Issue 3 Spring 2025

InMotion

A magazine for the Parkinson's community

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Fight Parkinson's™

Together we can

In this issue:

CEO update

As we welcome spring, we are reminded of the power of renewal, connection, and growth. Just as the season brings light and warmth, it is the sharing of experiences and voices within our community that brings hope and change.

Together we are stronger, and together we are building a better future for people living with Parkinson's.

Over recent months, many of you have taken part in National Parkinson's Action Plan workshops and surveys. The response has been extraordinary. By openly sharing your experiences, needs, and hopes, you are helping shape a plan that truly reflects the voices of our community. This engagement is at the heart of everything we do, and we are deeply grateful for the honesty and courage you bring.

We now enter the next critical stage, taking your experiences and using them to shape the national plan. You can read more about how the project has progressed on page 3.

One exciting opportunity ahead is the World Parkinson Congress (WPC), now less than nine months away. In May 2026, the global Parkinson's community will gather in Phoenix, Arizona, bringing together people living with Parkinson's, researchers, and clinicians to share knowledge and experiences.

Board member Sheenagh Bottrell is an Australian ambassador for WPC. She is eager to connect with our community and share what makes this international gathering so special.

On the back page of this edition, you can read about WPC grant and abstract applications.

Closer to home, as an organisation we welcome the Victorian State Government's renewed funding commitment to the Parkinson's community

The government contribution of $738,00 will in part fund our essential secondary health consultancy service and will be distributed over the 2025/26 and 2026/27 financial years. While we remain grateful for government contributions, 75 per cent of our funding for our health, education, and information services is from your generous donations and fundraising efforts.

Every dollar plays a vital role, which is why our annual fundraising appeals are so important.

This tax time, I shared Drew's story of living with Parkinson's. I want to thank Drew for his courage in opening up about the impact Parkinson's has on his life, his honesty and strength unites us all. I also extend my heartfelt gratitude to each of you who donated to the campaign. Your generosity ensures our services remain available to everyone who needs them.

Looking ahead, our health team is preparing to deliver the Your Care, Your Choice education program, supported by a NDIS Peer Support and Capacity Building grant for 2025/2026. Local Peer Support Groups leaders and the Fight Parkinson's team will share upcoming session information as it becomes available at group meetings and via our website respectively.

Fight Parkinson's CEO Emma Collin

In this edition you'll find insights from leading expert Dr Arthur Thevathasan on focused ultrasound it's uses and limitations for Parkinson's, and an overview of Dr Kishore Kumar's conversation with community on the social and scientific considerations in defining Young and Early Onset Parkinson's.

Articles such as these are key to developing our community's understanding of scientific developments in Parkinson's and help facilitate positive collaboration between scientists and those with lived experience.

Finally, I want to thank each of you who so generously share your stories, time, and talents. It is through your voices, your awareness raising, and your advocacy that we continue to lift the profile of Parkinson's in Australia. Your contributions are the heart of Fight Parkinson's, and together, we are creating real change.

Emma L Collin

Emma Collin
CEO
Fight Parkinson's

Members of the Parkinson's community attend the West Melbourne consultation.

Community consultation underpins the next steps towards the National Action Plan

The National Parkinson's Action Plan is one step closer after a successful community consultation period.

This is a significant milestone in the journey to improve the lives of Australians living with Parkinson's. Developed by the National Parkinson's Alliance with support from KPMG, the National Parkinson's Action Plan is a coordinated national effort to deliver positive change by addressing the complex and growing challenges faced by people living with Parkinson's in Australia.

Beginning in June members of the Parkinson's community from across Australia were invited to share their experiences living with Parkinson's to help shape the plan.

During this period Fight Parkinson's supported 135 Victorians to contribute to nine consultation sessions facilitated by KPMG. This includes six in-person focus groups for the Parkinson's community, an in-person consultation with those living with a Young Onset Parkinson's diagnosis, and two online sessions for the Atypical Parkinson's community.

In addition to these focus groups, the Parkinson's community was also invited to share their experiences through an online survey. Clinicians, health care professionals, and researchers were also invited to participate in national focus groups to share their experiences working with the Parkinson's community and identify areas for improvement and development.

Thanks to your input, the National Parkinson's Action Plan can move to the next stage of development – taking key concepts and guiding principles from community responses.

It's these principles that will inform and be used to provide recommendations to policy makers, service providers, and researchers.

Those of you who took time to share your insights in person or online have helped pave the way for a robust and inclusive plan.

The NPA will take this plan to government and advocate for our community.

Community members provide their insights in Warrnambool.

Your responses will help create systemic policy changes to support people living with Parkinson's.

The honest and open conversations the community so graciously had will help shape a plan that addresses the most pressing needs of the Parkinson's community.

The National Parkinson's Action Plan will not just help those living with Parkinson's, PSP, MSA, and CBS, but also their loved ones, carers, and their health professionals to provide better care.

Once complete, the Action Plan will reflect the collaborative efforts of the National Parkinson's Alliance, uniting the Parkinson's community, key stakeholders, organisations, and researchers from across Australia to drive meaningful change.

Community members at the Peninsula in-person consultation.

News & highlights

New website guarantees easier access to essential Parkinson's information

You now have easier access to up-to-date, in-depth, and accurate information about Parkinson's, PSP, MSA, and CBS.

Our new content-rich website has been designed to be simple to navigate while continuing to prove the trusted knowledge and resources you need, when you need them.

Living with Parkinson's is a fight - and no one should have to face it alone.

At Fight Parkinson's, we fight every day to realise possibilities for people living with Parkinson's, PSP, MSA, and CBS. These conditions are complex, unpredictable, and often raise more questions than answers.

That's why we're proud to launch our new website, a powerful resource created to empower and support people on this journey. It offers practical tools, reliable information, and a stronger sense of connection, ensuring no matter where you are, support is always within reach.

With accessibility front of mind, we worked with community members throughout the process to identify opportunities to improve and enhance the site.

We listened to your feedback and have revamped the navigation and content to make it even easier for you to find the answers you're after, while also improving the depth of resources available for all segments of the Parkinson's community. That's clear information for people living with Atypical Parkinson's conditions (MSA, PSP, and CBS) and Young and Early Onset Parkinson's, as well as carers, family members, and health professionals.

The internet is filled with information and when you're in need of answers it can be difficult to differentiate between reliable and unreliable sources.

That's why Fight Parkinson's is dedicated to ensuring the Parkinson's community knows that when you open our website, the information you access has been vetted by health professionals.

Whether you're after information on symptoms, treatments, peer support groups, or professional support, Fight Parkinson's has the answers you need.

Our content is under constant review and we're not afraid to make updates as needed. Parkinson's is an ever-evolving condition and as more research is completed and treatments developed, we will keep you updated.

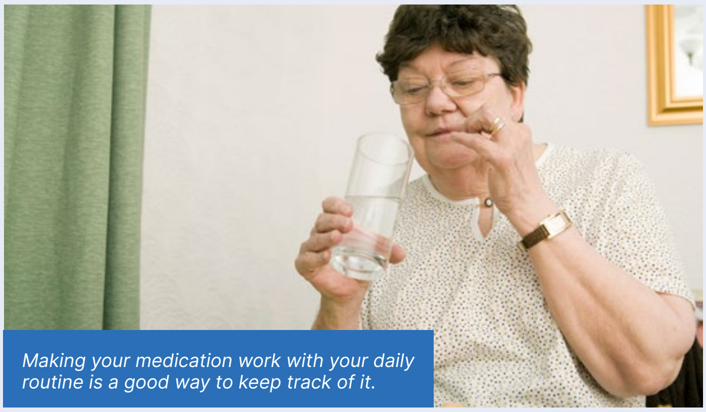
You can trust the information you find on our website to be evidence based and underpinned by best practice principles.

fightparkinsons.org.au will continue to be an important resource for people living with Parkinson's and their families, not just in Victoria but across the country.

Fight Parkinson's has always and will always be here to support the wants and needs of the Parkinson's community.

If you have suggestions or requests for what type of information should be available on **fightparkinsons.org.au**, please feel free to contact us on (03) 8809 0400 or via email at info@fightparkinsons.org.au

Managing symptoms



Making your medication work with your daily routine is a good way to keep track of it.

Working with your medications, and making medications work for you

Medications are an important part of managing your Parkinson's symptoms. Ensuring you understand how they work, how to incorporate them into your lifestyle, and how they interact with one another is essential to their effectiveness.

One of the first things your neurologist may discuss with you after a Parkinson's diagnosis is medications, and how they can combat or reduce your symptoms.

While medications cannot cure Parkinson's they are important tools in managing symptoms, alongside other supportive therapies.

What medications and dosages are right for you will be determined by your medical team. Regardless of what medications you are on, there are things to know to help keep them working as best as possible.

The Fight Parkinson's healthcare team have the following advice for managing your medications.

Consistency is key

For medications to have their intended effects, they should always be taken consistently. That's both across a period of time and at the same time of day.

Working your medication into your daily routine is the best way to ensure you take them on time, every time. Make your medication convenient for you. Speak with your prescribing doctor about what timing best suits your lifestyle.

There are many techniques that can be helpful in taking your medication consistently:

- Set alarms for the time of day you need to take your medication. There are applications for mobile phones and smart watches designed to assist with letting you know when to take medication
- Use sticky notes or other visual reminders throughout your house
- Ask your pharmacy to put your medication into blister packs divided by day and time. These are known as Webster-paks and help you know if you have missed a dose
- Consider medication timer devices, such as pill box timers and alarms

By making your medication part of your daily routine you are less likely to forget to take it. This could involve timing dosage around your morning wake-up time or in line with a show you watch each day.

Sometimes life gets busy, and you might miss a dose of your medication. You should always take your dose as close to its intended timing as possible. If you take a dose late, you should still wait the prescribed time period before your next dose. For example, if you usually take your medication at 9am and 1pm, if you take your first dose at 10am, you should take the next one at 2pm.

Watch out for side effects and interactions

All medications come with a risk of side effects. It is important to keep track of any side effects your medication is causing and discuss them with your medical team.

Nausea is a common symptom for many people living with Parkinson's. Nausea is treatable so make sure you have a conversation with your doctor who will be able to prescribe the best anti-nausea medication. By telling your doctor when you think you're experiencing side effects, they can assist in combatting them.

This may involve taking additional medications, however that should not deter you from seeking help. If side effects of your medications are impacting your quality of life, they're not serving you well.

It is also important to keep track of what medications don't interact well with the ones you are on. By returning to a single pharmacist for all your medications, they are more likely to flag any potential concerns than if you regularly change pharmacies.

Some common over-the-counter medications such as, anti-nausea medication, cold and flu medications, and some vitamins and herbal supplements may interact with common Parkinson's treatments.

If you are unsure if your daily medications will have negative interactions with something you wish to take, seek advice from your pharmacist or GP, or ring the Fight Parkinson's Information Line to speak to a Parkinson's nurse.

Protein and levodopa medications

Dietary protein can affect the uptake of levodopa. While this is a minor consideration when you are recently diagnosed, balancing when you consume protein becomes more important as your journey continues.

Protein is found mostly in meat, fish, eggs, cheese, beans, and legumes, so it is ideal to avoid having too much protein before you take your medication. However, it is important to remember that protein is an important part of a healthy diet, so you shouldn't cut it out entirely. Most people find that taking medication half an hour before you eat or 45-60 minutes after you eat is sufficient to reduce the impact that dietary protein has on medication uptake.

If you need support to plan the timing of your protein intake with your medication you can speak to your GP or call the Fight Parkinson's Information Line on (03) 8809 0400 to speak to one of our Parkinson's nurses.

Understand your medications

Many people living with Parkinson's will take numerous medications. While they are an important component of your care, it is important to always exercise caution when adding to or removing doses.

Every medication available in Australia has a consumer medication information summary. This is available online on the Therapeutic Goods Administration website and through your pharmacist. Some medications may already have this fact sheet in the box it comes in.

Fight Parkinson's also has a medication fact sheet available on our website with information on commonly prescribed Parkinson's medications.

> Each Parkinson's diagnosis is uniquely individual and each person will received tailored medication plans. Do not change or stop taking your medications unless you have spoken to your neurologist or GP.

Abby has been living with young onset Parkinson's since her diagnosis two years ago.

Taking diagnosis head on from day one

Abby was young and busy, with too much on her plate to think a sore foot was anything but a lingering injury from her long-distance running or that regression in her cello skill was more than the result of a break from playing. But with some encouragement from her family, she pursued medical assistance. Just months later she received a young onset Parkinson's diagnosis.

To look at her life from the outside, Abby says there isn't much that shows she has Parkinson's, except her eagerness to tell everyone and anyone she meets.

"I am not shy about sharing, if people ask me, I'll tell them everything," Abby said.

"When I was diagnosed my neurologist was like, you can take your meds, and nobody will probably notice for a really long time. It's up to you who you tell and when.

"I said okay and then two days later, I decided I'd tell everyone."

Though it was a quick decision to share her diagnosis, the path to receiving one was long and at times winding.

With easy explanations to the symptoms she was experiencing, it initially did not cross her mind that they could be connected.

Time stuck at home through COVID and increasing physical activity felt like the obvious things to pin physical ailments on.

In retrospect, Abby can see they were early warning signs.

"The first thing I noticed - but didn't pay attention to - was when I played cello, I couldn't do vibrato, I couldn't do it anymore," she said.

"It was post-COVID, so I thought maybe I just needed to practice more, I hadn't played as much.

"I got a couple of cello lessons, to go back to basics and I was like 'I don't know, I just don't seem to be able to do it' but I didn't worry at all.

"Then I was doing a lot of charity walks, training for the coast trek 45k, and my foot started doing weird stuff, but I thought I have been walking a lot of long distances so that makes sense.

"It took a year and a half before I went oh there's something weird with my left foot and there's something weird with my left hand.

"It took other people as well, saying it's been a few months since you did your 45k walk, why are you still limping."

Encouragement from her family sparks medical intervention

When Abby started to speak with her family about the changes she'd noticed in her body, they were quick to act.

Sharing their concerns with her, they raised that her ailments had been lingering for much longer than would be typical. Immediately they encouraged her to seek further help.

Assisting her secure an appointment with a neurologist, Abby said there were mixed emotions when the doctor affirmed her concerns.

Mixed emotions in diagnosis

In the moment, Abby said there were two thoughts in her mind when the neurologist indicated they thought something was going on.

There was concern that something was happening to her body she couldn't control, but also relief that what she was experiencing was real.

"When you've got something in your head that there's something wrong, you start noticing weird things like my foot does this weird twitch when I drive," she said.

"The neurologist had me walk down the hallway and said, did you know you don't swing your left arm, and that moment made me go 'oh, there is something weird', because I didn't know that, I wasn't conscious of that so I couldn't have made it up."

Abby recalls the neurologist in this first meeting saying that she could have Parkinson's but her age would make it surprising.

Referred to a movement disorder specialist, Abby said she understood that she had a neurological movement disorder but putting a name to it was still a big step.

With six months between her appointments, Abby had become comfortable with saying she had a neurological condition, but it didn't make receiving a formal Parkinson's diagnosis any easier.

"I'm chatty, a lot of parents at the school would see me limping, and they go 'what's happened?' and I'd say, 'I've got a weird neurological thing going on' and that was not scary for some reason," Abby said.

"When I was told it was Parkinson's it hit me like a brick and I got very emotional.

"My neurologist was excellent; they stayed with me for a really long time.

"I'd come alone as well, I have a very strong memory of walking to the car and holding my body together until I got to the car and then I called a friend.

"It was hard to say Parkinson's; it took me a couple of days to get the hang of it. In that moment though my friend offered to come with me to the pharmacy because I needed to get medications and I didn't want to go to the front and have them ask have you taken this medication before. My friend came with me, and she was ready to do everything I needed."

Continuing a positive life

Two years on from diagnosis, Abby continues to confront her diagnosis head on.

With the right medications and healthcare team, she hasn't stopped doing the things she loves.

She said Parkinson's is always with her, but she won't let it hold her back.

"Taking my medication is a prompt every few hours to think about it, so it is constantly there, and I think that's how it impacts me," she said.

"I always feel a bit of pressure like, oh, I should be exercising, I should be doing this or that, and everyone's telling you what you should be doing, and I'm like, yes but I also have two children to raise, and I have my own business so I'm busy with that.

"I do my best, but that's how it's impacted me, I'm constantly thinking about what I should be doing."

In her day-to-day life, small changes help Abby continue her hobbies, while long-term planning has also entered her mind.

Looking at house renovations, she is more considerate to what mobility needs she may have in the future. It's a big unknown to prepare for, but she said smart decisions now could help prevent a retrofit later.

Continuing her cello practice has also been important, and her community orchestra has been more than willing to help her continue to play.

Returning to group was emotional as she realised the positive impact her new medications were having on her ability to play. The support from her community to make adaptations to keep her playing was also overwhelming.

Abby knows she has a long journey ahead of her, but she is hopeful that by taking Parkinson's in her stride, she can continue doing the things she loves.

Abby has not stopped doing the things she loves.

Managing symptoms

Falls prevention and Parkinson's

Walking, freezing, and falling

The underlying cause of Parkinson's symptoms relates to a decline in the production of a brain chemical called dopamine. Many cells that produce dopamine are in the Basal Ganglia, a group of structures in the middle of the brain best known for their role in movement

The lack of dopamine levels in the brain means people can have difficulties in controlling their movements and moving freely. Movement slows, muscles stiffen, and posture can change. These changes can lead to challenges with walking, increasing the risk of falling and freezing.

Walking (Gait)

Gait is used to describe how a person walks and it is often impaired in people living with Parkinson's.

The most common changes include, slowed movement, small steps or shuffling, little or no swing of one or both arms, and a tendency to lean forward when walking.

It's also common for people living with Parkinson's to become easily tired during walking, even after short distances. This is likely to become more prominent as Parkinson's progresses. Changes to walking can be related to the medication cycle, e.g. because of the 'on/off' cycles of Parkinson's medications.

Tips for walking safely

- Always take medications on time
- Undertake regular exercise to help with balance and leg strength
- Wear supportive footwear
- Walk to a rhythm (listening to a beat or music can help)
- Focus on taking long strides

Falling

Gait impairment can make people living with Parkinson's more likely to fall. Other causes of falls include reduced blood pressure and environmental hazards, both outside and in the home.

While falls can occur at any stage of Parkinson's, they are more likely to happen during the later stages of the disease. Falling is particularly hazardous because of the risk of serious injury and are a common cause of hospital admission for people living with Parkinson's.

If you've had a fall recently, advise your GP and neurologist, particularly if falls are becoming more frequent. Adjusting medications can prove helpful in some situations.

Tips to reduce the risk of falls at home

- Remove hazards in your home, such as rugs and furniture that obstruct walkways
- Ensure you have good overhead lighting, particularly at steps
- Install handrails at steps and grab rails in bathrooms
- Apply strips of tape to the floor in areas where freezing of gait occurs
- Purchase a pendant alarm system to alert others if a fall occurs

Freezing

Freezing is when a person stops suddenly while trying to move and the movement becomes frozen.

Freezing typically, occurs in specific situations, such as when starting to walk, stepping through a doorway, attempting to turn a corner, or approaching a chair.

People living with Parkinson's may also experience episodes of freezing during other repetitive activities, such as brushing their teeth or writing. Freezing can also affect upper limbs and speech.

Freezing is normally only temporary, however is hazardous as it increases the risk of falling during walking and moving. Freezing is one of the movement symptoms that cannot be fully explained. Freezing is more common when completing complex tasks or multi-tasking becomes more difficult, suggesting a link between cognitive change and movement may contribute to freezing.

Tips to avoid freezing episodes

- Prompt yourself by saying aloud 'left, right, left, right' OR 'one, two, one, two' OR 'one, two, three, step'
- Stand still and start swinging your arms
- Start shifting your weight from one foot to the other foot
- Visualise an imaginary line to step over
- Identify visual prompts such as lines in the pavement to maintain bigger steps.

Tips to overcome freezing episodes

- Always take your medications on time
- Walk to a rhythm (listening to a beat or music can help)
- Avoid distractions when walking so you can focus on long steps

Support for you

If you are experiencing mobility difficulties or freezing, you should consult with your GP about building a team of health specialists to support you such as occupational therapist or a physiotherapist. You might also speak to your GP about creating a chronic disease management plan, which will allow you a limited number of Medicare rebated visits to allied healthcare professionals.

For further information on falls prevention, Fight Parkinson's offers a free course in Fight Parkinson's Community Learning Hub. The course equips you with practical tools and strategies to help prevent falls. Learn to identify risk factors in your environment, discover effective preventive measures, and build confidence in managing unexpected situations.

Like all Fight Parkinson's Community Learning Hub courses, this course is completely free and available to you whenever you need it, no matter where you are.

Research is hope.
Hope starts with you.

"She'd fall and make a mess in the kitchen - and blame herself. It broke my heart."

These are the words of Queeny Stafford, who cared for her mum in the years before and after Mae's diagnosis with Progressive Supranuclear Palsy (PSP). Queeny generously shared her story with us in the hope that other families will not feel as alone as she did, traversing the long and difficult journey to diagnosis.

When Queeny watched her mum struggling with unexplained falls and changes in movement and thinking, she knew something wasn't right.

"I work in healthcare, and I began to suspect PSP." But PSP is a complex, rare disease that is often misunderstood.

It was a routine visit to an optometrist that finally led Mae's healthcare team to a diagnosis. At last Queeny had a diagnosis and words for her mum's condition - PSP. By the time Queeny's mum was diagnosed, her PSP symptoms were advanced. It was also too late for Queeny's mum to participate in any clinical trials to have some hope of a better quality of life with the time she had left.

"It was a relief - and a heartbreak, when the diagnosis came" Queeny shared. "At last, we had a name. We could advocate for her care." In practice this meant that Queeny could share some of the PSP symptom management that she learnt about from the Fight Parkinson's Health Team. "We were able to say to her carers, "Her eyes are closed because of PSP, not because she's sleeping."

Dealing with a late diagnosis was very difficult for Queeny and her family. "I've seen palliative care before, but I was not ready for what a PSP diagnosis meant for my mum's care" Queeny said. "It was beyond all that I had ever seen."

Queeny's story is not unique. Every week, more families across Australia face similar heartbreaking journeys, with no cure, no treatment to slow progression, and far too often, **long, and difficult path to a late diagnosis.**

At **Fight Parkinson's**, we believe this must change.

We know the future can be different - with research that delivers earlier diagnoses, better treatments, new models of care, and ultimately, life-changing cures.

That's why Fight Parkinson's is committed to supporting research into better understanding Parkinson's and the Atypical Parkinson's conditions. We're growing the **Fight Parkinson's Research Fund** to fund Australian-led, promising, and under-resourced projects that aim to change the future for people living with PSP, MSA, CBS, and Parkinson's.

It is part of our three-pronged approach to fight Parkinson's and the Atypical Parkinson's conditions of PSP, MSA and CBS – an integrated multidisciplinary strategy covering research, support, and education to tackle the profound challenges of these conditions.

Innovation and understanding come at a cost, and we can't do it without you.

Please consider donating to the **Fight Parkinson's Research Fund** today. Your gift will fund vital research, so no family must face what Queeny's did.

A donation to the Fight Parkinson's Research Fund means that we can invest in:

- **Research into earlier diagnosis**
- **New models of care and treatment**
- **Clinical trials and prevention research**
- **Technology that supports timely detection**
- **Innovative projects that otherwise go unfunded**

PSP robbed Queeny and her family of their beloved mother and grandmother too early, but with your help we can invest in research so that families like Queeny's don't have to wait years languishing for answers. Investment in research could mean better care, earlier support, and more quality time together.

"No family should be left in the dark for so long," Queeny said. "Let's change the story for other families."

Thank you for supporting Fight Parkinson's Research Fund.

With more people diagnosed with PSP, MSA, CBS, and Parkinson's every week, a donation to support Fight Parkinson's research fund is essential to creating a better future for our community.

Dr Kishore Kumar, Sheenagh Bottrell and Victor McCovey at the Fight Parkinson's Research Symposium.

Early and Young Onset Parkinson's - Science and Society

Everyone's experience with Parkinson's is unique and it is important to understand how an early or young diagnosis presents unique challenges is important not only socially but clinically.

Dr Kishore Kumar spoke on the clinical considerations of Young Onset Parkinson's at Fight Parkinson's 2025 Research Symposium. His presentation was followed by a discussion on lived experience of Young Onset Parkinson's with Sheenagh Bottrell and Parkinson's nurse Victor McConvey.

What age is young – a very important question

The definition of Young or Early Onset Parkinson's has always been broad, and previously there had not been internationally accepted parameters for these terms.

This created difficulties when looking at cross-country collaborations for research and development projects.

Dr Kumar explains that without clear parameters for this group of people living with Parkinson's, researchers are faced with ongoing barriers. This can impact comparison of studies around the world and reduce access to funding.

Working as a member of the Movement Disorder Society Task Force on Early Onset Parkinson's Disease, Dr Kumar was part of the team that determined the recommendation for the cut off age for Young Onset Parkinson's to be 50 years old for scientific purposes.

Dr Kumar said setting an international standard is important in advancing research.

"If you don't have a consensus, the definitions are arbitrary because you can't compare apples with apples, you can't do research across different groups or compare data very easily," Dr Kumar said.

Previously, different jurisdictions had reported the maximum age for Young Onset Parkinson's as anywhere between 40 and 60 years old.

The taskforce also moved to use the terminology 'Early Onset Parkinson's' rather than 'Young Onset Parkinson's' scientifically, which drew mixed feedback from those with lived experience.

Genetic impacts on Young Onset Parkinson's

Defining clear population groups is essential for good research, such as ongoing studies into differences in genetic markers between people developing Parkinson's at a younger age compared to those who develop the condition later in life.

Dr Kumar outlined two key Parkinson's disease genes – the PRKN and PINK1 genes – that are commonly found in individuals diagnosed with Young Onset Parkinson's.

Such research is incredibly beneficial for individuals who undergo genetic testing, with specialists able to identify genetic contributors to a Parkinson's diagnosis. Dr Kumar said this knowledge can improve and assist in tailoring treatment for individuals.

Alongside creating age parameters, the taskforce also looked to identify the unique challenges and unmet needs of individuals with Young Onset Parkinson's.

Why focus on a small subset of diagnosis

It's estimated that only 3 to 7 per cent of those diagnosed with Parkinson's receive their diagnosis before the age of 50.

However, Dr Kumar explained research into Early or Young Onset Parkinson's will benefit everyone affected by the condition.

"Why should we pay a lot of attention to it? I think, because although it only represents a small fraction of the population, it can tell us a lot about the science of Parkinson's disease," he said.

"The other factor is that these patients will face unique challenges, and we should be spending additional resources to try and help them deal with these unique challenges."

Dr Kumar said investing in research in those diagnosed early could help lead to a greater understanding of Parkinson's, and in turn also assist those who develop the condition at an older age.

Limitations of the taskforce identifications

During their discussion, Victor and Sheenagh reflected on the pros and cons of the outcomes from The Movement Disorder Society's taskforce.

While acknowledging the benefits of providing a foundation for future and ongoing research, they said the designation of 50 years old as the cut off age can be misaligned with societal views.

In Australia, working age is up to 65 and people can access the NDIS until this age too, adding to the social norm that someone is 'young' (as opposed to old) until then.

Victor – who was also part of the Taskforce – also identified feedback from the local Parkinson's community, who were vocal in wanting the word 'young' in the name preferably to 'early'. The cohort told researchers they feel and identify with the term young, and wanted it included.

This was an essential learning opportunity for the Society on the importance of speaking with those they were talking about. As they continue to champion clinical developments for those living with Parkinson's, they also are open to ongoing feedback and involvement from the community.

Community members attend the Fight Parkinson's Atypical Parkinson's Community Seminar.

PSP researcher Dr Lucy Vivash presents to healthcare professionals.

Atypical Parkinson's Conference

Living with Atypical Parkinson's (PSP, MSA, or CBS) brings unique challenges, but connecting with others who share similar experiences and learning more about the condition can help.

This July Fight Parkinson's held our biannual Atypical Parkinson's Community Seminar, bringing together people with PSP, MSA, CBS and their families, friends, and carers to hear from industry experts.

The day was tailored to increase awareness and understanding of Atypical Parkinson's conditions. Movement disorder specialists, researchers, and allied health professionals shared their invaluable insights with the community.

The exceptional lineup included Neurologist Dr Kelly Bertram, researcher Dr Lucy Vivash, researcher Professor David Finkelstein, and neuropsychologist Dr Luke Smith, who shared their insights into the latest research, multidisciplinary care approaches, and evidence-based interventions that support quality of life.

From the event room and online, the experts' time was used to full capacity, with community members taking the opportunity to ask questions and expand their understanding.

The energy and connection in the room at the Treacy Centre in Parkville was truly special, and we were pleased to be able to support those in attendance, both in person and online.

The seminar included our newly developed Your Care, Your Choice education program - an innovative resource designed to support people living with an Atypical diagnosis. The sessions included practical guidance on navigating health and community services, finding the right supports, building skills in self-advocacy, communicating needs, and making informed choices.

Healthcare professional stream

To support the ongoing provision of quality care for people living with PSP, MSA, and CBS, Fight Parkinson's simultaneously held a seminar for the health professionals who treat this community.

Fight Parkinson's is grateful for the experts who gave their time to help educate other health professionals on the latest developments in Atypical Parkinson's treatment and care.

The commitment from the healthcare professionals who attended is a testament to their desire to provide the Atypical Parkinson's community with informed care.

Thank you to everyone who attended - whether in person or virtually - for making this such a successful and impactful event for our Atypical Parkinson's community.

Community connection

Feedback from those who attended the Atypical Parkinson's Community Seminar was overwhelmingly positive.

Those who attended in person were able to connect with others experiencing similar challenges.

Fight Parkinson's hosts a dedicated online support group for people living with PSP, MSA, and CBS, available to anyone anywhere in Australia.

With online access, no matter where you are, you can connect with a community that understands and is ready to support you. If you are interested in learning about this group please contact the Fight Parkinson's information line.

Further resources

If you or your loved one has received a PSP, MSA, or CBS, diagnosis, Fight Parkinson's has online resources available for you. Visit https://www.fightparkinsons.org.au/atypical-parkinsons for further information on Atypical Parkinson's.

Community members attend the Fight Parkinson's Atypical Parkinson's Community Seminar.

Ask the Expert

Focused Ultrasound- is it ready for Parkinson's?

Focused Ultrasound is a technologically-advanced treatment for essential tremor, but as Dr Arthur Thevathasan explains, there are still developments to come before it can be widely-adopted for the movement effects or tremor of Parkinson's.

With recent media coverage on the success of the procedure and its approval for use in the United States, Dr Thevathasan is fielding questions from the Parkinson's community regularly.

As excitement and anticipation grows within the community, he is helping provide a realistic understanding of the technology and its potential uses for those living with Parkinson's.

What is focused ultrasound

Focused Ultrasound is an "incision-less" treatment used to precisely target ultrasound beams into a specific deep part of the brain (the thalamus), which is a crucial node in the brain network that causes tremor. Creating a permanent, precise lesion (disrupted brain tissue) in this brain area can permanently reduce tremor.

This treatment has been offered as a potential alternative to deep brain simulation for some people living with different types of tremor.

"You will have to lie inside an MRI machine for 3-4 hours and we target about 1000 ultrasound beams to focus on one particular spot in the brain. In doing so we create a lesion or small hole in the brain tissue without actually entering your brain with wires," Dr Thevathasan said.

"It sounds scary, but at this stage several people seem to be more receptive to the idea of this compared to deep brain stimulation as the medical team does not need to make a physical hole to enter the brain. That means we can avoid a lot of the more serious surgical risks with focused ultrasound compared to DBS".

However, while the procedure is considered incisionless, it is still an invasive brain procedure that has specific risks to consider.

Use cases and Parkinson's

One of the reasons focused ultrasound has attracted attention is due to the near immediate improvements it has had on recipients' tremors in the US.

However, while these changes in tremor are undoubtedly impressive, it is essential to note these trials have been mostly successful for individuals diagnosed with essential tremor, not Parkinson's.

It can be easy to believe that a successful treatment for essential tremor could see similar results for Parkinson's tremors. However, trials involving individuals with Parkinson's have shown guarded results.

In Parkinson's, treatment with focused ultrasound may result in an initial reduction in tremors. However, data has shown that the treatment effect does not last – the Parkinson's tremor tends to return over a three-month period. Treatment with focused ultrasound to treat the other movement symptoms in Parkinson's (other than tremor) have also been very limited, at best.

Additionally, the current standard of care with focused ultrasound is for treatment on one side of the brain, meaning only one side of the body is positively impacted by the procedure's effects.

While studies have shown benefit with performing focused ultrasound on both sides of the brain, the side effect profile and long-term outcomes are being closely looked at. In short, while there is promise about expanding this to both sides, this is currently not the standard of care in Australia.

Dr Arthur Thevathasan speaks to the potential uses and constraints of guided ultrasound in treating Parkinson's.

"We don't have a big response for Parkinson's tremor and that's because, unfortunately, Parkinson's is a bit more complicated than essential tremor," Dr Thevathasan said.

> *"We think that there are other neural pathways involved, there's been lots of hope, but we're not there yet."*

Deep brain stimulation currently remains the gold standard as advanced therapy for Parkinson's and Parkinson's tremor.

Focused ultrasound and Parkinson's – what next?

Focused ultrasound continues to be studied and worked on, with hope that research will reveal evidence demonstrating benefits for Parkinson's.

Dr Thevathasan said research is continuing into its use to treat the condition in Australia and overseas. Several centers around the world are identifying ways to treat the symptoms of Parkinson's with focused ultrasound, including ways to benefit tremor and non-tremor symptoms.

"I'm optimistic, but I think realistically this is maybe about at least five years away. Focused ultrasound will likely not replace DBS entirely for Parkinson's," Dr Thevathasan said.

"But it may offer people an additional treatment option. It may also help people who are unable or who are not surgically fit enough for DBS to benefit from another advanced treatment option".

Support for you

Two decades of bringing the community together

The Essendon Parkinson's Support Group has been meeting regularly in a local church hall for more than two decades. Over the years, it has grown to become one of Fight Parkinson's largest and longest-standing support groups.

Run by a committee of volunteers, the group provides an opportunity for those living with, or caring for someone with, Parkinson's to connect with others who understand their experiences and challenges. The group provides a supportive and understanding community, participants may share ideas and tips for living well with Parkinson's.

Attendees range in age from their 50s through to their 80s and come from a variety of backgrounds and cultures. The group warmly welcomes newcomers. Fight Parkinson's encourages anyone looking to join a Peer Support Group to contact the office to discuss how these groups work and what to expect before joining.

Bill and Lesley, both committee members since 2016, say the group has made a real difference in their lives. For Bill, it meant forming new friendships and rekindling old ones, all within a warm, non-judgemental environment where he never felt embarrassed by his symptoms.

The group meetings provide a space for people with Parkinson's to be themselves without fear of being misunderstood or stigmatised. Carers who attend also have the chance to connect, chat and share their experiences.

Members of the Essendon Peer Support Group attend a presentation from a local healthcare provider.

Group meetings include presentations on a range of topics by special presenters throughout the year.

A highlight of each meeting is afternoon tea, offering a tempting spread of cakes, slices, and treats and providing a wonderful opportunity to relax, chat and share personal experiences with others.

The group also runs a long-standing painting and activities program, held weekly, excluding school holidays. These relaxed sessions are open to both members and carers. No previous art experience is needed, and all art supplies are provided.

Participants have produced beautiful artworks in many different mediums including watercolours, acrylics, pastels and charcoal and are currently experimenting with bark painting. Naturally, each session ends with a cuppa and a chat.

Support for Carers

Carer Gateway is proud to have partnered with Fight Parkinson's as a premier sponsor of A Walk in the Park 2025, acknowledging the vital role of carers in the Parkinson's community.

Carer Gateway is an Australian Government program providing free services and support for unpaid carers. It offers tailored support packages, counselling, emergency and planned respite, and coaching and peer support groups. Carer Gateway recognises the vital role carers play in supporting the wellbeing of family members and friends living with illness, disability, or ageing. By supporting carers, it helps prevent burnout and ensures they can continue to provide care while also maintaining their own health and wellbeing.

Marianne is one such carer who experienced the invaluable support offered by Carer Gateway. She cares for her husband, who is living with Progressive Supranuclear Palsy (PSP), a rare, progressive neurological condition that affects movement, balance, speech, and eye coordination, progressively leading to more significant impacts on daily life. Marianne had heard about Carer Gateway through her work as a nurse, but it wasn't until she reached a crisis point that she realised she needed to take control of her own health. She had injured her neck, was sleep-deprived, and struggling with the daily pressures of caring, challenges many carers face.

"When I finally rang Carer Gateway, I was able to speak to someone who really understood my issues, needs, and challenges," Marianne said.

Marianne received a tailored support package and was connected with a coach and a peer support group. The one-on-one coaching helped to focus on her own needs, like getting better sleep and finding time for exercise, while peer support helped her feel heard and less isolated.

Marianne was supported by Carer Gateway.

"Sometimes you feel like nobody understands, but people do. It's lovely to feel validated and receive kindness from people who get what you're going through," she said

Even through the most challenging aspects of her husband's condition, Carer Gateway empowered Marianne to navigate each day with greater strength.

Whether you care for a family member or friend every day or just a few hours a week, you're not alone. Carer Gateway offers free emotional, practical, and mental health support to help you. Call **1800 422 727** (Monday-Friday 8am-5pm) or visit **carergateway.gov.au** to learn more.

Carer Gateway
An Australian Government Initiative

Holstep Health

Running hard and raising funds

Fight Parkinson's relies on the community's generosity to fund our support services and invest in research. This year has been the year of the runner, with people across the country hitting the pavement to raise vital funds. We are so grateful to everyone who has run in support of Fight Parkinson's - their efforts are a powerful expression of hope and support for people living with Parkinson's. These are some of their stories.

Seven in Seven for Colin

It can be hard to choose a fundraising goal, but Colin was feeling optimistic when he decided to try and raise $3,000 for Fight Parkinson's. Just two weeks later he almost quintoupled his goal.

Colin's story is a reflection not only on how far Parkinson's reaches, but on how you can find community in the most unlikely of places.

A trip to remember

Coming to Australia from Ireland, Colin expected to find friends, adventure, a new lease on life. He hadn't anticipated connecting with the Parkinson's community.

After speaking to his neighbour in the elevator several times, they decided to get coffee. From here, Colin and Isa, a well-known member of the Fight Parkinson's community, friendship grew.

Colin said the friendship that blossomed over the years was one beyond expectation.

Over time, he started to learn about Parkinson's and Isa's commitment to being an advocate for the local Parkinson's community.

"We started meeting for coffees and we built a nice friendship from there," Colin said.

"Isa and her husband Alan have done so much for us in every sense, they're just so nice to us, so generous."

After years bonding, Colin said Isa felt more like a family member than a neighbour so when he decided to return home to Ireland he wanted to do something special to say goodbye.

After attending his first A Walk in the Park in April, Colin was taken aback by the strength of the Parkinson's community.

He had heard from Isa how widespread the community was, but this was the first time he had seen it for himself.

It pushed his plan from 'fundraise' to 'fundraise big'.

"That was absolutely wild, just how many people were there and seeing Team Isa and all the support around her was a big whoa moment," he said.

Colin with his friend, neighbour, and Parkinson's advocate Isa after one of his half-marathons.

"I was like okay, this fundraising idea is going to be a good thing. It's going to be a big thing."

It was then that Colin decided to do something he'd never done before, run seven half-marathons in seven days.

Running hard and running far

Outside of a charity fun run in 2018 Colin hadn't run much prior to 2025.

When a good friend asked if he'd run 20 kilometres with him at Christmas, Colin had to readjust expectations.

The question excited him though, and he decided to begin running training.

Colin running his final half marathon, flocked with supporters who joined him in the final push.

After running a half marathon, the idea came to him- an endurance effort unlike anything he'd done before.

"I was just like 'seven half marathons in seven days'," Colin said.

"Seven in Seven.

"The more I thought about it, I was just like, no, I think I actually have to do this now, because I wanted to do something that wasn't completely impossible.

"The longest distance I'd run is a half marathon, so obviously seven half would be difficult but I had this delusional confidence I'd be fine."

Telling Isa of his plan early on ensured he wouldn't back out.

One man run becomes a community movement

Over the week, Colin was joined by his partner and friends, some running, some riding, helping him get through each day.

The week started well, with the first two half marathons flying by, but as the days flew past Colin admits he started to struggle.

The impact of so much running on his body was undeniable and even with the best recovery he felt every step.

But the support from those showing up each day – including many early morning appearances from Isa herself kept him going.

Before Colin knew it, his week of half marathons was nearly done and he was shocked by the swell of support that built around him.

It wasn't just people he knew donating and reaching out, but members of his local community he'd never met. He even heard of a pub raffle that popped up to help the cause.

Not wanting to miss the opportunity to bring his supporters together, he invited the community to join him on his final run.

Meeting Isa at the finish line was the cherry on top.

"It was a beautiful day, I broke down at the end of that run because I was thinking about Isa, and what is happening, and just the bigger picture of Parkinson's," Colin said.

Outside of his fantastic fundraising efforts, Colin was also able to open a conversation on Parkinson's for his community.

Across the week he was blown away by the number of people who came up to him with stories of how Parkinson's was impacting their lives.

"One of my friend's parents, donated quite a bit of money and his sister and his brother donated. So I texted his dad to just say thank you for the donation, and then his dad text back and said my dad had Parkinson's, so this means a lot to our family.

"It became a lot more than just me raising money for Isa, it resonated with a lot of people and became so much bigger than I think anyone thought it was going to be."

Megan pictured with her supporters after running a half marathon as part of Run Melbourne.

Supporting Megan to support her dad

Megan Howard's father was diagnosed with Parkinson's eight years ago and she's seen how it impacts every part of his life.

With the chance to raise funds for her charity of choice as part of Run Melbourne, Megan nominated Fight Parkinson's.

Hoping to raise $2,000 in the lead up to running the half marathon, she was elated to double her goal.

"It was such an incredible experience doing the run, and I was blown away by the amount I ended up fundraising," Megan said.

"My dad, Greg, was diagnosed with Parkinson's Disease in 2017. Prior to his diagnosis, I knew of the disease and associated it to shakes or tremors but had no understanding of the other effects it can have on a person. Whilst his progression has been (thankfully) a slow one, watching him come to terms with his body and mind changing has been tough.

"Seeing him struggle with daily movements, be much more emotional and worry about his future has been challenging for all of us, especially him."

A mother to two young children, it'd been over a decade since Megan last ran a half marathon.

Determined to do something to support the Parkinson's community and eager to get back into running it was a win-win when she decided to tackle Run Melbourne.

"I knew having the motivation of the donations would be a huge factor in helping me across the finish line," she said.

Recognising how tight many budgets are at the moment, she was astounded to see large donations added to her page.

"Times are tough in this economy and I never expected people to donate. I asked people to spare a couple of dollars, if they could, but I had people donating all sorts of amounts, some over $100, and it was truly incredible," Megan said.

"I documented my whole journey on my socials and knowing I was raising money and awareness for Parkinson's as well as challenging my 40-year-old self with something I wasn't sure I could do, was truly so rewarding."

Megan hopes that one day there will be a cure for Parkinson's, but until then she wants to ensure everyone impacted by this condition gets the support they need.

"I hope that we can continue to spread awareness and help others understand the impact that Parkinson's can have not only on the person diagnosed, but their loved ones as well. I hope the donations keep coming, so those behind the scenes can continue working on a cure and keep supporting those who need it most."

Will with his family after completing his ultra marathon for his mum.

Will's Run 4 Mum

Will Hooper had never run further than 42 kilometres before, but with the energy of running for a good cause, he was confident he could push himself to 80 kilometres.

When Will's mum, Angela, was diagnosed with Parkinson's five years ago, it came as a shock to the family. A bubbly, energetic, caring woman it's been hard for the Hooper family to watch as the condition has progressed.

But not one to sit still and watch, Will decided he wanted to do something positive to help raise awareness for others living with Parkinson's.

Running home

Will was already an avid runner but an ultra-marathon was a whole new feat. He trained for months in the lead up but admitted prior to the event he was in for a tough challenge.

Following the beautiful 80km route from his home in Adelaide to his parent's house in Victor Harbour, Will was supported by friends and family, with runners joining him for 20- and 40-kilometre sections.

Finishing the journey on Mother's Day weekend made the effort even more special. It took a lot of band aids and a few pep talks, but after 7 hours and 42 minutes, Will was met by friends and family, including Mum, at his finish line in Soldiers Memoria Garden, Victor Harbour.

"My partner asked me the other day what is the most special moment in my life and I said the day of this run just seeing all my friends faces and how emotional and proud my mum and dad were and too see all the people who donated there I couldn't thank them enough," Will said.

"All the people that joined the last segment of the run to be a part of it was very special and was the only way I got to the end as it gave me a second wind knowing that most of them were not runners and still came out and pushed their comfort zone for my mum as well."

Exceeding expectations

When Will first set out to raise funds in his mum's honour, he thought $2,000 would be a mark of success. Fast forward to post-run and he's raised an astounding $17,290 thanks to support from family, friends, and local businesses.

Will couldn't have imagined he would receive the support he did and said the community's generosity reflects the profoundly positive impact his mum has had on the people in her life.

"In the back of my mind I was thinking $2,000 would be great but the donation page grew wings once I went public with it, all the people that know our family and how lovely my mum is and knowing that it could lead closer to a cure caused everyone's generosity to grow," Will said.

"When I saw some of the donations, I was amazed at the support mum has."

Will was touched by not only the financial support he received but the many messages he had from others in the Parkinson's community. He has hope that there is a brighter future for the Parkinson's community, with funding towards the Fight Parkinson's helpline and research essential in ensuring they can continue to live positively.

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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.

World Parkinson Congress 2026

Preparations for the 2026 World Parkinson Congress in Phoenix, Arizona are well under way. Community members wishing to attend the event are encouraged to begin planning.

Registrations now open

Early bird registration is available until 15 January 2026, with discounted rates for various categories including people with Parkinson's, care partners, and students. Registration is offered on a first-come, first-served basis, so we encourage you to secure your spot early.

Abstract submissions

The Congress is welcoming submissions in two categories, scientific and lived experience, providing a rare opportunity for researchers, clinicians, advocates and those living with Parkinson's to share knowledge and learn together. Abstracts must be submitted to the World Parkinson's Congress for review by Friday 17 October at 2:59pm (AEDT).

Travel grant applications

The Congress acknowledges the financial implications of attending the event in 2026. A limited number of travel grants up to $3000USD will help selected participates fund their journey. Applications for these travel grants close on Friday 17 October at 2:59pm (AEDT).

We couldn't do it without you.

Community fundraisers make a lasting impact.

Fight Parkinson's receives very little government funding. **You can get involved by:**

- Holding a fundraising function
- Joining a fun run
- Make Fight Parkinson's your employer's charity of choice for a year.
- Request in Memoriam and In Celebration donation packs for funerals and parties

For more information contact
fundraising@fightparkinsons.org.au **or call** (03) 8809 0400

Fight Parkinson's™
Together we can