Issue 4 Summer 2025

InMotion

A magazine for the Parkinson's community

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Fight Parkinson's™
Together we can

In this issue:

- Understanding changes to My Aged Care
- Managing symptoms through the summer period
- Approaching Parkinson's with a palliative care mindset

CEO update

As 2026 approaches, we look back on 2025 with pride and with hope that the new year will continue to advance our mission towards a better future for those living with Parkinson's.

At the Annual General Meeting the Fight Parkinson's Board honoured two exceptional members of the Parkinson's community. These individuals embody the spirit of our community through their dedication to those affected by Parkinson's.

Shona Cross was awarded the Sir Zelman Cowen Award in recognition of her extraordinary commitment to raising awareness, supporting her community, and inspiring others through her story.

As a long-standing ambassador for Fight Parkinson's, Shona's willingness to share her Parkinson's journey has not only raised awareness but provided hope and encouragement to many others living with the condition.

Louise Zajac was honoured with the Harold Waldron Carer's Award.

Louise has been a pillar of strength in the Geelong Parkinson's community alongside her late husband Paul.

Louise has been touched deeply by Parkinson's and, through her steadfast support, long-term involvement, and commitment to community, has made a significant difference.

The presentation of the award was the first since Harold's passing in October and we welcomed Helen Waldren, his daughter, to present the award in his honour. Fight Parkinson's extends our heartfelt condolences to the Waldron Family on the passing of Harold, a much-loved and deeply respected member of the Parkinson's community and thank them for allowing us to continue honouring his legacy.

It is due to individuals like Shona, Louise, and so many of our volunteers offering their time and dedication, that we can continue to support those living with Parkinson's, Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Corticobasal Syndrome (CBS).

I look forward to sharing more with you about our fantastic award winners in the next edition of *InMotion*.

I am pleased to share Fight Parkinson's new four-year strategic plan to guide us into the new year and to 2029.

This plan has been formed with community at its core, driven by community feedback and input, and we are inspired by our new vision: Freedom from Parkinson's - achieved through innovation, care, and prevention. Fight Parkinson's will continue to realise possibilities for people living with Parkinson's through providing research, education, and support. We look forward to using this plan to work with and support you over the next four years and towards a future free from Parkinson's. You can read more about the plan on page 4.

Expanding awareness continues to be a priority for Fight Parkinson's and we hope to share more opportunities to do so in 2026.

Get your calendars out and mark yourself busy on 19 April as we prepare for A Walk in the Park. This meeting of the Parkinson's community is commemorating its 15th year in 2026. We are ready to welcome new and familiar faces together to raise the profile of Parkinson's in a meaningful way. I am already forming my team, and I encourage you to do the same and help make this event, once again, a highlight of the year.

Since our last edition of *InMotion* the Fight Parkinson's team has been pleased to see many of you in person across various events.

Our health team has been travelling throughout the year to deliver seminars to local communities providing the latest advice and support. It has been important to see so many of you attending these events to become and remain empowered in your care. We are grateful to those who have supported this series, and I am pleased to confirm we will deliver more sessions in the new year.


Fight Parkinson's CEO Emma Collin

Details of confirmed seminar locations for 2026 will be available in the events calendar on the Fight Parkinson's website.

You may have noticed changes to the Fight Parkinson's website recently. Following community consultation and feedback the website has been redesigned to make it even easier to access expert Parkinson's advice and information online. We also ushered in our new freecall 1800 931 031 number for expert support. The Fight Parkinson's Health Team is just a call away and ready to support you.

Looking toward 2026 and beyond, we will continue working with community to advance Parkinson's awareness, care, and research opportunities.

Over the coming year we will share more research opportunities and developments on major projects, including the finalisation of the National Parkinson's Action Plan for delivery to government, and continuation of the ParkinsonNet pilot project for Australia.

In these pages you'll find valuable information and stories from our vibrant community. We are privileged to share the unique stories of people living with Parkinson's, PSP, MSA, and CBS. To everyone who has shared their time, insights, and expertise throughout this edition, we extend our deepest gratitude.

I look forward to meeting with and learning from the Parkinson's community over the next 12 months. Together we are working for freedom from Parkinson's achieved through innovation, care, and prevention.

Thank you for your unwavering support. I wish to express my gratitude to every member of our community. From our speakers, ambassadors, and appeal heroes who have generously shared their time and their stories, to our Fight Parkinson's Peer Support Group Leaders, who continue to create save spaces for people living with Parkinson's across the state. Thank you also to fundraisers, sponsors, and donors whom without we could not support the community in the ways we do.

As I wish you all the best for the new year, know Fight Parkinson's commitment to you and the entire Parkinson's community does not waiver.

Together we will create a better future for the Parkinson's community into 2026 and beyond.

Emma Collin

Emma Collin
CEO
Fight Parkinson's

News and highlights

Victor McConvey presents to community members at a Community Seminar.

Fight Parkinson’s Community Seminars

The Fight Parkinson’s Health Team has travelled across Victoria in recent months delivering in-person seminars to the Parkinson’s community.

These seminars offer valuable insights into Parkinson’s, explore current and emerging treatments, and help you recognise when claims about certain therapies may be too good to be true.

They have also featured a session from our Your Care, Your Choice* education program – an innovative initiative that helps people navigate health and community systems, find the right supports for Parkinson’s, and build skills in communicating needs, self-advocacy, and making informed choices.

The feedback from these community seminars has been overwhelmingly positive and a reminder that our community is always ready to support one another.

In 2026 the Fight Parkinson’s Health Team will continue to facilitate these seminars across Victoria. Peer support group leaders will be contacted if a seminar is to be held in their region over the coming months.

Fight Parkinson’s Community Seminars are free to attend. For information about upcoming seminars, visit our website https://www.fightparkinsons.org.au/events/

**Fight Parkinson’s is proud to be delivering projects for the Peer Support and Capacity Building (PSCB) grant for the NDIS. Together we’re ensuring that people with disability keep accessing supports to build their skills and connect with others who have shared similar experiences.*

New strategic plan

Fight Parkinson’s 2026-2029 strategic plan has been ratified by the Fight Parkinson’s Board.

Fight Parkinson’s new strategic plan – Driving equity, innovation, and impact, will guide our work over the next four years. It focuses on advancing equity, fostering innovation, and creating meaningful, lasting impact for the Parkinson’s community.

Developed in consultation with members of the Parkinson’s community, the plan sets the direction for how Fight Parkinson’s will continue working with and for the Parkinson’s community, providing guidance for all our work.

At the heart of the plan is our shared commitment to improving the lives of people living with Parkinson’s.

Our new vision statement - Freedom from Parkinson’s – achieved through innovation, care, and prevention – places hope and community at the core of our work.

Our mission is to work together to empower those living with Parkinson’s to lead fulfilling lives, advance advocacy efforts, and drive research toward effective treatment, care, and prevention.

Meanwhile, our values of inclusion, leadership, innovation, courage, and integrity empowers Fight Parkinson’s and our partners to push towards positive change for the Parkinson’s community.

This plan serves as a roadmap for our efforts to provide comprehensive support, drive research, and advocate for the Parkinson’s community.

Over the next four years Fight Parkinson’s will work towards four key strategic priorities:

1. Awareness and advocacy for change
2. Strengthen community engagement, education, and support
3. Best practice in care, advance research, and drive innovation
4. Sustainable growth, people, and digital transformation.

Enclosed in this edition of InMotion you will find an outline of the Fight Parkinson’s 2026-2029 Strategic Plan with further details.

News and highlights

Expert Parkinson’s advice now easier to access

Living with Parkinson’s, PSP, MSA, or CBS means you want reliable answers when you need them. That’s why Fight Parkinson’s provides free, confidential support from our multidisciplinary health team - and it’s now even easier to access.

Call our new freecall 1800 931 031 for expert support

Whether you’re newly diagnosed, managing symptoms, caring for a loved one, or need guidance on treatment options, our health team is here to help. Our experienced nurses, physiotherapist, speech pathologists and occupational therapist provide specialised Parkinson’s support:

- Personalised information about symptoms and treatment options
- Practical strategies for daily living and self-management
- Connection to local peer support groups and health professionals
- Navigation support of Australian health system and services
- Guidance for carers and families navigating Parkinson’s
- Access to our extensive resource library.

We are just a call away Monday to Friday, 9am–5pm AEST/AEDT (free translation services available).

Find everything you need any time at fightparkinsons.org.au

Our newly enhanced website makes it simple to access the full range of Fight Parkinson’s services:

- Free online courses through our community learning hub
- 70+ peer support groups across Victoria for connection and shared experiences
- Recently Diagnosed Seminars designed for those diagnosed within the past five years
- Expert resources on everything from managing symptoms to accessing NDIS support.

We’ve redesigned the site with your feedback in mind, clearer navigation, more comprehensive information, and easier access to the support you deserve.

Take the next step: Call 1800 931 031 or visit our website fightparkinsons.org.au.

New online courses

Fight Parkinson’s launches new courses on Community Learning Hub and Health Professionals Learning Hub

Sex, intimacy and Parkinson’s

Talking about sex and intimacy can be difficult, and it can be hard to know who to seek advice from when problems arise. Changes to sex and intimacy are a common symptom of Parkinson’s and can have a great impact on you and your partner’s quality of life.

If you are after a more in depth understanding of how Parkinson’s affects sex and intimacy, Fight Parkinson’s has a new short course on our Community Learning Hub.

The course shares information about sexual function and Parkinson’s, dispels some common myths, and shares practical solutions for the changes you might be experiencing.

This course is free for all members of the Parkinson’s community. If you are new to using the Community Learning Hub you can sign up using the code WELCOME. If you already have an account you can find the course on your home page. To get started visit our website.

Advanced and palliative care for Parkinson’s

Discussing advanced and palliative care can be a confronting task, especially if you are working with health care professionals who have limited experience with Parkinson’s.

Fight Parkinson’s new course for health care professionals aids them in understanding the unique challenges involved in caring for people living with Parkinson’s.

Designed for those working in aged care settings, this course covers the symptoms of advanced and Atypical Parkinson’s, complex symptom management, and palliative care.

If you are speaking with your team about advanced care you may recommend they complete this course. Your team can find further information on our website.

Sheenagh at WPC

Sheenagh's abstract poster on Young Onset Parkinson's displayed at the 2023 WPC

Parkinson's community to connect across the globe

Sheenagh Bottrell was diagnosed with Young Onset Parkinson's in 2011. Soon after, she found herself advocating for the Parkinson's community and quickly became an invaluable support for others diagnosed at a young age.

Sheenagh's dedication to the Parkinson's community led her to being named Australia's 2026 World Parkinson Congress (WPC) ambassador. She shares her experience with WPC and why she believes anyone who is able to attend the 2026 conference should.

In 2023, I had the incredible opportunity to attend the World Parkinson Congress (WPC) for the first time in Barcelona. I was encouraged to go by a fellow WPC Ambassador, and Fight Parkinson's CEO Emma Collin, both of whom had attended previously and spoke so highly of the experience.

To make the trip possible, I created an abstract poster and successfully applied for a travel grant. My poster focused on being diagnosed with Young Onset Parkinson's, the lack of understanding that still exists within the wider community, and my personal journey in advocating for greater awareness and support.

When the Congress began, I'll admit I was a little overwhelmed. There were thousands of people, an enormous program of talks and activities, and so much to take in. I quickly realised I probably should have read the schedule a bit more carefully! But after that first day, I began to settle in and really enjoy the experience.

The Congress offered an extraordinary chance to learn directly from researchers, clinicians, allied health professionals, carers, and people living with Parkinson's from across the globe. Each conversation was inspiring, but one story in particular stayed with me — a woman in Africa who had been outcast from her village because her tremor was believed to be a sign of possession. It reminded me just how fortunate we are to have access to education, support, and understanding here in Australia.

I returned home with new knowledge, stronger connections, and a renewed drive to continue my advocacy work. Soon after, I was encouraged to apply for the role of WPC Ambassador. I was deeply honoured to be selected to represent the people living with Parkinson's in Australia at the next Congress to be held in Phoenix, Arizona in May 2026.

If you have the opportunity to attend, I highly recommend you do. The World Parkinson Congress is a truly uplifting experience, a global gathering that celebrates learning, empathy, friendship, and hope. It reminds us that while Parkinson's is a shared challenge, it also connects us to a worldwide community determined to fight Parkinson's together.

The 2026 World Parkinson Congress will be held on Sunday 24 May to Wednesday 27 May 2026 in the United States. Further information on the event can be found on their website www.wpc2026.org. Early bird registrations close on January 15, 2026.

Members of the Fight Parkinson's community together at the 2023 WPC

A Walk in the Park

Save the date

APRIL
19

Australia's biggest community event supporting people with Parkinson's is back again in 2026.

After another hugely successful year in 2025, we look forward to welcoming the Parkinson's community together for our 15th A Walk in the Park.

For 15 years, we've watched as our community has grown in strength and numbers, uniting annually to support one another to fight Parkinson's.

Our flagship walk at Federation Square in Melbourne will be held on April 19 with regional walks across Victoria scheduled throughout the year.

A Walk in the Park brings together thousands of people, including those living with Parkinson's, their families, friends, and carers, and professionals working in the field, to raise awareness and funds to fuel hope.

Now is the time to begin thinking about how to get involved for 2026. Whether as an individual or with a team, everyone is welcome to join us for A Walk in the Park.

What you can do now

- Save the date: Sunday 19 April
- Start building your team with your family and friends
- Visit our website www.awalkinthepark.org.au for more information.

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

Hear why our community walked in 2025

"As a family, Parkinson's has definitely taught us to be a united front, we've all come together for my father, but also for mum, making sure she's got the support because she's the carer day to day, whilst we are out of home and not seeing dad as much."

A Walk in the Park ambassador, Georgy Hicks

"Young Onset Parkinson's is basically people of working age. Parkinson's is traditionally seen as something older people are diagnosed with, so I'd like to raise a bit more awareness that younger people are also diagnosed, such as myself being diagnosed when I was 51. I've still got a working career ahead of me, so Young Onset is important to understand."

A Walk in the Park ambassador, Peter Brown

"As an ambassador, I would like to reach out to people to show that there's more people out there that can help. There's so many people with Parkinson's these days, and no one really knows what they go through. There's no two people the same. It's things like this that help greatly with the support for Parkinson's."

A Walk in the Park ambassador, Jeanette Branch

Managing symptoms

Tips and tricks for enjoying the social season

The summer months can be filled with family, friends, and warm day trips, but as our calendars get busier, it can be difficult to manage your Parkinson's symptoms as well.

Fatigue is a common symptom for people living with Parkinson's, and when we are adding more outings and get togethers across the holiday period to our schedule, fatigue can feel overwhelming.

While fatigue and sleepiness are often used interchangeably in conversation, they are different symptoms.

Fatigue is the persistent feeling of exhaustion irrespective of whether you have a good sleep or not, while sleepiness is the urge to fall asleep often due to poor or broken sleep or a side effect of dopamine agonist medication.

Feelings of fatigue can change from day to day, especially when your schedule is changing due to additional commitments. You may feel quite fit and able one day and then too tired to do much the following.

It is essential to listen to your body when you are fatigued and take rests as required.

Managing fatigue

There are several measures you can take to help combat fatigue. Depending on your situation, when you are experiencing fatigue, and how frequently you are experiencing it, your best treatment option may vary.

There are also certain pre-emptive steps that you can take to help combat fatigue, some management strategies can be useful in the moment, while others have long-term benefits.

Ways you may manage fatigue include:

- **Medical solutions:** Talk to your healthcare team about adjusting your medications.
- **Energy management:** Pace yourself with regular breaks and adjust your routine to conserve energy.
- **Exercise:** Regular physical activity can boost energy levels and build exercise tolerance.
- **Sleep schedule:** Maintain a regular sleep routine.
- **Short breaks**: Take frequent, short breaks. Make a cup of tea, chat with a friend, or rest with your eyes closed.
- **Divide tasks:** Do household jobs you can manage more easily and ask someone to help you with those you struggle with.
- **Stay engaged**: Keep up with hobbies and interests to avoid boredom.
- **Healthy diet**: Eat a balanced diet with regular, healthy snacks to maintain energy levels.
- **Understand limitations:** Pace yourself and respect your limits.

Everyone's journey with Parkinson's is unique, so it may take time to find the best strategies for managing fatigue.

If you are experiencing consistent fatigue symptoms, you may need to visit your GP to discuss other treatment options or potential adjustments to your medications.

For further support and information, you can contact Fight Parkinson's on 1800 931 013 or at info@fightparkinsons.org.au.

Tips for travelling with Parkinson's

If you're travelling this summer, planning ahead for road trips, long airport walks, and time zone changes can make for a stress-free holiday.

Australians like to travel and travelling when you're living with Parkinson's is possible. Extra planning will ensure you can travel well and enjoy your time away.

Navigating airports and major train stations

If you are travelling by train or plane there can be significant walks between the entrance and your gate or platform. Most major airports and stations have assistance programs that can help you get from point A to point B safely.

Most airports and major railway stations have free assistance programs that can help you move between departure points via wheelchair or buggy.

Booking these services in advance can help prevent delays, though they are also available on a walk-up basis.

If you are travelling by plane, you can reach out to your airline when you book or before departure to request a seat closer to the bathroom or assistance navigating the airport or boarding if required.

You may also find it helpful to research drop off areas for stations and airports prior to your trip. This can help reduce how far you need to walk before receiving travel assistance.

If you have had DBS surgery be aware that some security scanners may affect DBS signals. Tell security that you have a 'pacemaker-like device' and they will pass you through a different security screening process if required.

Stretching and resting on road trips

Living with Parkinson's can affect many drivers, but it doesn't necessarily mean that you will have to stop driving.

Whether you're a driver or a passenger, a long road trip can lead to aches and pains.

Stopping regularly when driving is essential to managing fatigue. Be aware of when you take you medication and take a break before it is due, try to avoid driving when you are wearing off. Taking regular stretch and medication breaks will help prevent feelings of stiffness and discomfort and will keep you driving safely.

Medications when travelling

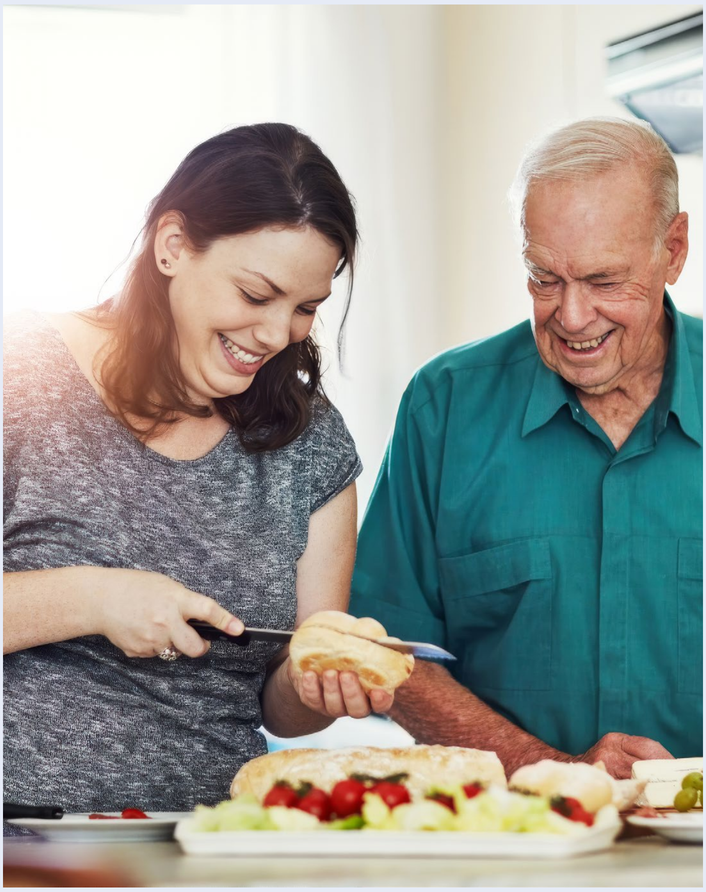
Many Parkinson's medications need to be carefully timed to ensure their effectiveness. Travelling interstate and/or internationally can result in crossing time zones, which can lead to complications when trying to plan when to take your medications.

If you're travelling to a different time zone, think about how you're going to plan your medication schedule. The Fight Parkinson's Health Team can help with managing different time zones and medications.

When you pack your medication, be sure to pack more than you need in case you stay longer or are delayed. Carry medication and any medical equipment such as your DBS charger and programmer in your hand luggage. Most airlines do not include medical devices as part of your carry on luggage allowance. Ask your GP to write you a letter describing your condition and the medications that you take, this may be useful as you go through security or customs and in case treatment is needed at your destination.

If you have questions about navigating travel while living with Parkinson's you can contact the Fight Parkinson's Health Information Line on 1800 931 031.

Support for you



Navigating the aged care system

Understanding and navigating the aged care system can seem complex and overwhelming. Ongoing changes to how the system works can exacerbate frustrations and lead to further misunderstandings.

If you are over 65 you can access aged care services via My Aged Care, the Australian government's gateway to help older people get the support they need.

My Aged Care offers a range of resources and support to help people understand and access various aged care services, whether they need assistance at home, respite care, or residential care.

Should I be considering aged care services?

Seeking assistance does not mean losing your independence, in fact it can mean maintaining it. Getting support with daily activities can help you can stay independent at home for longer.

If you have received a diagnosis of Parkinson's, MSA, PSP, or CBS, you might start to think about aged care services. Ask yourself the following questions:

- Can I still mobilise safely around home or in the community?
- Can I still perform daily activities that I used to manage independently or without causing excessive fatigue?
- Would I be able to manage at home if my support person was suddenly unable to support me?

If you answered no to any of these questions it may be beneficial to investigate what support is available to you now and for the future.

What government funded support might be available?

Receiving support will look different for everyone – it may include:

In home services to help

- Access the community and stay social
- Complete personal care tasks
- Plan and prepare your own meals
- Assist with household chores.

Nursing and allied health services

Nursing and allied health professionals including physiotherapists, occupational therapists, and speech pathologists may be available to assist with:

- Access to adaptive equipment (funded by My Aged Care)
- Recommendations for home modifications (funded by My Aged Care)
- Monitoring and managing chronic health conditions
- Managing continence issues.

Residential respite or permanent care

If you are unable to manage at home, you may also consider accessing residential care in an aged care facility which could be short term (respite) or long-term (permanent) care.

Am I eligible for government subsidised aged care services?

Services which are subsidised by My Aged Care are means tested. This means your income and assets are considered when determining if you will receive a subsidy or will need to make a co-payment to support the services you need.

Where do I start?

Before you can access government-subsidised aged care services, either in your home or residential care, you need to apply for an assessment. This can be done by calling My Aged Care or applying online.

After you apply, an assessment organisation will contact you. To ensure you do not miss the opportunity to book your assessment, it is best to answer all calls, including form private numbers, until you have booked your assessment.

They will confirm your needs and arrange an assessment, most likely in your own home. You will also receive a My Aged Care welcome pack in the mail containing helpful information and outlining what your next steps will be.

Will I need to wait for aged care assessment or services?

It is important to note there could be a lengthy wait for an aged care assessment. Once the assessment is complete there may also be a lengthy wait for services. Wait times are highly variable.

I already use My Aged Care, what has changed?

On 1 November 2025, the Support at Home program replaced the Home Care Package and Short-Term Restorative Care programs.

If you are already engaged with My Aged Care, or had an assessment prior to this date, your package coordinator will contact you in relation to any changes you may experience.

For further information

If you have further questions, you can contact My Aged Care (www.myagedcare.gov.au) or the Australian Government Department of Health, Disability, and Ageing (www.health.gov.au).

You can also contact Fight Parkinson's to discuss your individual situation on 1800 931 031 or info@fightparkinsons.org.au.

Research

Social support and quality of life

Psychologist Lou Cooper completed post-graduate research on Parkinson's and social support in 2005 but despite the passing of time, her findings remain as pertinent as ever.

Dr Cooper investigated the importance of social support in relation to quality of life for people living with Parkinson's and was interested in the impact of different types of this support.

What is social support

In its simplest terms, social support can come from any social interaction. It could be through small talk with your barista, catching up with friends and family, or seeking professional assistance from your multidisciplinary team.

Each person you interact with in your day-to-day life is important in your social support.

"Social support really just means having people in your life," Dr Cooper said.

"They may be colleagues or neighbours; it is all based on social interaction."

Buffering Parkinson's impact

Dr Cooper set out to explore the hypothesis that social support from spouse, family, friends, health providers and support groups would individually be beneficial to people with Parkinson's.

Working with a sample of 124 people living with Parkinson's, Dr Cooper found support for this hypothesis, and that social support buffered the adverse effects of Parkinson's on individuals' quality of life.

Choosing to focus on quality of life in her research was important to Dr Cooper. While she said her findings felt somewhat obvious, having the completed research is important in backing up statements on the importance of social support. It allowed Lou to champion the importance of social support in her work as a psychologist.

"Parkinson's can have many negative impacts on quality of life, but when there is social support, the impact of Parkinson's is less," Dr Cooper said.

"In other words, social support is really important in helping people maintain quality of life."

Some study participants even spoke about Parkinson's as a blessing. Diagnosis increased their quality of life by pushing them to evaluate their priorities and acting upon them, often through increased social interactions.

While Dr Cooper's research showed that all kinds of social support are beneficial to people living with Parkinson's, she found that support from friends and family is especially important.

Finding support outside of home

Seeing your friends or family can feel reenergising in the moment, but Dr Cooper's work suggests there are long-term benefits too. Participants in Dr Cooper's study indicated support from family and friends was found to have a stronger beneficial effect on the lives of people living with Parkinson's than that of their spouse.

This is not to say that people living with Parkinson's do not find support from their spouse beneficial. Of course not, this is a primary source of support. But the increasing intensity of spousal relationships as Parkinson's progresses makes support from others outside of the home increasingly important.

"The partner often becomes a primary carer and takes on this role with love. But it's also going to be a very intense and difficult relationship at times," Dr Cooper said.

"The results of this research were not saying that spouses or carers aren't important, rather it's stressing the importance of trying to maintain friendships and relationships with other family members, and it's also important to let those friends and other family members know how important their presence and support is".

Speaking up about support

Dr Cooper also encourages people living with Parkinson's to be explicit in the types of social support they want or need.

Without this conversation, she said, you may find yourself receiving the wrong kind of support.

"Support or care from people is given with the best of intentions but people actually don't always know what's needed," Dr Cooper said.

So it's really helpful for people with Parkinson's to try and be explicit about what it is that they need because without communicating this, there's a high possibility of you getting some kind of support that isn't appropriate or helpful. There is nothing like being told exactly what might be helpful to motivate people to offer support".

"If you can, it's going to be really beneficial to say, 'this is what's going on for me, this is how it impacts me, and it would be really helpful if you could do X, Y or Z'. People love to hear that."

If you would like to expand your social connections, joining a Fight Parkinson's Peer Support Group could be of interest. With more than 70 groups across Victoria, these groups are a great way to connect with others living with Parkinson's. You can read more about Fight Parkinson's Peer Support Groups on page 15.

Dr Benzie Kluger - Research Symposium 2025

The palliative approach to care in Parkinson's

The term palliative can be confronting, but Dr Benzi Kluger wants us to consider the true definition of palliative care which focuses on excellent symptom management by a team of health professionals centred around the person with Parkinson's from diagnosis to end of life.

Defining palliative care

Dr Benzi Kluger, Professor of Neurology and Director of the Palliative Care Research Center at the University of Rochester Medical Center, wants people living with Parkinson's to rethink what palliative care can mean — starting from the moment of diagnosis. He emphasises that this approach is not about initiating end-of-life care early, instead, it's about ensuring people living with Parkinson's have earlier access to support that enhances joy, wellbeing, and quality of life throughout every stage of their journey.

Dr Kluger describes palliative care as a "choose your own adventure" approach to living with Parkinson's. It focuses on allowing you, your care partner, and family to prioritise the outcomes that are important to you over many years as your condition progresses.

Dr Kluger encourages people living with Parkinson's to not only consider their clinical outcomes but how they can live with more love and joy in their lives despite a Parkinson's diagnosis.

"In a nutshell, my definition of palliative care is 'living your life as well as possible with an illness that sucks'," Dr Kluger said.

It's a philosophy that has merits, with Dr Kluger previously working on research that showed positive outcomes for those taking a palliative approach to living with Parkinson's. They were encouraged to look beyond clinical symptoms and at the social and emotional impact of Parkinson's on their lives to adapt their care to better address those concerns.

"We don't want to get rid of the things that we're doing, like DBS and other types of research, but we want to add to it," Dr Kluger said.

"We want to have this complementary layer of extra support for everybody living with Parkinson's."

The pillars of care

When looking at the impact of neurological conditions, such as Parkinson's, on individuals and their support networks, Dr Kluger identifies five pillars of care and what they incorporate.

- Physical (tremor, pain, motor function)
- Emotional (anxiety and depression)
- Practical (financial concerns, future needs, transportation limitations)
- Social (stigma, isolation, loneliness)
- Spiritual (loss of meaning, hopelessness, loss of identity and independence).

Early integration of palliative care principles can ensure people living with Parkinson's are holistically well, Dr Kluger said.

However, Dr Kluger said many clinicians miss the mark when it comes to addressing social and spiritual concerns. Without addressing them, he said people are missing out on the opportunity to pursue joy.

Even small changes, such as including a positive mindset in your approach – for example, focusing on what is working, not what is broken – can help improve your experience living with Parkinson's.

Building a palliative approach into your care can be as simple as speaking with your multidisciplinary team or extending it to include additional supports such as a social worker, psychologist, or chaplain to address psychological and spiritual needs.

"If you are struggling emotionally, struggling with limited quality of life, if care partners are struggling and needing guidance, if you're feeling like you're moving your way forward one day at a time in the dark. Those are all reasons to consider palliative or supportive care," Dr Kluger said.

"It's not about giving up. It's really about asking yourself how do I want to live my life going forward."

By working with your care team to address your physical, emotional, practical, social, and spiritual concerns, you can ensure you can keep doing the things that matter most to you.

If you are interested in hearing Dr Kluger's full presentation on taking a palliative approach to Parkinson's, please contact Fight Parkinson's via email for access to a full recording.

Personal story

How Fight Parkinson's helped Wendy through diagnosis

Without the right information and support, a Parkinson's diagnosis can be overwhelming.

Over a long career in physiotherapy, Wendy supported many patients living with Parkinson's and had done all the training available to her on the condition.

But none of that made her own Parkinson's diagnosis any easier.

"It's the most badly handled thing I've ever come across," she remembers.

"They just gave me my diagnosis, and no one checked in on me to see how I was, or if I needed help. I was left feeling confused and uncertain about what it all meant, and what I needed to do."

Wendy says the biggest challenge she faced was getting a clear picture of what her Parkinson's journey would look like, and what her treatment options were.

"My dilemma was that the specialists didn't actually know all the information," she said.

"They didn't take the time to explore my individual needs, or which treatments would best meet those needs. Most didn't even know about other treatments that were becoming available at the time."

The Fight Parkinson's Health Team helped Wendy fill in critical information gaps about her diagnosis and treatment, which eased many of her worries.

"I learned that Parkinson's doesn't have to be as bad as I first feared," she said.

"You can still live a long, full life if you've got the right treatment, and you respond to symptoms as soon possible."

In the years since her diagnosis, Wendy has become a prolific and talented painter, something she says keeps her brain active and allows her to express her creativity.

Careful management of her treatment and symptoms has also given Wendy more precious moments with the people she loves.

"One of my favourite things is spending time with my four grandkids. I get a lot of pleasure from doing things with them, and I'd hate not to have them in my life."

Wendy says the expert advice she's been able to access from the Fight Parkinson's Health Team has been vital to enjoying quality of life for as long as she has.

"They've been brilliant," she said.

"They give me answers that my own medical professionals cannot, and they're always very helpful and encouraging."

As Wendy's Parkinson's symptoms have progressed, the Fight Parkinson's Health Team has been a vital source of information on complementary treatments better suited to her changing needs.

These treatments included therapeutic procedures like Deep Brain Stimulation (DBS), which address movement symptoms and debilitating side effects of common drug treatments, and technology like pumps, which deliver medication continuously beneath the skin to provide more stable symptom control and more flexible, individualised dosing.

"If it wasn't for Fight Parkinson's, I wouldn't have known about those advanced therapies," Wendy said. "And I wouldn't be benefitting from them today."

The Fight Parkinson's Health Information Line provides people with free access to physiotherapists, occupational therapists, speech therapists, and specialist nurses.

Would you like to donate this Christmas to help make sure people living with Parkinson's always have access to the very best health advice? Scan the QR code or visit our website www.fightparkinsons.org.au/donate.

Fight Parkinson's helped Wendy understand her Parkinson's diagnosis

Personal story

Navigating Parkinson’s together

Rey and Nene Amen’s lives changed when Rey was diagnosed with Parkinson’s. Nene generously shared her story with the ParKanDo community this year. These are her words.

Caregiving is a life-changing experience.

After 39 years of working in the corporate world, I happily retired with a plan to check the boxes off our bucket list with Rey. The transition into retirement was going well, but Rey’s Parkinson’s diagnosis in early 2025 came unexpectedly and was mind-blowing.

The diagnosis

Before his diagnosis, Rey was independent, pursuing his hobbies, and enjoying time with our children and precious grandchildren.

His diagnosis was a life-changing experience for our family. The emotional, physical and mental demands of caregiving was a shock. There was a feeling of loss. One day we were both living independently, the next was a sudden transition into a role requiring constant attention, patience, and compassion, without prior preparation.

In retrospect, Rey’s symptoms started to manifest a few years before his diagnosis. We noticed subtle changes in his walking, stiffness in his left arm, and changes in speech. We thought it was part of ageing.

After a series of doctor visits to address a vision issue, Rey’s specialists confirmed his Parkinson’s diagnosis, a condition I knew nothing about. It was shocking to hear Parkinson’s is a progressive illness and has no cure – two words that make me sad and fearful.

As we were recovering from the shock of the diagnosis, I started to ruminate on what the path forward was. The diagnosis was unsettling, and I did not know where we were headed. I experienced intense emotions thinking about what we can do to delay Rey’s progression.

I was stressed and overwhelmed by the unknown challenges ahead. I was fearful of the caregiving responsibilities, because I am getting older. I felt sad thinking of Rey losing independence, including the emotional toll on his quality of life. I developed anxiety that led to a sleep disorder and high blood pressure – my first time ever experiencing these symptoms.

Understanding and coping with the diagnosis

Counselling helped us process and manage the emotional and mental impact of the diagnosis and learn coping strategies. It helped Rey rebuild his sense of identity, that he was the same person who happens to have Parkinson’s. For me, the sessions offered practical guidance on caregiving tasks, and I learned the importance of self-care to reduce caregiver burnout.

Actively communicating with the team of specialists regarding medication management and how to manage the symptoms has been invaluable. Coordinating with allied health professionals in creating a preventive care plan is also extremely helpful.

Integrating peer support systems

To cope with this new reality, I am educating myself to better understand Parkinson’s. I visit websites and listen to podcasts.

Support groups are life savers. The Fight Parkinson’s Werribee Peer Support Group and ParKanDo have been that for us. They provide opportunities for social connections and a safe place to share lived experiences, recognising that we are not alone in our journey. We get to learn from speakers about Parkinson’s, the importance of regular exercises and breakthroughs in research that give us hope that things will get better – not to mention the friendly conversations over tea!

Parkinson’s is a new challenge for Nene and Rey to face together

Incorporating spiritual health and self-care

Our Christian faith of constant prayers and scripture readings has greatly helped us find peace, comfort and hope as we navigate the storms and uncertainties of life.

In the area of self-care, I manage my physical health by getting enough sleep and regular exercise. I seek help from my children with some of the care responsibilities so I can get regular breaks. I have started attending carer peer groups and participating in mindfulness activities.

Moving forward

While hoping that a cure will come sooner than later, Rey and I agreed that we will not allow Parkinson’s to defeat us and will do everything we can to delay the progression by:

- Actively prioritising exercise and adhering to lifestyle factors like adequate sleep and wellbeing
- Maintaining strong support systems - support groups and social connections
- Actively seeking professional help to manage symptoms
- Adapting to changes and moving on with life, like carrying on with the daily activities and resuming holidays again.

Everyone’s journey is different. Let us find joy in life as we are experiencing it, because we can’t go back again. I end with this quote from Jon Kabat-Zinn, “you can’t stop the waves, but you can learn to surf”.

Personal Story

The two Me's

Rene Vivian has lived with Parkinson's for over a decade. In July 2020, she penned this personal piece detailing her experience living with the condition and the 'other' Rene she misses. She has shared her words to help others know they are not alone facing the challenges Parkinson's can bring.

Every morning my 'other' me springs out of bed bright and early, ready to face the coming day with vigour and vim. Perhaps she'll do a wash and hang it out to dry in the lovely light breeze, cook her loved one a tasty breakfast, or potter in the garden. Perhaps pop down the street to do a little shopping or just to socialise, before preparing a tasty midday meal, and catching up with all those little things that are always there to be done.

Meanwhile, the 'real' me has struggled out of bed, with the help of the trusty bedrail, had a shower of sorts (thank God for shower chairs and handrails), before going back to get dressed. Since when have my feet been so far away from the rest of my body? By the time I have put on socks, shoes and slacks I feel I have had my workout for the day, and it's not even breakfast time! I grab my trusty wheely, check my appointment book (once known as my social engagements book) for podiatry, physio, and specialist appointments. At regular times during the day the alarm on my mobile sounds, reminding me to take my medication.

In the evening, the 'other' me may go dancing with her loved one or watch TV; perhaps one of the quiz shows that she participated so successfully in, before going off to bed still fresh and vibrant, turning to her love for a hug before falling asleep contentedly in his arms.

But in reality, the only part of the 'real' me to dance is my dancing hand; better known as Parkinson's tremor. I may watch some quiz shows, answering the questions and imagining what will never be; winning. Then off to bed after the last of my medications, and another strenuous workout as I struggle to roll over in bed, only to finish somewhere in between, stranded like a beached whale, puffing and panting, and I'm still not in a comfortable position.

I squeeze my love's hand, tell him I love him and wish him "Goodnight, God bless, and thank you Darling for all the little things you did today, as always, to make things easier for me".

Then, while he sleeps, I toss and turn until my legs wear themselves out and I settle to sleep, waking to dreams of what the Parkinson's girl will be able to achieve tomorrow, whilst the other me has got up and gone out for the day with my darling family, perhaps morning tea, a movie, or a trip to the beach.

Then I remember, with gratitude and a sense of wonderment, the myriad aids and devices to assist us in all manner of ways, streamlining what must have been such a great trial years ago.

As the song reminds me, "some days are diamonds, and some days are stones". I cannot wait to see what tomorrow may bring; above all, the loving care and concern of my love and my beautiful children – I know I'm truly blessed.

So even on the stony days, you may find shimmers of diamond in the shape of newly shooting spring bulbs, with their promise of brighter days. Even on the cloudiest, overcast days, a chink of light breaks through briefly; so enjoy the moment.

Reach out for support from your local Parkinson's group or The Fight Parkinson's Health Information Line, where understanding people are always ready to answer every query. Find a local GP who is prepared to listen and lastly, a neurologist whom you can place all your faith in.


Rene has shared her reflection of living with Parkinson's

Support for you

Building community and strength: Joining a Fight Parkinson's Peer Support Group

Fight Parkinson's Peer Support Groups can be a vital component to living positively with Parkinson's.

Living with or caring for someone with Parkinson's can be challenging, but you don't have to feel alone.

Peer support groups offer people the opportunity to learn more about living with Parkinson's and to enjoy the company of others who share similar experiences, situations, and challenges.

Fight Parkinson's facilitates more than 70 peer support groups across Victoria including 8 special interest peer support groups and 18 activity groups.

A Fight Parkinson's Peer Support Group is a gathering of people whose lives are affected by Parkinson's. Each peer support group is unique in its membership and style. Most Fight Parkinson's groups meet once a month, some meet every couple of months, while others meet weekly. Some groups are associated with a local healthcare service, while others are run by dedicated members of the community who may or may not have Parkinson's.

Your first time

If you are not part of a peer support group yet and would like to be, one of the hardest steps can be walking through the door for the first time. Once you've made the decision to attend however, most people find attending a group to be helpful and supportive.

Speaking to a member of the Fight Parkinson's Health Team is the first step. They can help you find a group near to you and walk you through what to expect at your first session.

The team can also assist you in finding specialised groups if you are affected by MSA, PSP, CBS or have been diagnosed young.

Fight Parkinson's Peer Support Groups are free to attend and run by volunteer community members.

For information about your closest peer support group call the Fight Parkinson's Health Team on 1800 931 031.

Marie and I joined the Fight Parkinson's Werribee Parkinson's Support Group in 2015. Marie, (my wife) had been diagnosed with Parkinson's around 5 years earlier. We'd joined the peer support group to access information and advice regarding contemporary treatments, current research, and as a source of support and advice to people undertaking the journey.

We found more though.

At our group Marie and I came into direct and regular contact with people on their own Parkinson's journey. We shared stories and experiences, we discussed our tribulations and our triumphs, we shared our journeys. Marie and I came to realise that we weren't taking our own journey alone. There was something very comforting and supportive in coming to this realisation. The people we shared our journeys with became our life-long friends.

Marie died in December 2022.

I don't have Parkinson's but I continue to stay involved with the Fight Parkinson's Werribee Parkinson's Support Group in an assisting role. I do so because I saw how much the group meant to Marie, and how much her life was improved because of her involvement with the group. I also do so because the journeys for my friends are still ongoing and they're still happy to share with me. That means a lot.

Dennis, Fight Parkinson's Werribee Parkinson's Support Group

The Fight Parkinson's North East Peer Support Group has only recently been formed. The aim of the support group is to bring together people with Parkinson's and their carers in a supportive environment. The group provides the opportunity for members to discuss their experiences with Parkinsons and to pass on any words of wisdom that may be advantageous to others. We share tips such as where to get assistance at airports - which may not be that well known - or where to get help from Fight Parkinson's through either the website or the Fight Parkinson's Health Team.

It is also a forum to discuss any issues people have with Parkinson's in a friendly non-confrontational environment.

A further aim of the group is to introduce guest speakers, such as physiotherapists, exercise scientists, and exercise physiologists, who might be able to assist members to live well with Parkinson's.

Peter, Fight Parkinson's North East Peer Support Group

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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