance provides a periodic payment (usually fortnightly or monthly) that replaces around 75% of your pre-disability income. Most policies cover up to two years, though some extend to age 65. The payments are generally offset by other income sources, such as Social Security or workers' compensation.

Total and permanent disability (TPD): TPD insurance offers a lump sum payment if you cannot return to your previous role or any other work for which you're qualified. The benefit amount varies widely, with some policies offering up to $500,000 or more.

Terminal illness: This insurance provides a lump sum if two doctors certify that you have less than 24 months to live. Claims are usually processed quickly, often within three months.

Death benefits: Death benefits are also paid as a lump sum and are listed on your annual superannuation statement. These benefits are typically straightforward, with disputes usually arising over the designated beneficiaries rather than the payment itself.

Tips for managing your superannuation and insurance

Review your superannuation statement

Check your most recent superannuation statement to see the details of your insurance cover, including TPD and Death Benefits. Understanding the insurance policy definitions that might apply to you is crucial for assessing your eligibility and the quality of your insurance cover.

Get financial advice before making changes

If you're considering rolling over your superannuation into another fund or consolidating multiple accounts, seek financial advice first from a qualified advisor. Changes to your superannuation could affect your insurance cover, so it's essential to understand the implications fully.

Questions from our community

Can I make a claim after leaving work?

Yes, you can still make a claim after leaving work if you had the necessary cover on the date you last worked.

Can I be refused other insurances due to Parkinson's?

While some insurers may increase premiums or refuse coverage, they must comply with anti-discrimination laws. If you're denied, request an internal review and consider seeking legal advice about whether the insurer's decision is valid.

Is it too late to increase my insurance after a diagnosis?

You can apply for an increase, but it will likely involve an underwriting process. Your doctor can provide medical evidence to support your application.

How can I find a reputable financial advisor?

Seek an independent financial advisor who offers fee-for-service arrangements. Avoid commission-based advisors to ensure unbiased advice.

Is income protection available after using up leave?

Income protection policies generally have a waiting period (usually three months). During this time, you may need to use accrued leave.

Navigating insurance claims can be complex and stressful, especially following a Parkinson's diagnosis. However, understanding your entitlements and seeking advice from a qualified advisor before you stop work can provide much-needed financial security. This knowledge empowers you to make informed decisions, protect your financial interests and plan effectively for the future, despite the challenges posed by Parkinson's.

If you would like to attend a future Ask the Expert webinar or any other upcoming free education events, visit fightparkinsons.org.au/support-for-you/events to register online.

Atypical Parkinson's

Corticobasal Syndrome

Corticobasal Syndrome (CBS) is one of the rarest forms of Atypical Parkinson's, affecting only around 300 people in Australia. Despite its rarity, there is hope - with specialised care and support, people living with CBS and their loved ones can maintain the best possible quality of life.

What is CBS?

CBS is a rare progressive neurological disorder resulting from degeneration in a specific part of the brain. It involves the gradual loss and shrinkage (atrophy) of nerve cells in the outer layer of the brain (the cortex) and the deep basal ganglia. This cell loss dramatically impacts two core domains that make us human - movement and thinking.

What causes CBS?

The damage and shrinkage to the brain are thought to be caused by an over-production of a protein called tau. While tau occurs naturally in the brain, people with CBS have excess levels that form into clumps, which are believed to kill nearby brain cells. The cause of tau overproduction remains unknown, though research into factors such as infections and exposure to toxins is ongoing.

Currently, there are no blood tests or brain scans that can definitively diagnose CBS, although these tests and scans are often used to rule out other conditions with similar symptoms. Like Parkinson's, CBS can only be confirmed at post-mortem.

There is no evidence to suggest that CBS runs in families. However, recent research indicates that genetic factors can make a person more likely to develop CBS, which may relate to an environmental trigger. In other words, there may be some genetic susceptibility interplaying with an environmental agent that puts some people at risk, but specific genes and environmental triggers remain unknown.

CBS vs Parkinson's

Corticobasal Syndrome (CBS) shares several symptoms with Parkinson's, including muscle stiffness and poor coordination. However, they are fundamentally different conditions that affect the brain in distinct ways.

Due to the similarity in early symptoms and the rarity of the condition, people with CBS are sometimes misdiagnosed with Parkinson's or stroke. If there is a limited response to Parkinson's medications, seeking the opinion of a neurologist who is familiar with movement disorders is essential.

CBS Symptoms

The primary symptoms of CBS typically begin on one side of the body and remain more severe on that side as the condition progresses. Early signs often include the gradual loss of use in one hand or leg. Some people experience what's known as an "alien limb" phenomenon, where they feel they have no control over an affected limb, which may move in an unpredictable way.

Motor symptoms may include:

- Muscle stiffness and rigidity.
- Slow, awkward movements.
- Tremors and involuntary shaking.
- Poor coordination and clumsiness.
- Jerky movements.
- Balance difficulties.
- Numbness or loss of sensation in parts of the body.
- Dystonia (abnormal muscle postures).

As CBS progresses, both sides of the body may become affected, and walking becomes increasingly difficult. People may also develop problems with visual-spatial awareness, making simple tasks like picking up objects challenging. Speech can become slow and slurred as throat and mouth muscle control diminish. Eye movement control may also deteriorate, and repetitive blinking (or Blepharospasm) may occur, which increases the risk of falls. CBS often affects cognitive function as well.

Cognitive symptoms may include:

- Difficulty finding words.
- Memory problems.
- Challenges with planning and organisation.
- Speech disturbances.
- Personality changes, including depression, anxiety and irritability.
- Loss of inhibition.
- Emotional lability, including excessive crying.
- Obsessive-Compulsive Disorder (OCD) symptoms, such as repetitive behaviours or fixations with cleanliness or with checking activities.

CBS can affect anyone regardless of their background or lifestyle. While symptoms typically begin around age 60, younger people can also develop the condition, though it is rare. People with CBS typically live for around eight years after the onset of symptoms. As the condition progresses, it can lead to serious complications like pneumonia, bacterial infections and blood clots in the lungs (pulmonary embolism).

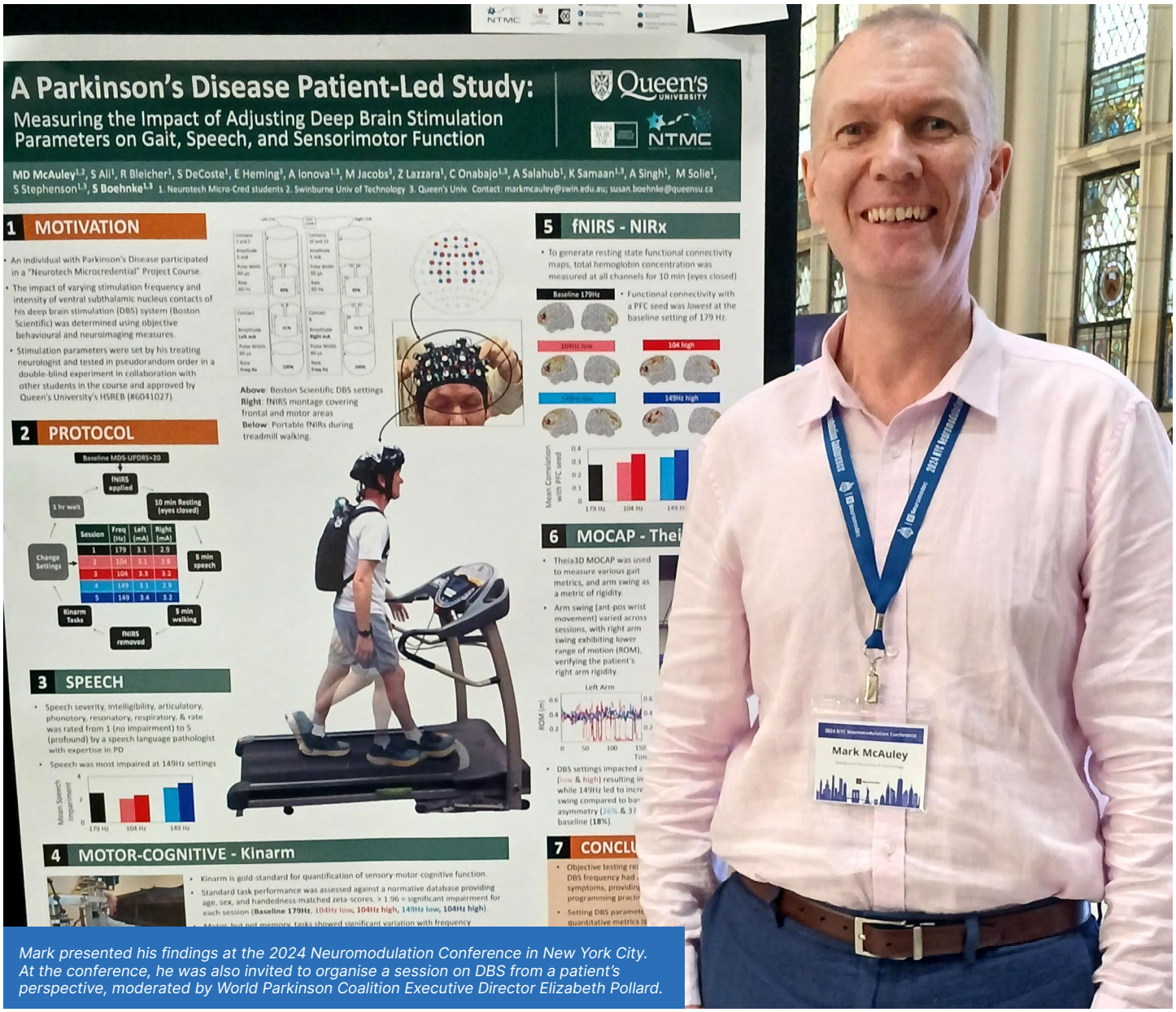
CBS Support

Being diagnosed with CBS can deeply affect a person's life. As symptoms worsen over time, they can impact both confidence and independence. Though there's no cure yet and we can't prevent or slow its progression, various treatments and therapies can help manage symptoms and quality of life.

It's important that people with CBS see a neurologist regularly for ongoing treatment and advice, preferably one with expertise in movement disorders, as they are more likely to be up to date with the latest advances in treatment and management. Fight Parkinson's can provide information about finding neurologists and other health professionals with an understanding of CBS.

Depending on symptoms, it's also important to seek the advice of a multidisciplinary team with expertise in the condition, including a physiotherapist, occupational therapist, speech pathologist and counsellor.

Fight Parkinson's hosts a bi-monthly online Peer Support Group for people with CBS and Atypical Parkinson's. If you are interested in attending an online meeting or would like to know more, please call us on 03 8809 0400 or email us at info@fightparkinsons.org.au



Mark presented his findings at the 2024 Neuromodulation Conference in New York City. At the conference, he was also invited to organise a session on DBS from a patient's perspective, moderated by World Parkinson Coalition Executive Director Elizabeth Pollard.

A patient-led study on Deep Brain Stimulation

Mark McAuley, Astrophysicist and Fight Parkinson's Research Committee member, has turned his personal experiences with Deep Brain Stimulation (DBS) into a catalyst for research.

Becoming a Parkinson's researcher wasn't a career path Mark had initially planned. Diagnosed with Parkinson's in 2010 at age 40, Mark's path would lead him to research DBS - driven by a desire to understand his device and how it can be optimised for better symptom management.

The man behind the research

After nine years of living with Parkinson's, Mark's symptoms progressed significantly and he found himself struggling. His "on" and "off" times were becoming less predictable and he needed to take medication every two hours.

"Do not eat an hour before or an hour after taking medication you take every two hours. If you do the math, then when do you eat? I could no longer have dinner at restaurants. You'd have to eat at exactly five o'clock because you've taken your last tablet at four and will take the next one at six."

The unpredictability of his symptoms also became a safety concern. "Just going to the shops, there was one time I froze and couldn't cross the road. I phoned my wife and had to stand by the side of the road for 20 minutes until she came and picked me up."

Mark underwent DBS surgery in 2020 and while his quality of life has significantly improved, the journey was not without its challenges. It took eight months of trial and error with neurologists to find DBS settings to effectively manage his symptoms, an experience he described as a nightmare.

For many people who undergo DBS surgery, it can take several months to achieve their optimal level of stimulation. This is due to the high degree of symptom variability across people with Parkinson's, the thousands of possible DBS settings and the fact that changes to DBS settings may take many hours to impact symptoms.

Mark notes there is a significant gap in communication between specialists and patients who are considering or have undergone DBS. Driven by a desire to better understand his own experience, Mark began searching for information on DBS programming.

"I was trying to find something I could read that would teach me how DBS devices work. You would find 20-page information sheets with two sentences about programming DBS settings

and 19 and a half pages about the actual surgery. Surgery is important, but then living with the device for the next 30 years is equally important."

The study

His research journey led him to a series of online courses through Queen's University in Canada. His growing interest led him to pursue a face-to-face capstone project. His project proposal, "Deep Brain Stimulation (DBS): A patient-led study measuring the impact on symptoms of adjusting DBS frequency", aimed to tackle a fundamental challenge in Parkinson's treatment: how to optimise DBS settings for better patient outcomes.

Eleven students from a range of disciplines joined his project, working alongside teaching assistants and under the guidance of Professor Susan Boehnke.

As both lead researcher and patient in the study, Mark provided valuable insights that helped connect clinical research with patient experience. The research focused on gait and speech, symptoms which are particularly challenging to treat with DBS and have significantly impacted Mark's life.

In his experience, DBS configurations that support gait can have a negative impact on speech. "So sometimes it's a bit of a trade-off, but I am greedy, I want to be able to walk and talk instead of just having to choose one or the other," Mark explains. "You have to concentrate on walking to try and compensate for the fact that things are not working naturally. It's a cognitive load – you have to focus and can't think about other things. That load, that costly focus on things, is not easy."

While DBS programming often focuses on electrode placement and current strength, this study examined how adjusting frequency - the number of electrical pulses delivered per second - affects gait and speech.

The team used functional near-infrared spectroscopy (fNIRS), which measures blood flow in the outer layers of the brain using infrared light to infer brain activity. This technology allowed them to measure functional connectivity between the prefrontal cortex (associated with concentration) and the motor cortex (associated with movement).

The results indicated that minimal functional connectivity between these two regions occurred when DBS settings were optimal. This resulted in Mark being able to walk more naturally without conscious effort.

The potential impact

By monitoring brain connectivity patterns, doctors might have an objective way to optimise DBS settings rather than relying solely on patient feedback and clinical observation. This could lead to more personalised and effective treatment approaches for DBS patients.

Before drawing that conclusion, further research is needed. The initial study had Mark as the sole participant and involved data collected over an eight-hour period in May 2024. Mark travelled to Canada again in October 2024, when multiple measurements were taken daily over a five-day period. The team are now analysing that data to better characterise the fNIRS results. The next step would involve the assessment of a small number of other people with Parkinson's and DBS.

Having navigated the challenges of DBS adjustment firsthand, Mark brings a unique perspective that bridges scientific understanding with lived experience. If you would like to learn more about Mark and his insights on patient-led research, you can listen to his interview with Professor Andres Horn from Harvard University for the Stimulating Brains podcast series. Available online at stimulatingbrains.org.

If you would like more information about DBS or wish to join our online DBS Peer Support Group for individuals considering or who have undergone DBS, please contact Fight Parkinson's at 03 8809 0400.

Mark and the team used a markerless motion capture system to measure how different DBS frequency settings affect gait and arm swing patterns.

Save the date

A Walk in the Park

A Walk in the Park, Australia's largest community event dedicated to supporting people with Parkinson's, returns.

Our flagship walk in Melbourne will be held on Sunday, 27 April 2025 and numerous regional walks across Victoria will be held throughout the year.

Thousands of people will be brought together, including people living with Parkinson's, their families, friends and carers, and professionals working in the field. A Walk in the Park is a moment for our community to showcase our strength in numbers, raise awareness and fuel hope for people living with Parkinson's.

Now is the time to start thinking about how you would like to get involved - just like Peter Brown, one of our A Walk in the Park ambassadors.

Peter Brown attended his first A Walk in the Park in 2024 and will be one of our A Walk in the Park ambassadors in 2025.

"I was diagnosed with Young Onset Parkinson's at the beginning of 2024. My head was still spinning from the diagnosis and my neurologist suggested I visit the Fight Parkinson's website for information and support. I came across A Walk in the Park and right there and then, I decided to focus my energy on raising money and awareness through this event.

The actual event was a game-changer for me as I met so many new people who were willing to share their stories and Parkinson's journey. It was a joyous day and I had a great time with the support of a few friends and my fantastic wife.

Raising money for this wonderful charity really became clear to me as the year wore on as I have used their website tools, joined the Young Onset Parkinson's Peer Support Group and reached out several times to the Fight Parkinson's Team for advice.

I am proud to be an ambassador in 2025 and look forward to seeing even more people there, raising awareness of Parkinson's and fundraising for Fight Parkinson's so they can continue their valuable work."

What you can do now:

- Save the date: Mark Sunday, 27 April 2025 in your calendar.
- Share the date with friends and family and start building your A Walk in the Park team.
- Visit our website, www.awalkinthepark.org.au for updates.

If you are passionate about bringing A Walk in the Park to your local area, we'd love to hear from you - email fundraising@fightparkinsons.org.au to find out more about organising a regional walk.

Stay tuned for further event details in the autumn edition of InMotion.

Melbourne's A Walk in the Park in 2024.

Personal story

Grandma, Parkie and Me

Vanessa Lynne, author of "Grandma, Parkie and Me".

Vanessa was determined not to let her Parkinson's diagnosis define her or how her family viewed her. This motivated her to create a book that would help her grandchildren understand her relationship with Parkinson's.

For years, Vanessa had been experiencing subtle signs of Parkinson's. But it wasn't until 2018, while rehabilitating from spine surgery, that additional symptoms emerged, leading to her diagnosis. Parkinson's was a condition she was painfully familiar with, having seen both her father and brother struggle with Parkinson's in their final years. Genetic testing has later confirmed a familial connection to Parkinson's.

Unlike her father's and brother's experiences with Parkinson's, Vanessa's quality of life has remained relatively high, which she credits to having a good health team and high fitness levels. Regular exercise has helped her manage some symptoms, though she acknowledges the unpredictability of living with Parkinson's:

"When I'm 'off', walking becomes very difficult - I stutter and freeze. But when I'm 'on', I can hop on a treadmill and walk six kilometres an hour. It's like I'm two different people." Despite these changes, Vanessa has learned how to coexist with her Parkinson's.

Family plays a central role in her wellbeing. In 2004, she met her husband Roger and their blended family has become a cornerstone of her support system. Together, they share ten grandchildren.

Vanessa describes her family dynamic as supportive and respectful; nobody belittles her or rushes in to do things they know she can do herself.

"Without my grandchildren and the rest of my loving family, Parkinson's would be giving me a much harder time. But with their collective love and understanding, I am living my best life."

Vanessa's experiences led to "Grandma, Parkie and Me," a children's book she wrote and illustrated. In the book's acknowledgements, she explains:

"Parkinson's is a complex, annoying, and often humiliating disease. At times it can feel as if you are possessed by an uncooperative and vindictive being manipulating your brain to make your body do things over which you have no control. Parkinson's is hard enough to understand oneself, but even harder to explain to others, especially children. This book grew out of my desire to explain to my grandchildren, in simple terms, why I can sometimes function normally and, at other times, be completely at the mercy of Parkinson's."

The book cleverly personifies Parkinson's as "Parkie," an olive-green, cranky cloud that follows "Grandma" everywhere. The child narrator, a blend of her ten grandchildren, shares their understanding of Grandma's condition, demonstrating their compassion as they navigate the challenges together.

"I think it's important to have a reference point for people with small children. For my grandchildren, it means that they have more empathy towards me. They understand that when I'm 'off', there are things I can't do."

The creative process has proved therapeutic for Vanessa and she says her family's response has been heartwarming. "It was a huge amount of fun and my grandchildren loved it. They even quote it back to me," she says.

Beyond her book, Vanessa's advocacy efforts are well-known in her local area. She has built a tight-knit community of neighbours who understand her condition and offer their support when needed. Her tricycle, featuring the message "Parkinson's is very annoying," has become a conversation starter, creating opportunities to educate others about the condition.

Vanessa's perspective on Parkinson's is both realistic and optimistic. While she acknowledges its degenerative nature, she refuses to let it define her. "Just because you've got Parkinson's doesn't mean your life is over. There's still plenty of life to be had. We can't change it, but what we can do is live the best life we can in spite of it." For Vanessa, this means staying active, maintaining a sense of humour and continuing to love and be loved by her large, blended family.

Through her book, her resilience and her advocacy, Vanessa has turned her challenges into an opportunity to educate and inspire. By giving "Parkie" a face and a personality, she is helping others to see beyond the condition and recognise the vibrant person living with it.

If you would like to read, "Grandma, Parkie and Me", please email the Fight Parkinson's Team at marketing@fightparkinsons.org.au

Excerpts from "Grandma, Parkie and Me"

Personal story

Strength in community support

Cheryl Barnes, Fight Parkinson's-Mildura Peer Support Group Leader, has courageously shared her Parkinson's story as part of our recent appeal.

For Cheryl, life before Parkinson's was filled with energy and purpose. As a school librarian in Ballarat, she found joy in inspiring young minds and helping children discover the magic in books. "I'd always been active too, filling my spare time with tennis, squash and other sports that kept me feeling strong," she recalls.

At 50, Cheryl and her husband took early retirement and moved to Queensland, hoping for a relaxing new chapter. However, the distance from their daughters left them feeling isolated, leading to their return to Victoria after six years. It was during this transition that Cheryl's health began to decline in ways she couldn't explain.

"At 54, I began noticing odd things about my body. My left arm didn't swing when I walked and my hand wouldn't cooperate when I tried to wash my hair." Initially brushing it off as a quirky habit or perhaps menopause, she watched as her strength gradually faded, leaving her feeling increasingly unsettled.

After two frustrating years and multiple doctor visits, Cheryl finally received a referral to a neurologist. When she walked into her appointment, the diagnosis was almost immediate: Parkinson's disease. "Those words brought both relief and fear," she remembers.

"I finally had a name for what was happening, but it was a condition I knew very little about."

The long drive home to Mildura with her husband, John, felt surreal. They were in shock, trying to take in the reality of the diagnosis.

For the past 20 years, Parkinson's has gradually reshaped Cheryl's daily life. Simple things that once came easily now require careful planning or even assistance. "Everyday tasks like opening jars, putting on jewellery or carrying groceries have become challenging and I often find myself depending on the kindness of friends, neighbours, and my daughters." Fatigue remains one of her toughest challenges—hitting hard and sometimes feeling overwhelming, requiring her to pause and rest.

However, Cheryl found her lifeline in community support. Early on, she connected with Fight Parkinson's (then Parkinson's Victoria) and co-founded the Mildura Peer Support Group. "The one thing that's kept me going is the support I've received from being part of the Mildura Peer Support Group," she says. Through coffee mornings, group lunches and shared experiences, members give each other strength and understanding.

Now at 75, Cheryl's focus extends beyond her own journey to building better support for others affected by Parkinson's. Each year, she helps organise Mildura's A Walk in the Park. "It's incredibly heartening to see friends and neighbours walk alongside me in support," she shares. Her hope is that with increased awareness and support, services for regional communities can expand, leading to an improved understanding of Parkinson's and, eventually, a cure.

In regional areas like Mildura, where Parkinson's resources are limited, Fight Parkinson's has played a crucial role in her journey. "Knowing that we can always pick up the phone and talk to someone who understands Parkinson's has made all the difference," Cheryl emphasises. The ongoing support has given her and others the confidence and hope to manage the daily realities of living with Parkinson's while looking toward the future.

Cheryl at her regional A Walk in the Park, the Mildura Slow Walk for Parkinson's.

Peer Support

From right to left: Janice, Val and Debbie representing ParkinSong Boronia at a A Walk in the Park.

Improving lives through song and social connection

ParkinSong™ is an evidence-based Peer Support program supported by Fight Parkinson's. One shining example of this program's success is ParkinSong Boronia, founded by Val Staddon and led by Janice Hickingbotham.

Val Staddon, has been living with Parkinson's for over 22 years. In 2016, she reached out to Fight Parkinson's (then known as Parkinson's Victoria) to establish a peer support group.

She was introduced to the ParkinSong™ program, which immediately resonated with her due to her experience with her local singing group, The Unforgettables.

With the support of Fight Parkinson's and friend Rosa, ParkinSong Boronia was formed to become a much-needed support hub in Melbourne's outer East.

Soon after the group was established, Val and Rosa brought in Janice Hickingbotham, who led The Unforgettables, to take on the role of leading ParkinSong Boronia.

For Janice, leading the group has been both an honour and an opportunity to understand the daily challenges faced by people with Parkinson's. "It's been a big learning curve for me, which I've really enjoyed," she reflects.

The group meets at Boronia Uniting Church, where Janice has hired two adjoining halls to provide space for wheelchair access. The church grounds are flat and there are no steps to worry about, ensuring an accessible environment for everyone.

As the group's leader, Janice is proactive in increasing understanding of Parkinson's among group members and frequently draws on resources from Fight Parkinson's. "There was some wonderful literature on the Online Learning Hub. I gave a presentation and read through it all. It was good for everyone, especially the carers, to know the bladder problems, the sleeping problems and even the sexual problems that arise in Parkinson's. A lot of them hadn't realised that it was a normal thing and how to cope with it, so I was pleased to be able to share that with them."

Fight Parkinson's quarterly Community of Practice meetings have also been valuable for Janice. These meetings offer her the opportunity to connect with other group leaders and health care professionals to share strategies and approaches to supporting the Parkinson's community.

At ParkinSong Boronia, group meetings are thoughtfully structured. The first half functions as a traditional peer support group, where members have morning tea, share insights and learn more about living well with Parkinson's. The second half focuses on vocal exercises, communication activities and singing together.

The group enjoys singing everything from 60s hits and rock 'n' roll classics to their favourite ABBA songs. However, as Janice points out, it's really about helping people strengthen their voices, boost their confidence and build connections with others who understand what they're going through.

The group's impact on its 15-20 regular members speaks for itself. One moment stands out in Janice's memory:

"One of our members came in and said that all the activities we did in our group had been a benefit once they got home. They were able to go home and talk louder to their partners. I thought, 'Wow, this is what it's all about.'"

ParkinSong Boronia is a true community effort. When Janice is unable to run the meetings, Val's daughter, Debbie, steps in to help. Even when formal sessions can't take place, members of the group often gather for coffee and a chat, ensuring that their social connections remain strong.

Looking to the future, Janice hopes to welcome more members to the group. She knows some people might hesitate to come along because they think of the group as a choir, but that is not the case. As she put it, "It's a group where we are training our voices and strengthening our lungs; that is the main goal. We strengthen those areas of the body and we do it through singing and doing exercises with our voices."

She acknowledges that newcomers might find it challenging to see others at various stages of their Parkinson's journey. "It's very confronting and that's why some people don't come back. For people coming to a meeting for the first time, I would carefully warn them not to be too concerned about what they see there because those people have had Parkinson's for a long time, and it affects everybody differently. But the support is there whenever they need it."

For Janice, leading ParkinSong Boronia is deeply rewarding. "It's a win-win situation. I'm winning because I can see the benefit, and they're benefiting by getting out of the house and being able to get together and communicate and find out things that people have tried and used in their Parkinson's journey – that's what it's all about."

If you would like to learn more about the ParkinSong™ program or are interested in finding a local Fight Parkinson's Peer Support Group near you, you can contact the Fight Parkinson's office. Call us on 03 8809 0400 or email info@fightparkinsons.org.au to register your interest.

Fundraising

Brady (left) and Tom (right) during their 50km trek.

Teachers team up to fight Parkinson's together

Primary school teachers Brady and Tom walked 50km to represent more than 50,000 Victorians living with Parkinson's, raising over $5,000 for Fight Parkinson's. Their team's name, "IM Walking," combines their parents' initials – Ian and Mary – both living with Parkinson's.

Brady and Tom were working together at Apollo Parkways Primary School when they realised they both had a parent living with Parkinson's.

Brady's dad, Ian, was diagnosed in 2012. At the time, he was working as a schoolteacher when a co-worker noticed a decline in his handwriting. Over the years, Ian has had ups and downs in his journey.

"He's had days and weeks where it's kind of gone downhill. And then he's had other times where he's more like his old self," Brady explains.

"We like going to the footy and we go to pretty much every game together. But because of the walk to the stadium and the long period of sitting down, he had a fall at the footy early last year. Initially, he was adamant that he was not going in a wheelchair, but he's changed his mind on that. He's become less stubborn with certain things which is nice. But overall, the effects of not being able to live his life the way that he wants to weigh on him."

Tom's mum, Mary, was diagnosed in 2014 after a long period of uncertainty and many tests. "We had some pretty significant chats when the diagnosis was first handed down," Tom recalls.

He asked his mum how he could support her while still respecting her boundaries. "I wanted to make sure she felt comfortable with how we addressed her condition. Her response was, 'Just ask me how I'm doing and if I say I'm fine, then I'm fine. I won't lie to you – I won't say I'm good when I'm not.'"

The impact of Parkinson's has required both families to adjust and embrace new ways of living; Ian and Mary have both had Deep Brain Stimulation (DBS) surgery to help manage their symptoms and both have made modifications to their homes to make them more accessible. The ongoing support of family has also been crucial for both - Brady's father has regular visits from family who help him with everyday tasks, while Tom's parents have embraced retirement and travelling together while they still can.

Shaped by their shared experiences, Brady and Tom have developed a unique bond as co-workers and friends. "I know if I need to talk with Tom about how my dad's tracking, he fully understands and has gone through similar things," Brady acknowledges. For Tom, it's more about what's not said. "It's nice to just have someone that's close to you. Just knowing that they get it."

Witnessing the impacts of Parkinson's on their loved ones has motivated Brady and Tom to make a difference. Since 2020, they have been organising fundraisers to show their support and raise awareness of Parkinson's. They previously walked 27km in a day to represent the 27,000 people living with Parkinson's in Victoria at the time. As that number has now grown, they chose to walk 50km for their most recent fundraiser, starting at Flinders Street Station and ending at the Diamond Creek Pub, where they were welcomed by friends and family.

Throughout the eight-hour walk, they managed to maintain a steady pace until heavy rain hit. "We basically swam the last part. It felt like we had jumped into a lake," they joked. Despite the conditions, they kept their spirits high and supported each other throughout the journey. "Having one another there was great. If we noticed the other person was struggling, we would up the conversation and help get each other through."

Brady and Tom also had the support of their school, which helped them organise a "Walk and Talk" fundraiser on campus. On the day, students and staff wore blue – Fight Parkinson's colour– and brought gold coin donations.

The cohort spent the afternoon walking around the school track while having meaningful talks about Parkinson's. "We had prompting cards to say things like, 'How do you feel if you know someone's sick?' There were a few people who came up to us and shared that a family member had Parkinson's. It was nice that you could tell it meant a bit to the families of people affected."

Together, Brady and Tom have demonstrated how shared experiences can create strong bonds and inspire people to unite for a shared cause. The parallel journeys of their families illustrate the common threads of navigating Parkinson's: the unpredictable nature of good and bad days and the crucial role of supporting one another.

Supporting Caroline's MSA journey

When Caroline sets her mind to something, there is no stopping her. "I can and I will" is her mantra and it's this unwavering spirit that led her to participate in the Gold Coast Marathon alongside her son Jacob, raising funds for Fight Parkinson's.

Three years ago, Caroline began noticing symptoms that would eventually lead to her life-altering diagnosis. "She was getting a bit wobbly and her speech was going a little bit," Jacob recalls. After seeing multiple neurologists across Australia and even travelling to England, Caroline was diagnosed with Multiple System Atrophy (MSA).

MSA is a rare and progressive neurological condition that affects multiple parts of the brain. For people living with MSA, symptoms vary depending on the brain region affected. In Caroline's case, her MSA impacts her muscle coordination, balance and speech, while also causing autonomic dysfunction. For Caroline, this meant significant life changes, including using a wheelchair and daily assistance from her support workers. But true to her nature, she has approached these challenges head-on, maintaining a positive outlook.

"People always comment that she always looks so happy," says Jacob. "I draw a lot of strength from my mum just for what she's going through."

Caroline has always recognised the vital role of a strong support network. Before her MSA diagnosis, she dedicated her career to support work and established Rainbow Respite, a Brisbane-based support service for people with disabilities. When her condition progressed, Jacob stepped in to help manage the business, ensuring his mum's legacy of helping others continues.

Currently, there is no cure for MSA and treatments are focused solely on managing symptoms. It's this reality that motivated Caroline and Jacob to make a difference by fundraising as part of the Gold Coast Marathon.

Cut out this useful card and keep it with you...

Some people may not understand what Parkinson's is. This card provides an explanation that you are living with Parkinson's and may be experiencing symptoms.

By cutting it out and keeping it in your purse or wallet, you can provide essential information to others that you are living with Parkinson's and may need their patience or assistance.

I have Parkinson's

Please be patient and give me time to move or communicate. I may:

- be slow, unstable or unable to move
- have a tremor or uncontrolled movement
- speak quietly or slur my words

Stressful situations can worsen my symptoms

Jacob and Caroline gearing up for the Gold Coast Marathon together.

The day before Caroline's 54th birthday, she and Jacob participated in the Gold Coast Marathon. Caroline completed the 5km event in her wheelchair accompanied by a close friend, while Jacob ran the full 42km marathon. Together, they raised $7,700 for Fight Parkinson's with the hope of raising awareness of MSA and accelerating research for more effective treatments.

Despite the challenges of MSA, Caroline remains as proactive as possible. As Jacob puts it, "She's left no stone unturned." Her weekly schedule includes exercise physiology, speech pathology, physiotherapy and psychology. When she's not attending appointments, she enjoys being out in nature, enjoying gluten-free treats at local cafés and spending time with family.

"Some days are good, some days are bad. Some days we fight, some days we love," Jacob reflects, highlighting their journey together.

As Caroline and Jacob look to the future, they remain committed to raising awareness about MSA and supporting others affected by it. They have taken their advocacy to social media, creating an Instagram page that documents Caroline's health journey. Her page (@caroline.msac.journey) offers a glimpse into life with MSA, featuring everything from her strength training sessions to medical appointments. Her posts often include inspirational messages, reminding others that "your illness does not define you. Your courage and strength does."

"I wanted to create this page to spread awareness and share my journey with MSA," Caroline explained in one of her posts.

"Despite the challenges that MSA brings, I refuse to let it define my life. My journey is a powerful reminder that our bodies and minds are capable of incredible things. Every workout, every step, and every moment of effort is a testament to strength and resilience."

Jacob, her proudest supporter, puts it beautifully: "Not all heroes wear capes, and my mum is my hero for turning up daily, even when the chips are down."

Caroline and Jacob's efforts show that despite the challenges posed by conditions like MSA, resilience and the support of others can help tackle even the most daunting obstacles. As Caroline would say, "I can and I will" – a simple but powerful motto that continues to motivate her and inspire those around her.

About Fight Parkinson's

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Community Callout

Be a positive voice

Fight Parkinson's online Positive Life Sessions offer practical tips and valuable insights from our health team and community members. Previous sessions have covered topics such as telehealth, medication management, emotional well-being, sleep, sex and staying active.

We're looking for community members who want to be a positive voice, and share their insights into living with Parkinson's, as a panelist in our Positive Life Series.

If you would like to join the discussion, sharing your successes and tips for managing challenges with the community, and inspiring others to live positively and confidently with Parkinson's, we want to hear from you.

Email us at marketing@fightparkinsons.org.au

Cut out card

See reverse for details.

My name is:

Fight Parkinson's
Together we can

_____

With my consent or in an emergency, please call:

Name: _____
Phone: _____
Relationship: _____