Issue 2 Winter 2024

InMotion

A magazine for the Parkinson's community

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Fight Parkinson's™
Together we can

In this issue:

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CEO update

It is our privilege to share with you the incredible community leadership we've witnessed over the past few months. It has been inspiring to see our community come together to support one another, raise awareness and lead the fight for Parkinson's Awareness Month in April and PSP (Progressive Supranuclear Palsy) Month in May.

Dedicated awareness raising efforts highlight the realities of living with these conditions and the importance of understanding, education and support. They are also a timely opportunity to celebrate the work being done by and for the community.

The success of A Walk in the Park was truly remarkable. Seeing the sheer size of our community gathered across Victoria demonstrated the far-reaching impact of Parkinson's and our strength in numbers.

The lively atmosphere at Fed Square was a beautiful reminder of the strong support network we have, ensuring that no one has to manage Parkinson's alone.

I was particularly heartened to see so many regional walks taking place on the same day and other walks being organised over the coming months. A heartfelt thank you goes out to the dedicated community members who make these regional walks possible.

A Walk in the Park is a powerful reminder that we are stronger when united. Together, we can achieve better outcomes for our community and support each other through the often complex and challenging journey of Parkinson's.

We extend our thanks to all the fundraisers, sponsors and volunteers who contribute to making A Walk in the Park such an impactful event.

Following A Walk in the Park Melbourne, we hosted the annual Parkinson's Research Symposium with longtime partners, the Florey and the WEHI. Joining us this year was Parkinson's NSW.

This event successfully brought together clinicians, researchers and community members to discuss the latest research paving the way for targeted treatments. You can read more about the presentations and topics covered on page 12.

The Symposium underscored the extensive research underway and highlighted the importance of bridging the gap between researchers and the lived experiences of people living with Parkinson's. Fight Parkinson's seeks to involve more community members in research. By doing so, we can achieve better outcomes and improve the quality of life for those living with Parkinson's.

Fight Parkinson's is always working behind the scenes to advocate on your behalf, ensuring our health services can continue to provide essential support, filling the gaps in services and aiding navigation. To support the growing demands for both information and health education, we are pleased to share that Fight Parkinson's has secured a contribution of funding toward our Health Information service from the state government for FY 24/25. With the community's continued support through fundraising, we are looking to expand our Health Services team.

Contributing to advocacy on a systemic level, the efforts of the National Parkinson's Alliance, of which we are a founding member, has led to significant Federal Government funding.

We are thrilled to share that after a campaign with our partners, the National Parkinson's Alliance has been announced in the Federal Government budget to be funded $800,000 over two years. This funding is for the development of a National Parkinson's Action Plan, which will inform government and the sector of the priorities and actions necessary to deliver real impact and change for people living with Parkinson's in Australia.

Fight Parkinson's CEO Emma Collin

To further extend education opportunities for the Parkinson's community, we are launching three new online courses on Fight Parkinson's Community Learning Hub, generously supported by the John and Mary McAlister Howden Charitable Trust.

The courses are designed to support carers, women and the LGBTIQA+ community. These are groups within the community that experience unique challenges related to Parkinson's and often face barriers in accessing support. You can read about the courses on page 9.

We hope you enjoy reading about our community and the amazing individuals who bravely share their experiences. Each of their stories reflects the resilience of the Parkinson's community and the deeply personal nature of each person's experience.

You will find a collection of personal stories: from those living with Young Onset Parkinson's, to individuals sharing their experiences with Deep Brain Stimulation (DBS) and Progressive Supranuclear Palsy (PSP) and fundraising events from dedicated community members.

I trust this edition of InMotion reminds you that you are not alone. You have a strong community standing by your side and Fight Parkinson's a phone call away.

Emma Collin
CEO
Fight Parkinson's

News & highlights

From left to right: Noel Passalaqua, John Eren, Clyde Clyde Campbell, Sheenagh Bottrell, Prof Carolyn Sue, John Watkins, Dr Harley Stanton, Andrew Urquhart and A/Prof Michele Callisaya.

National Parkinson's Alliance hosts the Australian Summit to End Parkinson's

Fight Parkinson's, along with other members of the National Parkinson's Alliance hosted the first Australian Summit to End Parkinson's at Parliament House in Canberra.

Among the attendees were people living with Parkinson's and representatives from Parkinson's NSW, Parkinson's Tasmania, Shake It Up Australia Foundation, Neuroscience Research Australia (NeuRA) and Walter and Eliza Hall Institute of Medical Research (WEHI), Queensland University of Technology (QUT), Wings for Parkinson's and Parliamentarians.

At the Summit, more than 30 individuals and families, each with a unique experience of Parkinson's, bravely shared their stories. These stories, shared with the government and national media, shed light on the impact of Parkinson's on Australians.

Together, they advocated for the first-ever National Parkinson's Action Plan. This pivotal framework will shape government strategies, policies and investments to support people living with Parkinson's now and into the future.

Among the inspiring advocates representing people with Parkinson's from Victoria were Young Onset Support Group leader/Board Member Sheenagh Bottrell, Fight Parkinson's Ambassadors former MP John Eren, Iain McLean and Belinda Zipper and ParKanDo Support leader Pam West. Their voices contributed to a collective Australian voice for people living with Parkinson's.

On the day of the Summit, John Eren shared the significance of the Summit and the call for a National Parkinson's Action Plan.

"It's important for not only people like me, one of more than 200,000 people in Australia who are living with Parkinson's, but it's also important for the wider community to do the right thing. And this Summit is a great way to get the message across. As long as we have a strategic plan, we will get that message out so that people can understand their own symptoms, get diagnosed and get treatments as quickly as possible."

Monash Men's Shed visit

The Fight Parkinson's Health Team visited the Monash Men's Shed in Glen Waverley to share valuable insights on Parkinson's research and treatments.

The Monash Men's Shed provides a welcoming space for men to socialise and learn new skills. Fight Parkinson's was invited to speak to the group, as some members are living with Parkinson's or caring for someone with Parkinson's.

During the session, Health Team Manager Victor McConvey OAM shared an overview of Parkinson's, including its prevalence, potential causes, symptoms, medications and treatments. He also dispelled common myths and misconceptions about Parkinson's, enhancing the audience's understanding of the condition.

The presentation attracted longstanding members of the Men's Shed and new faces, all eager to learn more about Parkinson's. The presentation sparked engaging discussions during the Q&A, where members opened up about their personal experiences.

The audience was surprised to learn about the variety of symptoms associated with Parkinson's. This information was especially eye-opening for those who have a loved one living with the condition. Several audience members shared that their partners had specific symptoms that they had not previously attributed to Parkinson's, bringing newfound clarity and understanding.

Men's Shed member and event organiser Barry Roberts said, "The information presented offered a lot of hope for sufferers and carers, particularly the research being done locally and the advances made in earlier diagnosis."

Monash Men's Shed member Barry Roberts and Fight Parkinson's Health Team Manager Victor McConvey OAM.

Committee call-out

Fight Parkinson's is seeking community volunteers with special skills.

We are seeking Expressions of Interest (EOI) from our community to join our Finance and Investment, Governance and Risk, and Consumer Engagement and Advisory Committees.

The Finance and Investment Committee develops processes for evaluating and enhancing financial performance. It supports the Board in fulfilling its financial responsibilities, obligations and compliance requirements, as well as evaluating investment, income generation and fundraising strategies. The Governance and Risk Committee develops robust and effective processes to ensure the Board fulfils its legal, ethical and functional responsibilities. It is also responsible for risk and the development of Board and corporate policy.

The Consumer Engagement and Advisory Committee provides advice and feedback that draws on the lived experiences of community members. It supports Fight Parkinson's in advocating for system improvements, developing education and information resources and creating programs that reflect the daily realities of living with Parkinson's.

The committees meet six times each year. If you are interested, please email your EOI to info@fightparkinsons.org.au including a CV detailing your relevant experience.

A Walk in the Park

A Fight Parkinson's community event

The Parkinson's community gathered for A Walk in the Park 2024 – a day filled with emotion, fabulous entertainment and a strong sense of solidarity.

More than 1900 people registered for A Walk in the Park at Fed Square on Sunday, 21 April. This year's Walk was held during Parkinson's Awareness Month, making it particularly special.

"April is an important month for Parkinson's Awareness around the world. It's a time to recognise and acknowledge the impact that this condition has on millions of people worldwide," said Fight Parkinson's CEO Emma Collin.

For some attendees, this year marked their first experience at A Walk in the Park, while others have been participating since the very beginning. People travelled from all over Victoria to participate in the Walk, while other community members stepped up to organise walks in their local areas.

Every person had their own reason for walking, but seeing everyone gathered, proudly wearing their t-shirts, sent a powerful message of solidarity.

"When this number of people come together, I feel nothing but pride—a real sense that nobody has to go on this journey alone. There's nothing more powerful than when our community comes together. It really shows their support for one another and everybody living with Parkinson's," Ms Collin said.

Warming up

To ensure all participants were well warmed up and ready to walk safely, Rina Sawaya, who leads a Tango for Parkinson's program, brought energy to the crowd. The sight of everyone in Fed Square joining in and moving in unison was unforgettable.

Ready to walk

The enormous gathering at the inflatable archway marked the start line. After the countdown, $1K Club members led the way in their vibrant blue shirts. The excitement among the crowd was infectious, with cheers and applause echoing through the air. The sheer number of attendees filling up the path along the Yarra demonstrated the awareness-raising impact of the event.

This year's Walk was our most inclusive and accessible one yet. For attendees who needed mobility assistance throughout the day, Fisher Lane Mobility's sponsorship provided free wheelchair hire and Traveller's Aid offered buggy transport.

Walk ambassadors

This year's A Walk in the Park ambassadors did a fantastic job raising the profile of the Walk. As community leaders, they courageously shared their stories with the public, spoke to the media, engaged their networks and raised awareness of Parkinson's within the wider community.

A big thank you to Damian Rann, Georgy Hicks, Iain McLean, Jeannette Branch, John Wijsma, Sean Anderson, Michelle Mendes and Sheenagh Bottrell for their efforts.

Entertainment

Crowd favourite, Creature Comfort, entertained attendees with multiple sets throughout the day. The Glee Club energised the crowd with an uplifting performance before the Walk and surprised participants by singing them through the finish line. Stormtroopers, stilt walkers and face painters added to the fun-filled atmosphere.

Tribute wall

Attendees visited the tribute wall, where they honoured and remembered those they were walking for. The wall was a beautiful demonstration of the deep connections between families and friends and the profound impact of Parkinson's. By the end of the day, the wall was filled with heartfelt notes, creating a powerful visual representation of the community we all fight to support.

Volunteer support

Our volunteers are integral to A Walk in the Park. On the day of the event, 60 dedicated volunteers helped to ensure that everything ran smoothly, providing support to participants throughout the day. Some of the volunteers have personal connections to Parkinson's, while others simply wanted to support the community.

To see more moments from the day, visit our online A Walk in the Park Gallery at fightparkinsons.org.au/awitp-2024-gallery

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

Top fundraisers

A Walk in the Park is a day of community connection, but it also plays a vital role as a fundraiser supporting Fight Parkinson's services. This year, over $201,000 was raised – an incredible effort by those who donated and fundraised.

We extend our appreciation to everyone who contributed to this year's fundraising efforts. We would also like to acknowledge the top 5 individual fundraisers and teams for their outstanding contributions.

Top 5 individual fundraisers

Peter Brown	$8,002
Jeannette Branch	$5,965
Sean Anderson	$5,427
Ron Keilar	$3,725
Geoff Fitzpatrick	$3,152

Top 5 team fundraisers

Team G-Train and Sticko	$13,070
Hyxy's Team	$12,101
Jeannette's Team	$9,252
Young@Park	$9,118
Team Isa	$7,510

Inspiring community through strength and support

Ron Keilar has found a supportive community that has helped him navigate life with the condition and empowered him to lead and inspire others.

Ron's fight against Parkinson's began long before he received his formal diagnosis. "I used to go fishing a lot with my mates. I found that I was having trouble baiting my hooks and it got gradually worse." Simple tasks that once came easily to him became increasingly challenging, citing, "Even with a screwdriver, I couldn't do up screws."

Ron visited various doctors, seeking answers. Finally, one recognised the signs of Parkinson's and he was diagnosed immediately.

A few years into his diagnosis, just before the COVID-19 pandemic began, he discovered Fitlife, a local boxing club that ran a program for people with Parkinson's. There, he found a supportive community of people he could relate to.

In addition to the physical benefits he gained during classes, the sense of solidarity provided Ron with much-needed support and a space to share experiences with others facing similar challenges.

"What we do after the gym is we go and get coffee together. We sit down and talk about who's got what. It helps you understand and accept the situation that you're in. The ability to talk to one another about Parkinson's is fantastic."

Motivated by the desire to give back and support the Parkinson's community, Ron became actively involved in fundraising efforts.

He has raised money for A Walk in the Park for two years in a row now. This year, he helped raise over $3,700 towards the Fit Life Boxing Fighting Parkinson's Team, which raised a total of $6,559.

When asked about his outstanding fundraising efforts, Ron highlighted the collective effort of his loved ones in rallying around him. He had support from his fellow gym members, friends from his motorbike touring group, family members and his local community in Upwey, where he put up posters in shops and received donations from the Upwey RSL.

On the day of the Walk, Ron had a team of 20 people there to support him. This year, the Walk looked a little different for him. "Because I can't walk very far anymore, I had to do it on the scooter," he explained. Despite the new challenge, Ron adapted and pressed on.

Reflecting on the day, Ron recalls being overcome with emotion at the start line during his interview with the MC.

Ron surrounded by family and friends at A Walk in the Park to cheer him on.

"What I really wanted to say was that Fitlife Boxing is why I'm here today, because they've done such a wonderful job. I wanted to do something to give back to the people supporting me."

Ron says his network of support has been instrumental in helping him navigate the ups and downs of the condition. "I've got a good support group and I'm just so lucky," he acknowledges.

In addition to his personal support network, he is a member of Fight Parkinson's Knox Peer Support Group. Attending the meetings has given him practical insights about living with Parkinson's that he wouldn't have otherwise had. "When you go to the GP or your neurologist, they don't tell you things that I think are important—details like planning your medication around your meals. But if you go to information sessions with fellow Parkinson's sufferers, you get that sort of information."

For Ron, community connection has been key to living well and he is committed to helping others and raising awareness.

"I find that a lot of people don't want to talk about Parkinson's. They want to hide it. I am totally the opposite – I want to tell the world that I've got it."

Finding camaraderie and strength through mutual support, Ron is thankful for the network of support around him.

A Walk in the Park

Newly diagnosed, Peter rallies support for Parkinson's

Peter Brown was this year's top individual fundraiser, newly diagnosed and inspired to join the community and raise awareness with family and friends.

Born and raised in Melbourne, Peter, 51, has always been deeply connected to his community. He has shared his life with his wife Melanie for 22 years.

Amidst years of working in sales, travelling with Melanie and going on trips with his friends, Peter began experiencing subtle hints of Parkinson's that he initially dismissed.

He recalls moments like struggling to get his leg into a pair of shorts or shuffling his feet after a long day playing golf. Peter now looks back at these moments, recognising that they were Parkinson's symptoms.

It wasn't until last year when they were watching a Michael J. Fox documentary, that Melanie pointed out that Peter had some of the symptoms mentioned. He was referred to a neurologist, who officially diagnosed him with Parkinson's in March.

He asked his neurologist what support was available and she recommended the Fight Parkinson's website. He saw that A Walk in the Park was happening in a few weeks and he signed up right then and there.

Peter took the approach of, "I'm only going to get diagnosed for the first time once. I just really leaned into that and reached out to people to ask for support."

His fundraising efforts were met with overwhelming support from his network. Through social media and reaching out individually to his friends, he had 51 separate people donate to his fundraiser, raising over $8,000.

Peter attributes the success of his fundraising to building a strong network of support. He says the donations just added up over time, whether it was $20 from his friend's kids or those who had returned the favour of Peter's generosity in previous years.

On the day of A Walk in the Park, Peter had with him his wife Melanie, his brother-in-law and some close friends. Reflecting on the day, he says the best part of A Walk in the Park was meeting other people living with Parkinson's.

"What I've found so far about the Parkinson's community is that they're open to talking to you. I met people and asked, 'How's it been for you?' And they just open up and tell you. And for me, who's just been diagnosed, it's really interesting to see what to expect."

Since then, Peter has attended several online and in-person education events and has even joined the Young@Park Group for people living with Young Onset Parkinson's. He is enthusiastic about getting involved and learning as much as he can about the condition.

"I saw a neurologist for half an hour, who, following a diagnosis and discussion, gave me a pamphlet and wished me all the best. If I hadn't reached out to you guys, I wouldn't know half the stuff I know already. I wouldn't have been at the Research Symposium and learned all about Deep Brain Stimulation and things like that."

Peter enjoying the day with his loved ones at A Walk in the Park.

Immersing himself in the community has provided Peter with practical insights into navigating life with Parkinson's. "I realise that everyone's journey's a little bit different, but it's giving me an understanding of what to expect. I'll probably need to do some travel in the next decade. I'll probably need to work and bank some money now because I'll probably have to retire earlier than expected. I'll be doing the Fight Parkinson's course on the NDIS."

For Peter, his involvement in the Parkinson's community is not just about his journey; it's also about supporting Melanie. "The other reason I wanted to get involved in the Parkinson's community was for my wife. We don't have kids, so she's going to have to be a lot of support for me. And if I'm cranky and she doesn't want to talk to me, she needs other people to talk to. I think it's important for her to have a network of people within the community who can empathise with her. I need to ensure that she's going to have support as I get older and more difficult to deal with. I think that's why the Parkinson's community will be good for both of us. And meeting other people at A Walk in the Park like that, who care for other people and understand. It will be good for her."

As Peter navigates his recent diagnosis, he remains pragmatic: "I can't change the diagnosis, so you can either embrace it or not. I'm not working at the moment and I've got time on my hands. So, let's just try and learn about it, learn what I can do to help it and support people where I can."

A Walk in the Park

Regional walks

A Walk in the Park created an outpouring of community support felt across Victoria.

A Walk in the Park continues to be a resounding success across Victoria, thanks to the efforts of Fight Parkinson's Peer Support Groups and local community members.

Some regional walks have already taken place, from Echuca to Bairnsdale, Lakes Entrance, Mildura, Moorabbin, Hastings, Colac, Swan Hill, Geelong and the Forster/Tuncurry area.

Each event was unique, reflecting the local community. Featuring things like entertainment, raffles, morning tea, delicious food, a planned walk and the company of furry friends. Local MPs made appearances and delivered speeches at the Geelong and Echuca walks. Although each event had its own distinct offerings, they all united for a common goal: to lift the profile and voice of Parkinson's.

The regional walks provided a wonderful opportunity for attendees to connect and support each other and raise awareness about Parkinson's in their respective regions.

"As soon as we start promoting the event, we bring out new people within the community and we connect them with our services and supports," said Fight Parkinson's CEO Emma Collin at Geelong's A Walk in the Park.

A Walk in the Park ambassador Jeannette Branch was the driving force behind the Echuca Walk. Reflecting on the day, Jeannette shared her joy. "The day was amazing," she said. "Approximately 75 people attended, with 63 of us walking around the leevee bank. Everything was donated, from 26 raffle prizes, the sausage sizzle, the advertising and the equipment." The group's collective efforts raised an impressive $2,267.

Coming together in various communities across the state fostered a sense of mutual support, amplifying our strength in numbers. As a result of these collective efforts, significant funds were raised, helping Fight Parkinson's to expand our reach and enhance our programs and services for the Parkinson's community.

A big thank you to our regional walk organisers, including Cheryl Barnes, Elizabeth Maher, Helen Brunt, Danielle Busch, Ian Temme, Jeannette Branch, Jenny Disney, Lynn Crawford, Naomi Lettieri and Russell Wardle. We would also like to extend our thanks to the Peer Support Group members, volunteers and attendees who made these events possible.

There are more regional walks being planned for later in the year. If you would like to see what's available, visit awalkinthepark.org.au/regionalwalks.

Every Walk contributes to improved outcomes for the Parkinson's community. If you would like to host A Walk in a Park in your local area, it can be organised with the support of Fight Parkinson's year-round. To register your interest, please email our Fundraising Team at fundraising@fightparkinsons.org.au.

Fight Parkinson's CEO Emma Collin with MPs Ella George and Christine Couzens at A Walk in the Park Geelong.

Attendees enjoying the vibrant atmosphere at Eastern Park, Geelong.

A Walk in the Park Bairnsdale and Lakes Entrance, held at the Lakes Entrance Foreshore.

A Walk in the Park Echuca, held at Echuca Aquatic Reserve.

A Walk in the Park Swan Hill, held at Riverside Park.

A Walk in the Park Tuncurry-Forster, held at John Holland Park.

COMMUNITY
Learning Hub

Three new online courses added to Learning Hub

We are thrilled to announce the launch of three new online courses on the Fight Parkinson's Community Learning Hub, generously supported by the John and Mary McAlister Howden Charitable Trust.

Health information and education are critical to building knowledge and skills to inform choices to best manage living well with Parkinson's.

The three courses are specially designed to support carers, women and the LGBTIQA+ community, who often face unique challenges related to Parkinson's and can face barriers in accessing the support they need.

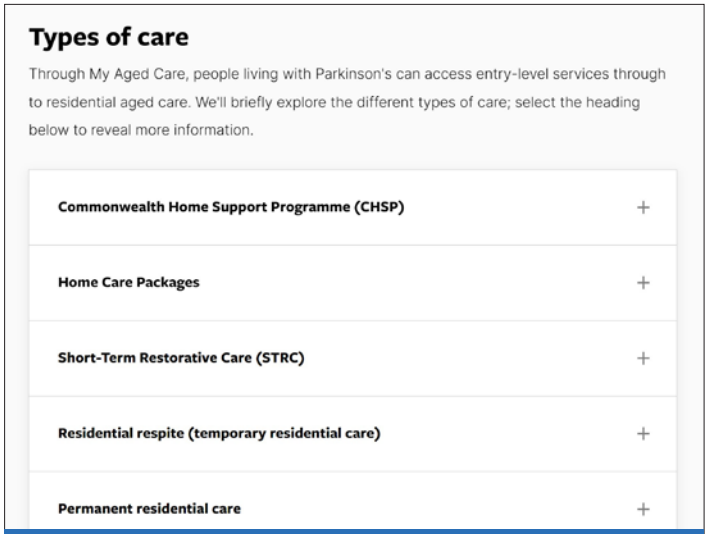
These courses are recommended to enhance your understanding of Parkinson's and how each person's experience is unique.

Carers and Parkinson's

Caring for someone with Parkinson's can be both rewarding and challenging. This course provides essential tools and knowledge to help carers manage daily care tasks, understand the progression of Parkinson's and maintain their own well-being.

Topics include practical caregiving tips, emotional support strategies and resources for financial and legal advice. Through this course, carers will understand the benefits of building a supportive network and gain the confidence to provide the best care possible.

Recommended for: Anyone living with or caring for a loved one with Parkinson's.



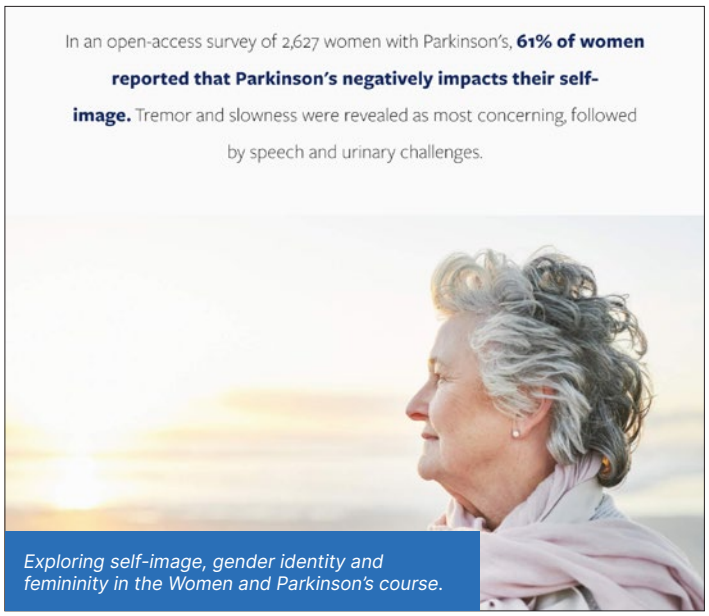
Information on government-subsidised supports, from the Carers and Parkinson's course.

Women and Parkinson's

Women with Parkinson's experience unique symptoms and challenges that are often underrepresented in mainstream discussions about living with Parkinson's. This course is tailored to address these specific needs, offering insights into how Parkinson's affects women differently.

The course covers hormone-related symptoms, managing menopause with Parkinson's and strategies for maintaining mental health. This course will provide women and those who care for a woman with Parkinson's the information they need to understand how living with Parkinson's as a woman differs and how to receive relevant support.

Recommended for: Women with Parkinson's or anyone living with or caring for a woman with Parkinson's.



Exploring self-image, gender identity and femininity in the Women and Parkinson's course.

LGBTIQA+ and living with Parkinson's

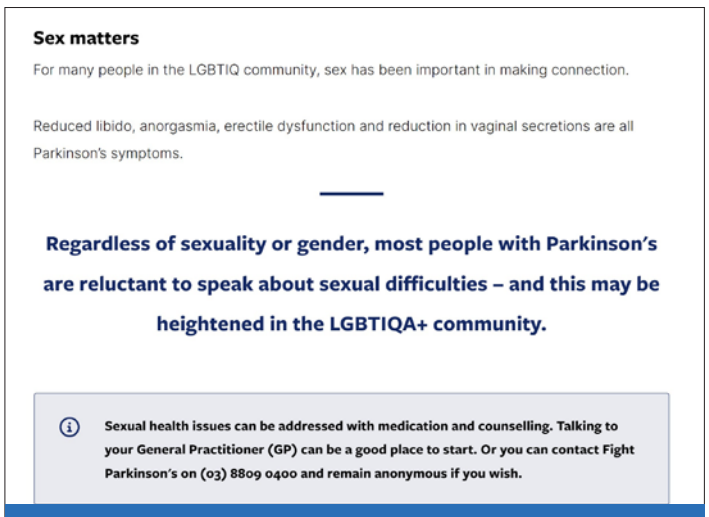
The LGBTIQA+ community faces distinct challenges in accessing Parkinson's care due to stigma and lack of tailored resources. This online course aims to create an inclusive space where individuals can find support and information relevant to their experiences.

Topics include navigating health care systems, understanding intersectional issues and building supportive relationships within the community. This course helps members of the LGBTIQA+ community and those supporting them, engage with relevant supports and access resources that respect and affirm their personal identity.

Recommended for: Anyone who identifies as a member of the LGBTIQA+ community who has Parkinson's or is living with or caring for a member of the LGBTIQA+ community. Also recommended for anyone interested in understanding inclusive care for all living with Parkinson's.

These courses have been designed to empower people with relevant knowledge, support and resources to best suit their needs. Together, we can fight Parkinson's and build a stronger, more inclusive community.

To discover more about these courses and how to access them, please call us on 03 8809 0400 or visit fightparkinsons.org.au/about-us/media-release/community-learning-hub.



Information from the LGBTIQA+ and living with Parkinson's course.

Managing symptoms

Deep Brain Stimulation (DBS)

Deep Brain Stimulation (DBS) Surgery can help alleviate some of Parkinson's most debilitating symptoms. However, certain factors determine whether the procedure is right for you.

What is Deep Brain Stimulation (DBS) surgery?

Deep Brain Stimulation (DBS) is a surgical procedure used to alleviate the symptoms of Parkinson's. The procedure involves the insertion of fine probes, also known as leads, into the basal ganglia region of the brain. The specific area of insertion depends on the patient's symptoms and is determined after extensive consultation with a neurologist.

Electrical impulses are sent through the leads to stimulate the patient's brain. The electrical impulses stimulate underactive areas of the brain and block electrical activity in overactive areas. Stimulation is delivered, continuously reducing fluctuations in motor symptoms.

What does the procedure involve?

In Australia, it's common to insert the leads on both sides of the brain, known as bilateral DBS. Once the leads are inserted, they are connected to an Implantable Pulse Generator (IPG) which serves as a battery to send electrical impulses to the brain. The IPG is typically placed under the skin in the chest, just below the collarbone, similar to a cardiac pacemaker.

The insertion of the IPG is carried out under general anesthesia in the second stage of the surgery.

Currently, in Australia, most DBS procedures are performed while the patient is awake. The patient wears a "halo" or stereotactic frame to ensure the precise placement of the leads into the target area.

Having DBS while under general anesthesia is possible, but it is less common and is mostly performed in private hospitals. This technique involves creating a model of the brain and having an MRI (Magnetic Resonance Imaging) scan during the surgery to check the placement of the leads.

Fortunately, current research is underway to identify a biomarker in the brain's electrical activity. This will help increase the accuracy of electrode placement, further enabling "asleep" DBS.

After DBS surgery, patients may need to stay in the hospital for up to five days. However, the length of the hospital stay will vary depending on the neurologist's recommendation. During this time, the patient's neurologist will make necessary adjustments to the stimulation to determine the best possible setting.

It can take 3-6 months to achieve the optimal level of stimulation to manage symptoms. Some people may be able to stop medication for some time following implantation, while others will need to continue taking medication. It will take several visits to the neurologist to achieve this.

Who should consider DBS?

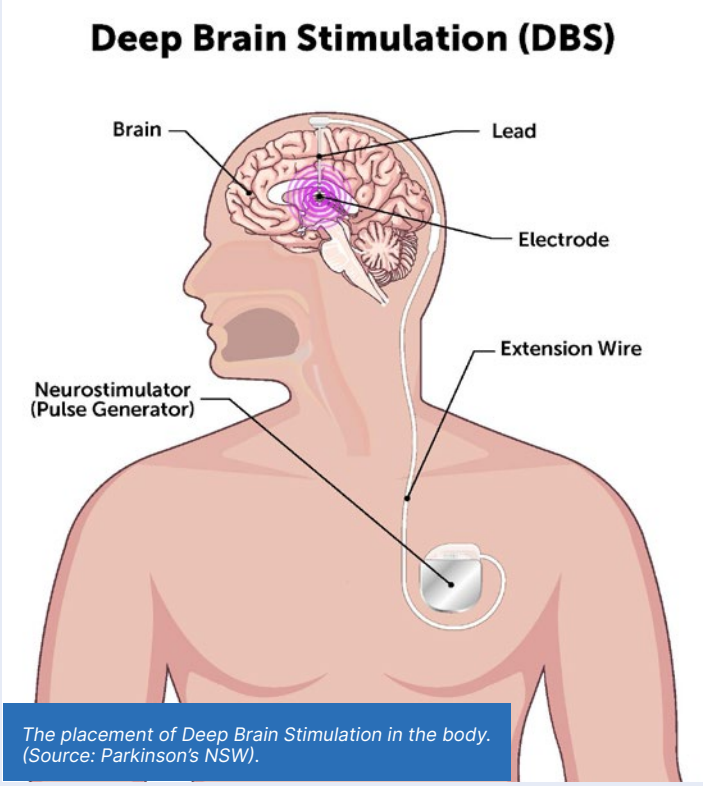
If you're living with Parkinson's, DBS may be a suitable treatment option if your symptoms respond well to Levodopa-based medication and you stand to gain noticeable benefits from the procedure.

DBS can be considered in both early and later stages of Parkinson's. If you are physically and mentally healthy, you may be a suitable candidate for the procedure.

However, not everyone with Parkinson's is a suitable candidate for DBS, particularly if you are experiencing memory issues, hallucinations or severe depression.

If you're interested in exploring DBS as a treatment option, the first step is to talk to a neurologist. They can evaluate your individual situation and provide guidance on whether DBS may be a suitable option for you.

Speaking with a neurologist about the possibility of DBS surgery can help you identify the right time for surgery. DBS can be considered a treatment at any point as Parkinson's progresses,



The placement of Deep Brain Stimulation in the body. (Source: Parkinson's NSW).

though clinical research has found that patients who undergo DBS earlier, around two to three years post-diagnosis, experience a significant improvement in their quality of life.

Why choose DBS?

When it comes to treating Parkinson's symptoms, there are various medications and treatments available. DBS, however, has some specific advantages.

One of the main benefits of DBS is its ability to provide continuous electrical stimulation. This reduces motor fluctuations, resulting in better symptom control for an extended period of time.

Additionally, stimulation settings can be adjusted to keep up with Parkinson's symptoms as they progress. DBS also reduces the need for oral levodopa, resulting in fewer side effects such as dyskinesia.

Apart from treating symptoms such as tremors, stiffness and dyskinesia, DBS provides various other benefits, such as:

- Providing more time in the 'on' state, equivalent to when oral medications are working well.
- Increasing predictability of movement, leading to fewer motor fluctuations.
- Allowing individuals to reduce oral medication in most cases.
- Targeting specific areas based on the key symptom - whether it is tremor, stiffness or dyskinesia.
- Improving sleep quality.

Safety and precautions

DBS is generally considered a safe and effective procedure. However, just like any surgery, there are potentially serious risks and side effects. Serious side effects include infection, seizure or a bleed/stroke during surgery. It's important to discuss these risks with your neurologist before deciding on DBS as a treatment option.

Fortunately, certain effects can be managed by adjusting the stimulation settings or with support from a health care professional.

Other side effects, such as weight gain, word-finding difficulties and decreased quality of speech, are mild and can be managed.

For some DBS patients, there is a minor risk of suicidal ideation, which is screened for in the regular follow-up appointments.

Following DBS, it's important to keep in mind that certain activities can impact the device's functioning and will require extra caution and care:

- There are some restrictions on having an MRI scan as it uses magnets, which can alter the DBS settings. If you need to have an MRI, speak with your neurologist beforehand. The DBS may need to be turned off or switched to an MRI setting (if available), and the programming may need to be checked after the MRI.
- When having any dental or minor procedures following DBS, taking antibiotics before and after procedures is usually required to minimise the risk of blood-borne infection affecting the implanted DBS.
- If you are going into hospital, let staff know that you have DBS as it may interfere with hospital monitoring equipment, especially if you need an electrocardiograph (ECG).
- If you are having a surgical procedure, you will need to advise the anesthetist and surgeon that you have DBS in case they need to take any necessary steps to ensure a smooth procedure.
- When travelling, you should avoid going through airport metal detectors and you must always carry your programmer and charger with you.
- You should also avoid activities that expose you to electrical currents (e.g. arc welding) as they may affect the DBS impulse generator.
- Extra care is required when swimming, as it can lead to difficulty coordinating limbs. You should always exercise caution and not swim alone.

What is the cost of DBS surgery?

Currently, the cost of DBS is not fully covered under Medicare as there is a limited number of individuals undergoing DBS in the public hospital system.

As a result, most people opt for DBS surgery through private health insurance. However, it's important to note that all insurance policies are different and doctors have different billing schedules, so there may be some out-of-pocket costs.

If you're considering DBS, it's important to clarify the costs with your treating team to have a clear understanding of the financial implications.

Community testimonials

"In early 2023, I qualified for the DBS procedure and had it done in June 2023 at the Austin Hospital after a cancellation where I accepted the offer to bring my turn forward. The results from day one have been amazing and have been life-changing for me! The post-care attention I've received has also been exceptional." ***- Daryl***

"I had DBS surgery in 2022 and I got an infection to the battery and to the head, so they had to remove it. In October 2023, I had the surgery done again and it seems to be going really well. My walking is getting better every day and improving gradually. It's not been the most positive journey but I don't want people to feel that's the end result. I was just unlucky the first time, but things are improving now. I'm also part of the DBS support group and it's good to be connected to different people who have had DBS or considering it." ***- Michelle***

"At the time, there was a real fear of having the operation while I was awake, so finding a neurologist who could perform DBS while I was asleep was a game-changer for me. I had DBS in February last year, and it was life-changing. There's no silver bullet, but the change has been huge. I've just recently completed renovations at home where I've been doing the landscaping, which beforehand, I wouldn't have had a hope of doing. I wouldn't say I'm back to where I was before Parkinson's, but pretty close. And it's been a game-changer for my wife and my boys. Now my wife can go to work, come back home and not have to rescue me when I would be struggling trying to push through to get dinner on the table." ***- John***

"I am four and a half weeks post-Deep Brain Simulation. Now, I have two electrodes deep in my brain, which are controlled by a device mounted inside my chest. The road to recovery is a tough one. But when the device is tuned right, life is so much different. My balance has returned (no walking stick), most tremors have disappeared and some of my flexibility has returned. Now I am working on getting my body and mind ready to return to full-time work, which should be a few weeks away." ***- Shayne***

"My advice to someone considering DBS is to remember that it's not a cure - it's a way to control your symptoms. But I have had a great impact with it and quality of life has improved tremendously." ***- Linda***

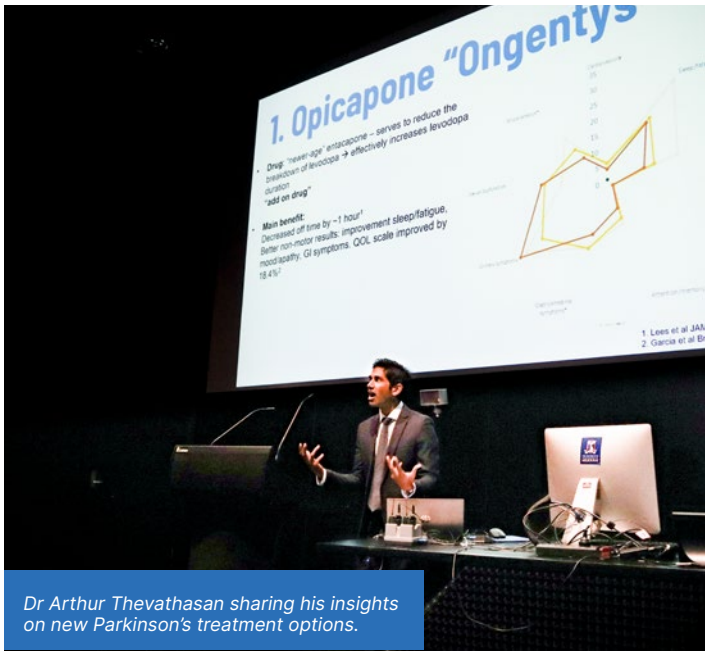
Can I talk to someone who has had DBS surgery?

Fight Parkinson's runs a DBS Support Group for people who have had DBS and for people who are contemplating the procedure. This group meets bimonthly and is supported by a health professional from the Fight Parkinson's Health Team.

The meetings provide an ideal opportunity for people who are considering DBS to ask questions and hear firsthand from people who have had DBS recently or in the past.

The meetings are facilitated online. To register your interest or find out more, you can contact the Fight Parkinson's Health Team on 03 8809 0400.

Research



Dr Arthur Thevathasan sharing his insights on new Parkinson's treatment options.

Parkinson's Research Symposium

Fight Parkinson's held our 2024 Research Symposium in collaboration with the Florey and WEHI. We also joined forces with Parkinson's NSW, who hosted the Symposium in Sydney.

The Melbourne Symposium, held at the Florey, brought together over 250 participants, all eager to learn about the latest advancements in Parkinson's research. This free community event was an opportunity for our community to hear from leading Parkinson's experts in Australia.

Presentations

The keynote address by Dr Andrew Evans laid the foundations of the day's insights. His presentation, "Advances in Parkinson's Research," captivated the audience, offering insights into the many causes of Parkinsonisms and the future direction in finding groundbreaking developments in the field.

Participants were enlightened by neuroscientist and research neuropathologist, Professor Glenda Halliday. Her presentation on Parkinson's at the cellular level delved into the intricacies of the disease's pathology. Professor Halliday's unique ability to make complex science digestible was appreciated by all. She clearly demonstrated the positive path towards the development of future targeted and individualised treatments and care potential. Professor Meg Morris shared innovative approaches to exercise in Parkinson's, highlighting how physical activity can serve as a neuroprotective measure.

A/Prof Andrew Evans delivering the keynote address.

Professor Glenda Halliday's presenting on Parkinson's at the cellular level.

Afternoon sessions were equally engaging, featuring Dr Arthur Thevathasan, also a neurologist, presented on how scientific advances are shaping treatments in clinical practice and how existing medicines are being looked for potential benefits of people with Parkinson's.

A joint presentation by was delivered by Associate Professor Jane Alty and Professor David Finkelstein on the significance of recent Biomarker discoveries. These discussions underscored the critical role of Biomarkers and their potential for providing more targeted and accurate research.

Dr Wesley Thevathasan, a neurologist who specialises in Deep Brain Stimulation (DBS) (cousin to Dr Arthur Thevathasan!), shared technology advances in DBS, enhancing targeting accuracy and, therefore, improved outcomes following DBS. Dr Thevathasan also shared the future direction of DBS and how the procedure and hardware technologies are constantly improving.

A/Prof Jane Alty discussing early detection of Parkinson's during her joint presentation on Biomarkers.

Panel discussion

One of the event's highlights was the panel discussion, moderated by Professor Grant Dewson, Lab Head at the Walter and Eliza Hall Institute of Medical Research (WEHI). It included experts like Dr Arthur Thevathasan, Associate Professor Richard Gordon from the University of Queensland and community members including Iain McLean and Sheenagh Bottrell, who are living with Parkinson's.

Their dialogue on the value of involving people with Parkinson's in research was both enlightening and inspiring. The panel explored the ways community members are being included in research development and the questions needing to be answered by research and how to get involved as a community member.

"The Symposium was well presented, although a few hiccups with audio," noted Shona Cross, who is living with Parkinson's. "Very interesting to hear from the leaders in their fields. Thank you, Fight Parkinson's, for providing the Zoom option."

Health care professionals' breakfast – building sector knowledge

Prior to the community-focused symposium, health care professionals with an interest in Parkinson's care joined a breakfast session, which fostered early discussions on clinical applications of recent research findings.

Fight Parkinson's and Parkinson's NSW are grateful for the enthusiastic participation and support from the presenters, clinicians and researchers who contributed to the agenda and for the community members and health care professionals that attended.

The symposium exemplifies our shared commitment to advancing research and improving lives. There is a ground swell of hope in Parkinson's Research as we work toward a future filled with hope and scientific breakthroughs.

The Research Symposium was a hybrid event, with attendees joining in-person at the Florey and via livestream.

Professor Meg Morris exploring innovative approaches to exercise in Parkinson's.

Panel Discussion featuring Sheenagh Bottrell, Dr Arthur Thevathasan, Iain McLean, A/Prof Richard Gordon, Prof Meg Morris and Prof Grant Dewson.

Atypical Parkinson's

Progressive Supranuclear Palsy (PSP)

Navigating PSP can be overwhelming, but it's important to remember that no one has to face it alone. Fight Parkinson's is here for you to get the support you need.

Specialised support

Call the Fight Parkinson's Health Team for tailored information about symptom management, services, health-related benefits, entitlements and everyday living. Fight Parkinson's can also advocate on your behalf to medical and health care professionals.

Free resources

Discover online resources and information about living with PSP. Visit fightparkinsons.org.au/living-with-psp or scan the QR code.

Community connection

Join our bi-monthly online support group for people living with PSP, MSA and CBS. Share your experiences and connect with others who understand what you're going through.

Call: 03 8809 0400

Email: info@fightparkinsons.org.au

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

Young Onset Parkinson's

Travis' Parkinson's story

Travis grew up in Upper Ferntree Gully alongside two brothers. After years of study and exploring different career paths, he found his calling when he enlisted in the Australian Army in 2013. Five years later, at age 31, he was diagnosed with Parkinson's.

How it began

"It started when I was at the computer typing away, and my hand got a slight tremor. People used to say I needed to lay off the coffee. It was probably a week later that I woke up with my left arm completely dead, down by my side."

Travis faced continuous setbacks in receiving an accurate diagnosis and was medically downgraded while in the Defence Force for twelve months. During this period, his unit accommodated his limitations, including re-allocating him to office duties only. They also remained flexible with his medical appointments and provided support for his recovery.

Travis' Commanding Officer recommended an additional twelve-month extension, which was approved. However, at the end of the extension period, Travis was still unable to be deemed medically fit to deploy and as a result, he was medically discharged from the Australian Defence Force.

Travis respected this decision and embraced the opportunity to return to Melbourne to be with his family and friends, who could support him while he came to terms with his diagnosis.

Returning home

Leaving the army and adjusting to a life with Parkinson's was a difficult transition for him. "When you leave the Defence Force, one of the common things is you're losing that sense of identity and the family you create there."

Upon returning home, he was confronted with the task of having to rebuild his identity, find employment and reconnect with his loved ones. The challenge was made even more daunting by his Parkinson's and he found himself pushing a lot of his friends away during the early stages of his diagnosis.

He would limit going out, worried that his tremor might play up and people might look down on him. Unfortunately, he had some negative experiences. He recalls, "I found it quite hard having a few people laugh when you tremor."

As a lifelong lover of physical activity, losing some of his physical abilities was also hard for him. "Before Parkinson's, my fitness level when I was in the army was high, whether it was running and swimming, doing pull-ups, or just being able to do whatever beforehand. It was hard accepting that I can't return to those fitness levels yet."

New beginnings

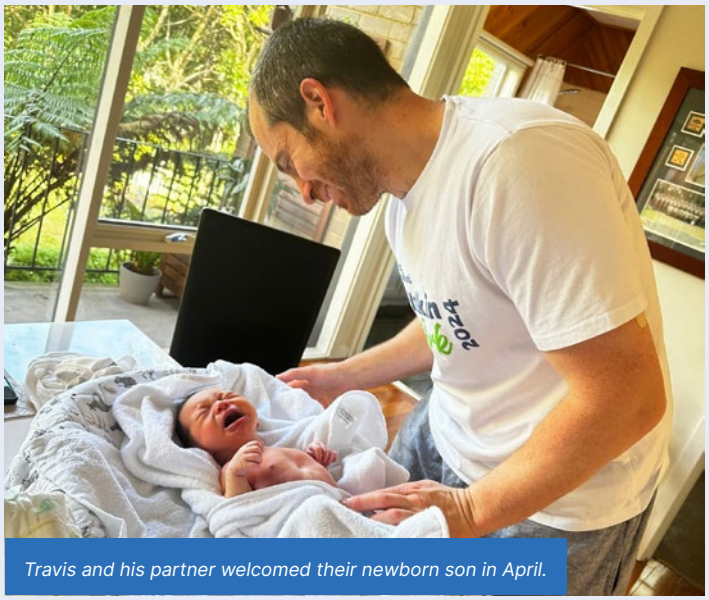
One thing Travis found beneficial for his physical and mental health was starting Krav Maga classes. It was an opportunity to integrate back into the community while keeping active and learning new skills. He also started a movement program in his local area to help improve his strength and movement.

To support his transition back to regular life, Travis connected with an organisation called Helping Heroes, which supports veterans. They encouraged him to connect with different specialists and Parkinson's support groups.

They also helped him get back into the workforce and he began working remotely for a defence contractor. Travis says getting back into the workforce was one of the best things for his mental health.

DBS surgery

Travis underwent Deep Brain Stimulation (DBS) in June 2023. Reflecting on his DBS experience, the hardest part for him wasn't the surgery itself but it was having to be off his medication the day before.



Travis and his partner welcomed their newborn son in April.

"You're going from getting all this medication to having to go cold turkey beforehand. It was definitely rough. It wasn't just rough on myself, it was hard for my parents to see me off medication. My neck was fully contorted; it was a real look at how my Parkinson's had progressed and how important my medication was."

After the surgery, Travis, his family and his partner Rose were thrilled with the results and Travis says that his quality of life had greatly improved.

Navigating changes

Despite the positive outcomes of his DBS surgery, having the procedure has meant that he's had to make some additional changes to his lifestyle.

Instead of going to his regular Krav Maga class where he would meet people and socialise, he now has private training sessions to avoid having contact with his head.

His cognitive symptoms also continued to impact him. He struggled to remember things at work and he transitioned to a back-of-house role. In January 2024, Travis' position was made redundant. While he and his employer remain on good terms, Travis notes that it was an especially difficult time for him, given that he and his partner were expecting a baby in three months' time.

On living well

Although Travis acknowledges the obstacles he's faced, he maintains his positive mindset, knowing that it's possible to live well with Young Onset Parkinson's. "DBS has changed my life for the better. Also, learning to understand the support available and the lengths people go to help you out has definitely changed me. I've always known that it doesn't matter how bad it gets - there's always help out there."

Travis has gained a lot from living with Parkinson's and says he's learned a lot about himself as well. "There have been times that have been really challenging, but I wouldn't have the kind of levels of resilience and intestinal fortitude that I have now when dealing with the challenges of Parkinson's."

Looking ahead, Travis is looking forward to fatherhood and is committed to maintaining his health and well-being. In his free time, he loves hiking, climbing and running as much as his medication allows.

He's also excited about connecting with other people with Young Onset Parkinson's and wants to share his candid experiences, sense of humour and unwavering enthusiasm for not letting Parkinson's define him.

Personal Story

Carol Pritchard

Carol Pritchard and her husband Derek were running a motel and restaurant in Mildura when her life took an unexpected turn.

With the hustle of managing their business, Carol led a busy life. Her days were filled with early wake ups for the breakfast service, administration, managing her team and supporting the restaurant in the evenings. Between work and caring for her three kids, she loved playing tennis and being social wherever possible.

Her initial concerns began when her writing started changing. She would begin writing a sentence and the letters would taper off smaller and smaller as she wrote, to the point where her writing became illegible.

This prompted a visit to her GP, who then referred her to a neurologist in Melbourne. After an appointment with the neurologist, Carol was diagnosed with Parkinson's. It was during this discussion that she realised she had been experiencing other Parkinson's symptoms for at least five to six years prior.

As well as her ability to write, her cognition was also affected.

"Words became more difficult and I found myself having to ask others how to spell the simplest of words, which is a mystery because I can still read well."

She had to manually lift her leg with her arms when stepping into her car, she was walking with a toe-heel gait instead of heel-toe and was carrying her right arm bent instead of swinging her arm as normal.

After Carol came home from her first neurology visit, her daughter Lauren, who is an exercise physiologist, wisely encouraged her to begin an exercise program. Through consistent exercise, Carol managed to alleviate some of her symptoms.

Over the years, despite her best efforts, her Parkinson's has progressed and she has experienced other recognised symptoms. This includes challenges with hand movement and dexterity, posture changes, perspiration, freezing, shuffling and voice hoarseness. She's also had several falls, resulting in broken bones and many bumps and bruises.

Despite these challenges, Carol remains optimistic. She tries to stay as social as she can and with the help of medication and exercising, she has managed to maintain a good level of self-care.

Another key element to her wellbeing is her network of support. Very early in her Parkinson's journey, Carol's neurologist informed her of the many Fight Parkinson's Peer Support Groups that are active among Victoria.

She began attending meetings with the Mildura Fight Parkinson's Peer Support Group and has made some wonderful friends through her involvement. In particular, the group leader Cheryl Barnes, has been a great support to Carol through her journey.

We would like to extend our thanks to Carol Pritchard and Sharyn Sturre for sharing Carol's story.

If you are living with Parkinson's, support and information can make a significant and positive difference. If you would like to speak to a member of the Fight Parkinson's Health Team or learn more about local Fight Parkinson's Peer Support Groups, you can contact us on 03 8809 0400.

Peer support

Margo Adams: a lifetime of service to Ballarat PSG

At 92, Margo Adams is bidding farewell to her Peer Support Group, leaving behind a legacy of compassion and support.

Margo Adams and her husband Frank joined the Ballarat Parkinson's Support Group in 2003 shortly after Frank was diagnosed with Parkinson's. Even after Frank's death, Margo continued to be an active member for two decades, helping shape the group into what it is today.

The Ballarat Parkinson's Support Group began as an informal gathering for people to share their experiences and situations. Over time, as more people began attending, the group became more structured to better serve the needs of the community.

When Margo joined, the group was led by Merl Bridges and Margaret Hocking. The group had been running for many years by then. Margo remembers her early days in the group, where she would welcome attendees, manage raffle tickets, handle finances and organise afternoon teas.

"Any jobs that needed to be done to help the club run smoothly, Margo was there just getting them done," said fellow group member and newsletter editor Diana. "Very punctual and proactive, she made things happen."

With support from other members of the Peer Support Group, Margo helped out wherever she saw a need, driving people to and from exercise classes, visiting community members in aged care and respite care, baking cakes for Christmas in July functions and donating potted flowers from her own garden for Mother's Day.

Margo also maintained and regularly updated a scrapbook to commemorate group events, newspaper clippings about members and any key news and information about Parkinson's.

Margo was a natural when it came to her role in the group. She had extensive experience running meetings and was involved in various other organisations, including the Ballarat Brass Band committee, back when Frank could still play his instrument.

Caring for others came naturally to Margo, who, from a young age, was expected to take care of immediate family members.

At the Ballarat Support Group, she played a crucial role in supporting members and fellow carers. Margo ensured that the needs of carers were well-represented by helping organise carer events and applying for carer grants.

She would also take the time to visit anyone who was struggling within the group. Diana noted how Margo would take them out for afternoon tea and lend a listening ear, helping people get along as best they could at her own expense.

"Margo didn't need accolades. When you're helping others, it warms your heart that you're making a difference"

In her own time, she would send sympathy cards and attend funerals and continued to do so, even when most of the group members that Margo knew had passed away and she found it hard to keep up with new members.

Reflecting on her time at the Ballarat Parkinson's Support Group, Margo says her highlight was getting to meet so many different people and hearing all the interesting stories and insights shared.

Thanks to Margo and other members over the years, the Ballarat Support Group has grown and evolved into a dynamic and engaged community. The number of members is steadily growing, with about 160 casual members.

The group formally meet on the first Friday of each month at North Ballarat Sports Club, where they discuss a range of topics and have guest speakers attend. They also run "Catch Up Cuppa & Chat" meet-ups, organise fundraisers and are involved in exercise programs and walking groups, such as the one run by Heartbeat Ballarat Walking Group.

Margo with fellow PSG member Norma Goodwin celebrating Margo's service to the Ballarat Parkinson's Support Group.

Looking ahead, Margo is eager to see the Ballarat Parkinson's Group continue to thrive as they enter a new chapter. "I'd like to see them stay very social and connected. We have some movers and shakers in our group and some nice personalities who are welcoming and integrating new members. Just keeping that connection going."

"Margo has helped shape this group. We have been very privileged to know Margo and blessed with her caring and thoughtfulness. Margo's selflessness and dedication to helping others is truly inspiring," shared Diana.

If you are interested in attending a 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 & awareness-raising

The PD Avengers gearing up for the competition at the 2024 Moomba Festival.

Soaring high

Community leader Geoff Constable does it again at the Birdman Rally.

Geoff, living with Young Onset Parkinson's and his spirited team, the PD Avengers, returned to the Birdman Rally, a long-held Moomba tradition.

For the past three years, the PD Avengers have made ingenious flying aircrafts to leap over the Yarra River, all in the name of raising awareness and funds for Parkinson's.

This year's event was particularly special, with teammate James piloting their craft, designed with innovative bat wings by Geoff himself. The team's hard work and creativity paid off as they soared to an impressive second place.

Geoff, who has been the PD Avengers' pilot for the past two Birdman rallies, was a media sensation, sharing his inspiring journey and motivation with Channel 7 and Channel 10. His message was clear: raising awareness about Parkinson's and supporting the community are at the heart of his mission.

Geoff's tireless advocacy and enthusiastic participation in events like the Birdman Rally are truly commendable. This event raised over $10,000 for the Parkinson's community.

Congratulations to Geoff, pilot James and the PD Avengers team for their incredible accomplishments and ongoing dedication to raising awareness of Parkinson's.

The day was made even more memorable with congratulations from Sally Capp, Lord Mayor of Melbourne.

Fundraising & awareness-raising

For PSP Awareness Month: sharing Dana's story

May is PSP Awareness Month: a reminder of the incredible power of support and the importance of awareness and research for PSP.

Dana Walker, originally from the US, lives with her husband Dean and their two sons, aged 14 and 17. Before her diagnosis in 2020, Dana worked alongside Dean in their company. However, her life took a challenging turn when she was diagnosed with PSP, a rare and rapidly progressing neurological disorder.

Over the past four years, Dana's condition has significantly progressed. She has gone from using a walking frame to being in a wheelchair full-time. Despite these challenges, Dana's spirit remains strong, thanks to the support of her loved ones and a dedicated health care team that includes her physiotherapist, speech pathologist, and support worker, Deanne.

Deanne accompanies Dana to her appointments and supports her with exercise and daily activities, ensuring she stays as active as possible.

In a heartwarming show of solidarity, Dana's close friends formed Dana's PSP Walking Warriors, a fundraising team dedicated to raising awareness and funds for PSP research.

"Every time you talk about PSP, people often don't know what it is. It's important to get the word out there," Deanne explained.

The group's dedication and ambition to support Dana was so strong that they decided to bite off a 30km hike in Daylesford as their first fundraising event.

Dana's PSP Walking Warriors about to embark on their 30km hike in honour of their dear friend, Dana.

Deanne recalls the event as challenging yet rewarding: "We had people with different fitness levels. Some were struggling a bit, but we supported one another and tackled it as a team. At the end of the day, we were all there to raise money for Dana."

In addition to the hike, Dana's PSP Walking Warriors organised a trivia night and silent auction at a bar in Emerald. The event drew a significant crowd, including Dana who came along and enjoyed the fun.

To boost the team's fundraising efforts, Dana's favourite local café gathered all their tips and then matched the total. This heartwarming gesture was commemorated with a cheque presentation held at the café where Dana was surrounded by her loved ones.

Dana's PSP Walking Warriors have come together with determination, raising over $4,000 to support Dana and raise the profile of PSP. Their dedication, coupled with the support of Dana's local community, has ensured additional funds to strengthen their cause even further.

Dana's story and the efforts of Dana's PSP Walking Warriors highlight how people can come together to bring hope to those affected by PSP.

A function was held to commemorate the café's heartfelt contribution to the fundraiser, with Dana, her loved ones and Fight Parkinson's in attendance.

Fight Parkinson's™

Together we can

During this time of year, a member of our community shares their personal experience of living with Parkinson's. We are very grateful to Shona for bravely sharing her story with us as part of our current appeal.

Community member Shona Cross has been accessing Fight Parkinson's services and support since being diagnosed with Parkinson's eight years ago.

Shona was working full-time in a food processing factory. Alarmingly, she started passing out at work and she struggled to find answers to her concerns. Eventually, Shona was forced to stop working and she went on a disability pension, still grappling with an undiagnosed condition.

For several years, Shona sought answers for different health symptoms until she discovered she had Parkinson's. "I knew something wasn't right, but when I got the diagnosis, I thought, why should it happen to me," Shona said.

Following her diagnosis, Shona reached out to Fight Parkinson's, where she was connected to a support group in her local area. "The support group was amazing. They greeted me with open arms. The group has been very important and supportive of me," Shona shared.

Whenever Shona has needed support or faced a challenge, she has called Fight Parkinson's support line to get the vital information she needs.

After receiving her diagnosis, she and her partner made the decision to buy a camper trailer and travel around Australia as much as they could and they have been travelling ever since.

Twelve months ago, Shona decided to have Deep Brain Stimulation (DBS) surgery to help her continue living her active life. Leading up to the procedure, Shona joined the DBS support group which met regularly via Zoom. Shona connected with Fight Parkinson's for extra guidance and got the detailed information she needed to make an informed decision.

The procedure has allowed Shona to maintain a high quality of life whilst significantly reducing her medication from 11 tablets a day to now just one tablet per day.

Whenever she needs advice or answers for managing her Parkinson's, Shona calls the support line for help.

Over the last 12 months, we have received 4856 calls - a 58% increase from the 2021-2022 period. In February alone, we received 520 calls - the highest number of calls we have ever received in a month.

Calls to Fight Parkinson's free Health Information Line at a record high as we fill the gap in health services for the Parkinson's community.

Call duration times to our support line remain high, detailing the complexity of issues individuals and carers in the community continue to face. For regional and remote areas, specialist support is not available, restricting the level of care the community receives.

We want to ensure that all people in the Parkinson's community can access the best possible support. Thanks to your generosity, Fight Parkinson's can continue to deliver vital information, education and support programs to the community free of charge.

Over the past 12 months, donations have supported:

- **66 community education sessions**
- **Over 4600 community members participating in online and in-person webinars and education programs**
- **65 active peer support groups**

Every donation ensures that people living with Parkinson's have access to our specialised health services and supports.

If you would like to support this appeal, visit fightparkinsons.org.au/donation or call us to make a donation on 03 8809 0400.

About Fight Parkinson's

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While submissions for inclusion in *InMotion* are welcome, the final decision rests with the editor. All submissions are subject to the publisher's editorial guidelines and may be edited for space or clarity.

Upcoming events

For the latest information on all Fight Parkinson's events, visit www.fightparkinsons.org.au/events or call us on 03 8809 0400.

DATE	NAME	EVENT DETAILS
Friday 12 July, 10.30–11.30am	**Online Singing**	Join our Volunteer Musical Leader and welcoming community members for a lively, open singing session on Zoom.
Thursday 18 July, 10.00–11.00am	**Positive Life**	Learn about the cognitive changes in Parkinson's and practical strategies to manage them.
Wednesday 24 July, 5:30–6:30pm	**Ask the Expert**	Neurologist Dr Wesley Thevathasan will explore frequently asked questions about Deep Brain Stimulation (DBS), as well as advancements in DBS and future possibilities.
Friday 26 July, 10.30–11.30am	**Online Singing**	Join our online singing community and get ready to belt out some tunes in the comfort of your own home.
Thursday 8 August & Friday 9 August, 4.00–5:30pm	**Recently Diagnosed Seminar**	Discover essential information for recently diagnosed individuals and their families. Topics include understanding the diagnosis, managing symptoms and accessing support services.
Wednesday 14 August, 5:30–6:30pm	**Ask the Expert**	Learn about managing finances, accessing government and other available entitlements for people living with Parkinson's. Featuring Principal Wealth Adviser, Kathryn Humphreys.
Thursday 15 August, 10.00–11.00am	**Positive Life**	Learn more about wellness, mindfulness and holistic health and how you can apply these approaches to live well with Parkinson's.