**Issue 3** Spring 2024

# InMotion

## A magazine for the Parkinson's community


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Fight Parkinson's™
Together we can

### In this issue:

# CEO update

**Together, we can realise possibilities for people living with Parkinson's. With greater resources, collaboration and support, we strive to help our community to live full and active lives.**

Our efforts are focused on providing support to people living with Parkinson's as well as those with atypical conditions such as Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), and Corticobasal Syndrome (CBS).

We are proud to introduce a new online course to support better care for people living with PSP. The course for health care professionals provides an introduction to PSP, which we believe will be invaluable in building the capabilities of health care professionals in supporting people with this rare condition.

Whilst Fight Parkinson's focus is on service, we know it is through collaboration and partnership that we can have a significant impact on policy and funding to better meet community needs.

Fight Parkinson's is now a member of the Neurological Alliance Australia, a collective of organisations representing people living with neurological or neuromuscular conditions in Australia. Together, we aim to identify and advocate for opportunities that will promote improved quality of life for people living with these conditions and funding to support research.

It has been wonderful to support regional Victorians through our Community Seminars, most recently those in the Wimmera from Horsham and at Benalla. Recognising the limited access to Parkinson's experts in regional areas, these seminars, along with our visit and presentation in Ballarat, have enabled more people in these communities to access vital information.

Recently, a spotlight has been placed on supporting those living with Young Onset Parkinson's. The Young@Park Young Onset Parkinson's Conference in August provided valuable insights shared by experts and community members. Our hope is that everyone who attended gained practical tools, made meaningful connections and left feeling empowered. Congratulations to the Young@Park Peer Support Group for organising this event, in particular Sheenagh Bottrell as the group's volunteer leader, who was instrumental in coordinating the event with the support of the Young@Park Committee and Fight Parkinson's.

We had the pleasure of attending the annual community expo hosted by ParKanDo, a Peer Support Group supported by Fight Parkinson's. The turnout was fantastic, showcasing the value of mutual support and leadership within our community.

Additionally, we had the privilege of attending the Parkinson's Fundraising Gala Luncheon, organised by advocate Sean Atkinson in support of the Shake It Up Australia Foundation, garnering support for Parkinson's research.

This year, our October will look a little different as a community. Rather than running our usual 27forParkinson campaign, we are redirecting our efforts to focus on community fundraising and lifting the lid off Parkinson's.

27forParkinson's has been an integral part of our community and fundraising program for several years. During COVID-19 it served as a way for us to connect, raise awareness and stay active when A Walk in the Park was unable to take place due to government restrictions.

However, with the return of A Walk in the Park in 2022, many of our supporters naturally opted to focus their support, awareness raising and fundraising efforts here. After feedback and careful consideration, we have decided to discontinue the 27forParkinson's campaign. This decision will enable our community to concentrate efforts on strengthening awareness-raising via A Walk in the Park.

We know the 27forParkinson's Facebook group is an important place for our community to connect and share their experiences. We are keeping this page active and we encourage everyone to continue sharing your journeys and supporting each other there.

*Fight Parkinson's CEO Emma Collin*

We would like to take a moment to acknowledge the contributions of two key community members and former board members, Andrew  Suggett OAM and Shane Murphy who died in the past few months.

We don't typically name individual members we have lost and we know that the community is feeling the loss of valued members all the time. However, Andrew's unwavering dedication to the Warrnambool Parkinson's Support Group, tireless advocacy up until the day he died and his sudden loss has been felt across the Parkinson's community.

We also deeply appreciated Shane's valuable work with the Fight Parkinson's Board, his involvement in several of our committees and his willingness to share his personal experience with Young Onset Parkinson's with the media and wider community.

In this edition of InMotion, we explore how insurance and superannuation can support people who are of working age or nearing retirement. You'll also read about a breakthrough in research—a blood test biomarker that could be a game-changer for early detection of Parkinson's. While its potential brings hope, we also recognise the daily struggles of hundreds of thousands of people who are directly or indirectly affected by Parkinson's. If you need support, Fight Parkinson's is a phone call away.

I want to express our deepest gratitude to those who have graciously shared their stories with us. This edition shines a light on the dedicated efforts of families supporting their loved ones. These stories highlight the extraordinary lengths people go to for our cause and the support within our community is truly inspiring to witness.

Whether you are living with Parkinson's, PSP, MSA, or CBS, or caring for someone with any of these conditions, we hope this edition reminds you that you are part of a diverse and strong community. No one chooses to be part of this community, but for those who are, there is a supportive group of people alongside you.

**Emma Collin**
CEO
Fight Parkinson's

# News & highlights

## ParKanDo's annual community expo

**ParKanDo, a Peer Support Group supported by Fight Parkinson's, hosted their community expo, bringing together community members to learn, connect and share their experiences.**

Since its inception in 2020, ParKanDo's community expo has been part of its community activities, growing into a crucial support hub for community members in the Western suburbs of Melbourne.

Their expo took place at the Newport Community Hub, where the day was filled with insightful talks from experts offering clinical information and personal insights into Parkinson's from a range of perspectives.

Highlights included presentations by Fight Parkinson's Board Members Professor David Finkelstein and Sheenagh Bottrell (providing lived experience), Fight Parkinson's CEO Emma Collin, Fight Parkinson's Director Health Service Victor McConvey OAM, speech therapist Caitlin Grima and carer Janice Reardon.

"The quality of speakers was just phenomenal. To have so many people interested and to have such great speakers was a perfect combination. They really brought home the fact that there is so much support out there" said Peter Wall, one of ParKanDo's group leaders.

Attendees enjoyed the expo's high-energy atmosphere and the wide range of topics covered, ensuring that everyone, regardless of when they were diagnosed, could find the support they needed.

The success of the expo was truly a community effort, driven by promotion through brochures, local papers and word of mouth, along with support from Fight Parkinson's and the Hobson Bay City Council.

*Fight Parkinson's Director Health Service Victor McConvey OAM speaking with attendees at the expo.*

## In the media

**Several Fight Parkinson's ambassadors have stepped into the spotlight to raise awareness of Parkinson's, the need for increased funding and breakthroughs in research.**

In an interview with Channel 9, former MP and Fight Parkinson's ambassador John Eren opened up about his personal experience living with Parkinson's. John shared the challenges he faces daily and highlighted the significance of the Federal Government's recent announcement of $800,000 in funding for the National Parkinson's Alliance's National Parkinson's Action Plan - a significant step forward for all Australians affected by Parkinson's.

Professor David Finkelstein, Fight Parkinson's Board member, Chair of Fight Parkinson's Research Committee and Head of the Parkinson's Disease Laboratory at the Florey Institute, appeared on Channel 7 to elevate research breakthroughs on Parkinson's. He explained how the new diagnostic tool, a blood test powered by artificial intelligence, works and its potential to accelerate research efforts, offering hope for earlier and more effective treatments.

Our Appeal hero, Shona Cross, spoke with ABC Wimmera, sharing her Parkinson's story and insights into living well with the condition. Shona's radio interview served as a platform to raise awareness of the condition and highlight local support initiatives, such as the Fight Parkinson's Wimmera Parkinson's Community Seminar held recently.

These media appearances highlight the ongoing need for community representation. If you would like to share your story with us and help lift the lid off Parkinson's, please email us at marketing@fightparkinsons.org.au.

## Strengthening national collaboration

**Fight Parkinson's is now a member of the Neurological Alliance Australia, a significant step in advocating for the representation of individuals affected by neurological conditions across Australia.**

The Neurological Alliance Australia (NAA) is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or neuromuscular diseases in Australia.

The NAA was established to promote improved quality of life for people living with these conditions and increase funding to support research.

A key focus of the NAA is calling for the establishment of a Taskforce for Neurological Conditions. This Taskforce aims to address the needs of millions of forgotten Australians in six key areas: increased funding for medical research; strengthening the NDIS (National Disability Insurance Scheme); establishment of a nationwide neurological dataset, ensuring fair access to assistive technology; eliminating age discrimination within the NDIS; enhancing integration within the Aged Care, Health, and Disability sectors.

There are more than 27 organisation members of the NAA including Dementia Australia, Brain Injury Australia, Emerge Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Epilepsy Foundation and many more.

By joining forces, we hope to enhance our capacity to advocate for our community on a national level and work towards securing the resources, research and recognition needed to improve outcomes and foster a better future for all Australians living with neurological conditions.

# Managing symptoms

## Eating, swallowing and saliva

**Parkinson's brings a wide range of symptoms that can impact everyday life, with some being more disruptive and frequent than others. Managing changes in eating, swallowing and saliva can be especially difficult, but there are strategies and support available to help with these issues.**

### Eating and swallowing

For people living with Parkinson's, eating and swallowing can become difficult. Swallowing movements may slow down or become more effortful and less coordinated. Other symptoms related to posture, attention and concentration can also exacerbate the situation.

The medical term for swallowing difficulties is dysphagia. Some signs of dysphagia include:

- Coughing or choking when eating or drinking
- Difficulty swallowing certain foods, fluids or medications
- Meals taking longer to finish than usual
- Needing beverages to wash down food
- Sensation of having too much or too little saliva

Dysphagia can lead to weight loss, malnutrition and dehydration. Taking medication can become challenging and food and drink might accidentally enter the lungs, leading to chest infections or pneumonia. The emotional toll of dysphagia can also impact quality of life, causing embarrassment and anxiety around eating.

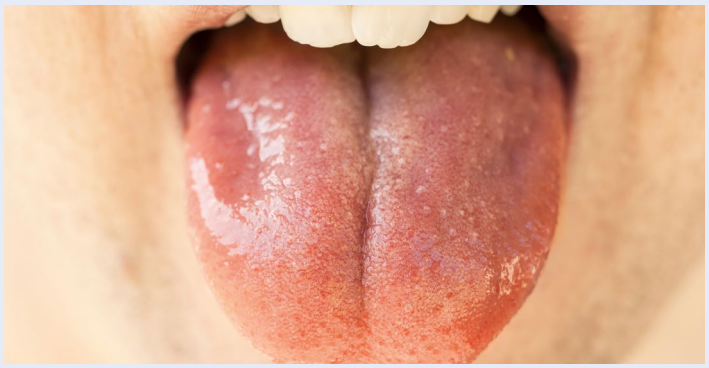
#### Tips for overcoming swallowing problems

- **Sit up straight:** Always sit up straight when eating and drinking.
- **Small bites:** Take small mouthfuls and regular sips of fluid during meals.
- **Concentrate:** Avoid all distractions during mealtimes and plan conversations either before or after.
- **Monitor your health:** Be alert to fever and coughs and seek help immediately if they occur.
- **Timing:** For some people, eating and drinking during their medication 'on' period when symptoms are better controlled may be easier and more comfortable.
- **Take your time:** Do not rush when eating and drinking. Finish each mouthful before starting the next.
- **Cut and chew:** Cut food into small pieces and chew well before swallowing.
- **Head position:** Keep your head level with your chin slightly tucked or eyes directed to your knees

Foods with certain types of consistencies, like hard, dry or fibrous foods can be more challenging to swallow. If this happens to you, keep a record of foods you find difficult and avoid these until you get advice from a health professional, such as a speech pathologist.

If you experience any difficulties with swallowing your tablets, speak to your treating specialist. There may be strategies and/or alternative substances to water that can make swallowing tablets safer and easier.

### Excess saliva



Some people may experience an increased saliva sensation in the mouth or throat, which can lead to wetness around the corners of the mouth or drooling, a condition known as sialorrhea.

The natural tendency to swallow saliva is reduced in Parkinson's, causing discomfort when talking, eating or drinking. This can cause embarrassment and increase stress and anxiety, especially in social settings.

#### Tips for managing excess saliva

- **Conscious swallowing:** Make a conscious effort to swallow your saliva often.
- **Food awareness:** Be mindful of foods that can make saliva thick or sticky and more difficult to swallow, like sugary foods, caffeine and alcohol.
- **Professional help:** Ask your doctor to refer you to a speech pathologist who can assess and advise on swallowing and saliva management.
- **Medication:** Speak with your doctor about medication options to help reduce or control saliva production.

### Dry mouth

Some people may experience dry mouth, which can make chewing and swallowing difficult. Saliva acts as a lubricant and has antibacterial properties to protect your teeth and mouth from decay and neutralise acidic foods. Therefore, dry mouth can lead to dental problems and increase the risk of mouth infections.

### Tips for lubricating a dry mouth

- **Frequent sips:** Take frequent sips of water to keep your mouth moist and avoid dehydration.
- **Use lip balm:** Apply lip balm regularly to keep your lips moist.
- **Dentures:** Remove and clean dentures at night to give your mouth a chance to recover.
- **Oral products:** Ask your pharmacist about oral lubricants and artificial saliva products.
- **Dental visits:** Visit your dentist regularly to monitor and manage oral health.

## Eating healthy

Maintaining a healthy and balanced diet is crucial for everyone, especially if you're living with Parkinson's. Proper nutrition helps maintain muscle strength and overall energy levels, which are essential for mobility and quality of life.

### Tips for maintaining nutrition

- **Regular meals:** Have regular meals with possible mid-meal snacks.
- **Balanced diet:** Ensure your diet includes all food groups (carbohydrates, protein, fruits, vegetables and dairy).
- **Fibre and fluid:** Maintain an adequate intake of fibre and fluids to avoid constipation. High-fibre foods include wholegrain and wholemeal products such as multigrain bread, high-fibre cereals, fruits and vegetables.
- **Exercise:** Regular exercise can help manage bowel function.
- **Professional guidance:** Consult a dietitian, GP, speech pathologist or other health professionals for personalised advice.

## Support for you

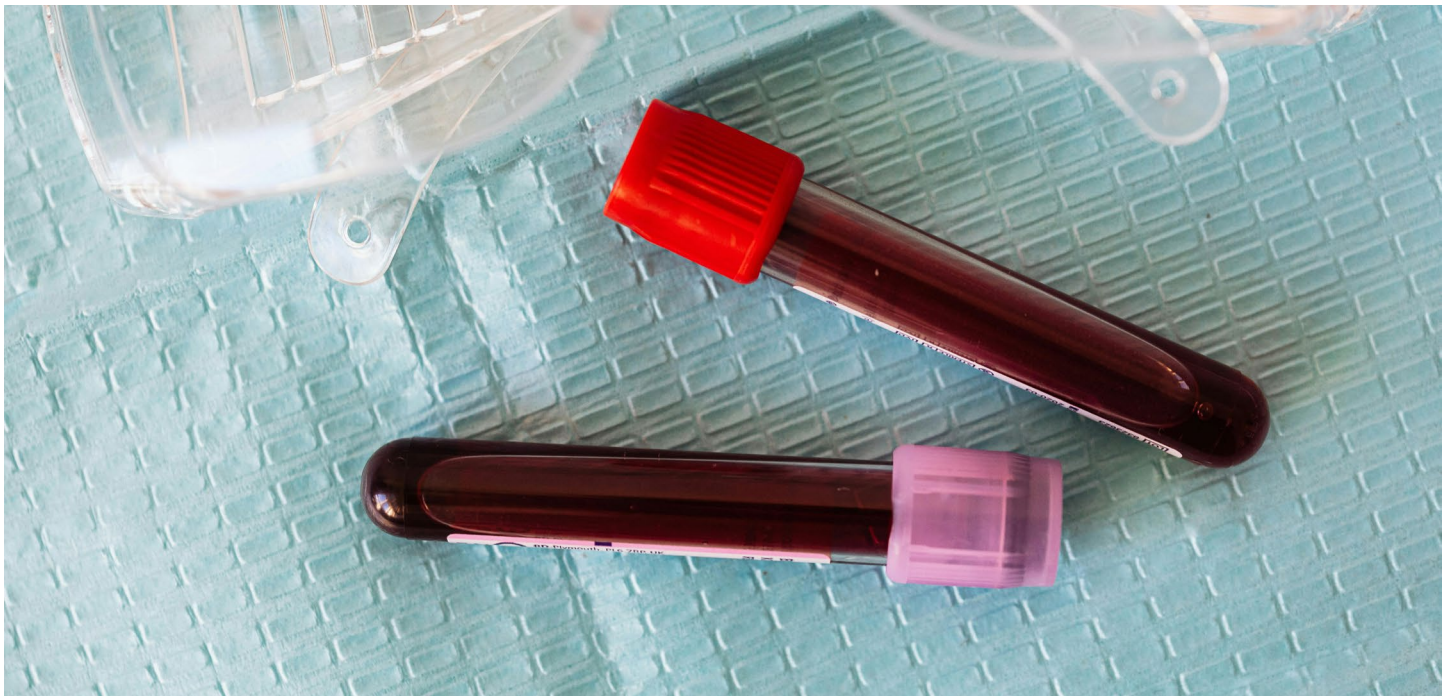
If you are experiencing issues with eating, saliva or swallowing, it's important to work with your GP to develop a Chronic Disease Management Plan, which will allow you a limited number of Medicare-rebated appointments.

Your GP can help assemble a team of health care professionals to support you. This team may include:

- **Speech pathologist:** Can examine structures of the mouth and throat involved in swallowing such as lips, tongue, jaw, soft palate and larynx and provide individual recommendations and strategies for optimal and safe eating, drinking and saliva control.
- **Dietitian:** Works with the speech pathologist to ensure that food and drink meet your nutritional needs. They also focus on preventing constipation through the intake of fibre-rich foods and maintaining a healthy weight.
- **Physiotherapist:** Can provide guidance on optimal body posture during mealtimes or reducing drooling when walking and general physical exercises that can benefit gut health and mobility.
- **Occupational therapist:** Advises on seating, specialised equipment (if needed) and other environmental factors to make mealtimes and swallowing comfortable and safe.

For more advice and information on the above, you can call Fight Parkinson's on 03 8809 0400 to speak with our multidisciplinary Health Team.

# Research



## Breakthrough in early detection of Parkinson's

**European researchers have developed a blood test powered by artificial intelligence that could predict Parkinson's seven years before the onset of symptoms.**

We need reliable biomarkers to detect Parkinson's early and improve the quality of life for those diagnosed. A groundbreaking new blood test could be the solution. Published in the journal Nature Communications, this discovery has the potential to revolutionise how we diagnose and treat Parkinson's.

### The study and its findings

Researchers from University College London and University Medical Center Göttingen have developed a blood test that uses artificial intelligence (AI) to examine blood samples for signs of Parkinson's.

The blood test looks at eight specific proteins in the blood:

- Granulin precursor
- Mannan-binding-lectin-serine-peptidase-2
- Endoplasmatic-reticulum-chaperone-BiP
- Prostaglandin-H2-D-isomerase
- Intercellular-adhesion-molecule-1
- Complement C3
- Dickkopf-WNT-signalling pathway-inhibitor-3
- Plasma-protease-C1-inhibitor

These proteins were selected because their levels in the blood change in people with Parkinson's. The researchers looked at samples from three groups: people recently diagnosed with Parkinson's, individuals with isolated Rapid Eye Movement sleep behaviour disorder (iRBD), a condition that is often an early sign of Parkinson's and those with neither condition.

The AI tool analysed the blood samples and found that 79% of the iRBD participants had protein changes similar to those seen in people with Parkinson's. Over ten years, the researchers tracked the participants and confirmed that their predictions were accurate: they successfully identified 16 iRBD individuals who developed Parkinson's up to seven years before they developed motor symptoms of Parkinson's. This means that this initial study achieved 100% diagnostic accuracy.

The research team are continuing to follow up on those predicted to develop Parkinson's to further verify the accuracy of the test.

### Why this matters

While the test is not yet available for public diagnostic use and further research is required, it represents a significant step forward in the early detection and management of Parkinson's.

The study needs to be replicated in larger trials across different ethnic populations in multiple countries. We also need to research if these blood markers are a consequence of Parkinson's and if their appearance can be altered by treatments. However, the study is incredibly promising.

A simple blood test is less invasive, more efficient and more affordable than current methods. Detecting Parkinson's early means treatment can start sooner, which can help manage symptoms early and improve quality of life.

Additionally, having a reliable early diagnosis method would open new doors for clinical trials. Researchers could identify at-risk individuals much earlier, allowing them to test new treatments aimed at slowing or even preventing the onset of Parkinson's motor symptoms. This could lead to the development of effective therapies that change the course of the condition.

### Looking ahead

Currently, the blood test is being used in labs and its main purpose is to identify candidates for clinical trials. One day, it could become a routine blood test available at your local pathology lab.

The journey from lab research to everyday medical practice can be long, but the potential impact of this blood test is enormous.

To discuss the significance of the research, Channel 7 interviewed Professor David Finkelstein, Physiologist and Neurobiologist and Chair of Fight Parkinson's Research Committee. When asked whether the research brings us any closer to a cure, he said, "Absolutely. One of the impediments to finding a cure is accurate and selective clinical trials. This will allow us to get new drugs into trial and potentially a cure."

For people living with Parkinson's, their families and the scientific community, this research is a reminder that science is continually progressing. This new blood test is a beacon of hope, signalling a future where Parkinson's can be detected early and hopefully managed more effectively.

# Community safety

## Chemical under review

**There has been widespread discussion regarding the association between the herbicide paraquat and the development of Parkinson's in farming regions in Victoria.**

Our commitment to the continuous development of evidence-based best practices ensures the community can trust that the information we provide is current and reliable.

Our understanding of Parkinson's is increasing through progressive research, but there is still much that doctors and scientists do not know about its causes.

It is likely that for most cases, there is a complex interplay between genetic and environmental influences in the causation of Parkinson's.

Studies worldwide have considered pollution, pesticides, herbicides and plastics as environmental factors that may increase the risk of developing Parkinson's.

Understanding the distinction between correlation and causation is important in interpreting research findings. A correlation indicates a relationship between two things but doesn't prove one causes the other.

Risk does not necessarily imply causation but rather indicates how likely an event is to happen given certain conditions.

### Fight Parkinson's position on paraquat

A number of scientific studies have established a clear association between the herbicide paraquat and development of Parkinson's disease.

Paraquat is a non-selective herbicide which kills most green plant tissue on contact through inhibition of photosynthesis and can also desiccate crops. Paraquat is also used as an alternative for weeds that are resistant to glyphosate, another common herbicide.

There is evidence in Australia and around the world, showing a correlation between heightened incidence of Parkinson's in environments where paraquat is used.

International research has provided evidence that paraquat dichloride exposure is associated with a greater risk of developing Parkinson's. Some studies have shown that the greater the exposure, the greater the risk.

There is currently no definitive 'scientific proof' that paraquat causes Parkinson's in an individual. As Parkinson's is thought to be influenced by a combination of genetic and environmental factors, it is difficult to isolate a single cause, such as exposure to a specific herbicide.

Animal models have however provided evidence of the biological mechanisms through which paraquat could cause Parkinson's.

There is also no clear way of proving a causal rather than correlative link between paraquat exposure and Parkinson's in humans in a reasonable timeframe and in an ethical way.

Here are some current key findings from the scientific literature:

- **Epidemiological findings:**
  Numerous credible studies have shown an increased risk of Parkinson's among individuals exposed to paraquat. For example, agricultural workers who handle paraquat or live near treated areas exhibited a higher incidence of Parkinson's disease.
- **Molecular Mechanisms:**
  Animal studies have shown that paraquat is known to be toxic to nerve cells. It can damage mitochondria (the 'powerhouse' of the cell) and can cause oxidative stress, damaging cellular components including DNA, proteins, lipids and can cause cell death.

The European Union, United Kingdom, Canada, China and many more countries have banned the use of paraquat to mitigate potential risks.

The use of paraquat is currently permitted in Australia – a decision that is now under review.

Based on the evidence and the actions of the international community, Fight Parkinson's supports a ban of paraquat in Australia.

### Regulatory review

Currently, the use of paraquat does come with cautions and safe use guidelines including protective gear and health warnings, however, exposure guidelines established by Safe Work Australia provide limited information on what is considered safe exposure limits to paraquat.

In Australia, paraquat is currently a listed chemical under review under the Australian Industrial Chemical Introduction Scheme's reconsideration program.

As part of the review process, a report has been undertaken by the Office of Chemical Safety at the request of the Australian Pesticides and Veterinary Medicines Authority (APVMA) and published July 2024.

The APVMA are inviting written submissions on a proposed course of action by 29 October 2024.

When the risk assessments have been completed, the proposed regulatory decisions will be drafted. The process is forecasting a decision in February 2025.

### In summary

Given the body of current evidence, Fight Parkinson's supports a ban of paraquat to mitigate risk to farmers and their families and the wider Australian community.

We hope the APVMA will follow the lead of the countries who have placed a ban on paraquat use.

Parkinson's has been described as a global pandemic and as the fastest growing neurological condition. The APVMA is in the position to create change and prevent more people from paraquat exposure that may contribute to them developing Parkinson's.

A ban would be Australia's first preventative measure to reduce the risk of Parkinson's.

Fight Parkinson's vision is for a world free of Parkinson's and until a cause, prevention or cure is found, we aim to empower those living with Parkinson's to lead full and active lives.

The review under the Australian Industrial Chemical Introduction Scheme's reconsideration program provides an opportunity to make submissions with our community.

*If you are living with Parkinson's and want to share your experience with Paraquat exposure as part of our submission to the APVMA Paraquat Chemical Review, please call Fight Parkinson's on 03 8809 0400. If you would like to make your own submission, you can visit apvma.gov.au for details. The deadline for submissions is October 29 2024.*

*To view our full position statement, including all studies and statistics referenced, visit fightparkinsons.org.au/about-us/media-release*

# Atypical Parkinson's

Ginda and her husband, Michael.

## Poetry on PSP

**Ginda Simpson's collection of poems captures the emotional landscape of caring for a loved one living with PSP, offering comfort and hope to others in similar situations.**

Ginda Simpson, a painter and writer living in the US, has lived a life of creativity and compassion. Her early experience caring for her father, who had Alzheimer's, prepared her for the unexpected role she would take on for her husband, Michael. He was diagnosed with Progressive Supranuclear Palsy (PSP) two years ago.

Michael's tremors were initially misdiagnosed as essential tremors, but Ginda's intuition told her something more was amiss. She recalls, "I don't know that I could have put into words the things that were concerning me – episodes of slurred speech and unsteadiness as if he were drunk, but he wasn't. Extreme apathy, but not depression. Shutting down and not speaking - although he has always been a quiet man, this was different." It wasn't until Michael experienced multiple falls that a neurologist took a closer look and eventually diagnosed him with PSP.

*"It was difficult for me to adjust to the diagnosis and prepare myself for the long road ahead. I have done everything I can to educate myself about the condition so that I can be a more patient and effective care partner. But the future frightens me. Writing poetry has been my refuge."*

### Seeking solace and support

During National Poetry Writing Month in the US, Ginda wrote a poem a day, which evolved into her book, "Hummingbird: Poetry on PSP & Parkinson's."

"Hummingbird" is a testament to the strength and resilience of those affected by PSP and Parkinson's. Ginda's poetry captures a wide spectrum of emotions, from fear and uncertainty to acceptance and hope. Her poetry offers comfort to others as they navigate the complex journey of caring for a loved one.

Over the past two years, Ginda has sought knowledge and support from various organisations around the globe, including Fight Parkinson's. "Each fact shared is like a little piece of the puzzle we are trying to assemble so that we can better understand what we are seeing," she notes. Learning from others' experiences provides strength and hope, which Ginda strives to offer through her poetry.

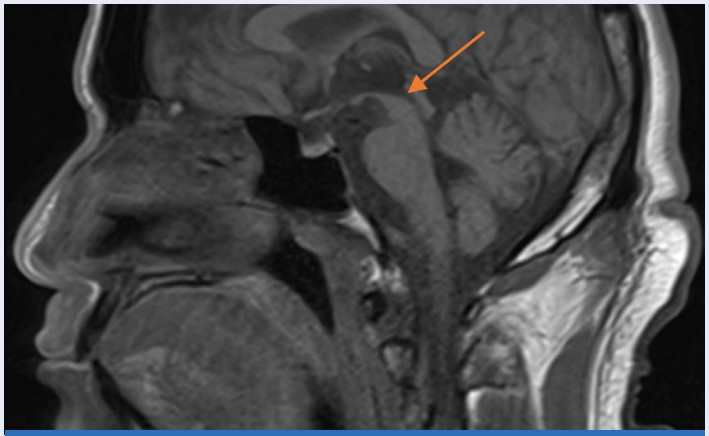
"We are not alone. It is important to learn about the condition and to embrace hope and healing in whatever way we can, wherever we can, no matter what," she says.

Despite her husband's diagnosis, Ginda says Michael is unstoppable. "He has remained positive and engaged in the programs that we know are helping him." Activities like water aerobics, boxing, spin biking and speech therapy have been game-changers in managing his symptoms.

### Ginda's advice for fellow carers

For other carers and families dealing with PSP, Ginda offers heartfelt advice: "Make an effort to learn as much as you can about PSP but take it in small doses to reduce overwhelm. Don't put off activities you can enjoy together; find ones you can do apart to give yourselves time to regroup. Surround yourself with friends and activities that lift you up and let go of everything else."

"Hummingbird: Poetry on PSP & Parkinson's" is available to order on Amazon. If you or a loved one is living with PSP, Fight Parkinson's Health Team offers national specialist support for you. Call us on 03 8809 0400 to speak with a member of our Health Team and learn about the tailored information and resources available.



*The "hummingbird sign" refers to the appearance of the brainstem in individuals with progressive supranuclear palsy (PSP).*

# Atypical Parkinson's

## Multiple System Atrophy (MSA)

**Although MSA shares similarities and may be initially diagnosed as Parkinson's, it is a distinct condition with a unique set of challenges. However, specialised care and support can significantly improve the quality of life for those living with MSA and their loved ones.**

### What is MSA?

Multiple System Atrophy (MSA) is a rare and progressive neurological condition that affects multiple parts of the brain. It involves the gradual loss and shrinkage (atrophy) of nerve cells, which in turn affects various systems in the body. This cell loss occurs in the areas of the brain that regulate movement, balance and automatic bodily functions such as bladder and blood pressure regulation.

In Australia, it's estimated that there are around 2,500 people living with MSA. As our understanding of MSA improves and more neurologists can recognise it, the number of diagnosed cases is increasing.

### What causes MSA?

We are still uncertain about the causes of brain cell shrinkage in MSA, but we do know that structures called glial inclusion bodies, which contain an abnormal protein called alpha-synuclein, appear to be involved. Further research is ongoing to understand why and how the cells become damaged in people with MSA.

Currently, there are no blood tests or brain scans that can definitively diagnose MSA, although these tests and scans are often used to rule out other conditions with similar symptoms. In some cases, advanced brain scanning methods may detect abnormalities in patients with MSA.

There is no evidence to suggest that MSA is hereditary, although recent research indicates that genetic factors can predispose a person to develop MSA. In other words, there may be some genetic susceptibility that makes some people more at risk than others, but MSA rarely affects more than one person in a family.

### MSA vs Parkinson's and PSP

Some MSA symptoms, such as stiff muscles and balance problems, are similar to those seen in Parkinson's and Progressive Supranuclear Palsy (PSP). Despite these similarities, there are fundamental differences between these conditions.

Parkinson's, MSA and PSP all involve the basal ganglia, the area of the brain that affects movement. However, in MSA, additional areas of the brain are affected, such as the cerebellum and the brain stem. This impacts balance and coordination as well as autonomic functions like blood pressure and bladder function.

Due to the crossover between Parkinson's and MSA, it's very common for people showing early signs of MSA to initially receive a Parkinson's diagnosis. It's important to note that treatments for Parkinson's are not as effective in treating MSA and may cause blood pressure to lower. If there is a limited response to Parkinson's medications, or unexpected blood pressure changes occur, seeking the opinion of a neurologist is essential.

Because MSA is rare, some doctors may not be familiar with its symptoms, which can lead to misdiagnosis and further complicate the challenges faced by those living with MSA. Therefore, it's incredibly important to consult a neurologist who is familiar with movement disorders.

### The Intruder

*I sought to put a restraining order*
*on my wild imaginings*
*of whom this visitor might be.*
*But he would slither towards me*
*As silently as a snake*
*and nest in the unguarded places*
*of my soul.*

*Eventually,*
*he climbed over the ramparts*
*of my secure compound*
*and boldly unlatched the gate*
*ready to lay claim*
*to everything I hold dear.*
*He handcuffed my heart.*
*and forced me to unmask him,*
*to look him in the eyes.*

*"Name is Parkinson's," he bowed,*
*his voice raspy and slow.*
*His hand trembled*
*as he pointed to his companion,*
*a distant cousin,*
*an unsavory character,*
*callous and calculating,*
*the one few people knew,*
*the one no one welcomed,*
*the one that should have been jailed*
*long ago...*

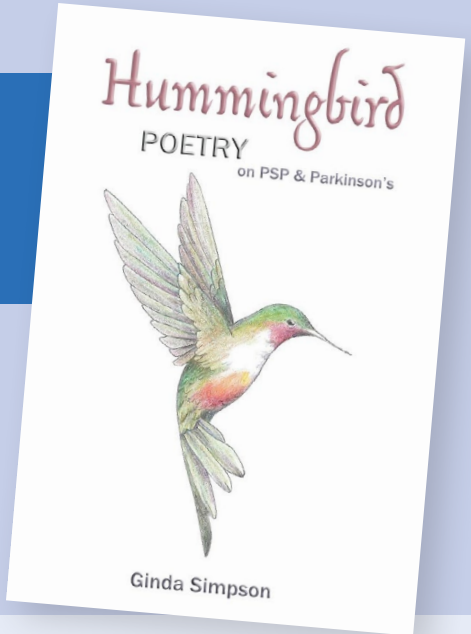
*"Meet Progressive Supranuclear Palsy,*
*PSP, for short" he exhaled loudly,*
*"He's come to live with your husband.*
*He has come to stay."*

*This is not an introduction.*
*This is an invasion...*
*a declaration of disease,*
*of impending damage and decline.*

*I know very little.*
*I know enough.*
*I know.*
*I don't want to share my home with him.*
*I want to vanquish him,*
*annihilate him.*
*But there are no weapons.*

*Except Love.*

*An excerpt from Ginda's poem, "The Intruder,". The poem reflects the period before Michael's diagnosis, filled with unknowns and unease.*



## MSA symptoms

Symptoms can be many and vary from person to person.

Different symptoms are experienced depending on the part of the brain affected, as follows:

**Movement problems – related to the basal ganglia:**

- slow movements
- stiff muscles
- small and spidery handwriting
- difficulty turning in bed

**Poor balance and coordination – related to the cerebellum:**

- clumsiness
- difficulty fastening buttons
- unsteady on the feet
- loss of balance
- slurred speech
- bladder problems
- dizziness or fainting
- cold hands and feet
- problems with sweating control

**Other symptoms:**

- weakness of arms and/or legs
- unusual emotional response (laughing or crying)
- restless sleep
- nightmares
- noisy breathing and/or snoring
- unintentional sighing
- weak/quiet voice
- swallowing problems

Symptoms of MSA typically appear between the ages of 50 and 60, though they can appear in younger or older people as well. The severity of symptoms tends to gradually increase and worsen over a period of 5 to 10 years, however, the rate of progression varies from person to person.

On average, people with MSA live for around nine years after the onset of symptoms. As the condition progresses, people with MSA are at risk of developing serious complications such as pneumonia, bacterial infections, or pulmonary embolism. Research into MSA is currently underway, giving us hope for the future, particularly in relation to more effective management of symptoms.

## MSA management

Treatments and therapies are available to help manage symptoms of MSA, but there is no known cure or way to prevent it from occurring or slowing its progression.

It's important that people with MSA see a neurologist regularly for ongoing treatment and advice, preferably one with expertise in movement disorders, as they are more likely to be up to date with the latest advances in treatment and management.

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

Fight Parkinson's can provide information about finding neurologists and other health professionals with an understanding of MSA.

## MSA support

Most people are diagnosed with MSA after being diagnosed with Parkinson's and this may cause a range of emotions, including grief, fear, sadness, denial, anger or concern for the future. Some people may feel a sense of relief in finally putting a name to the difficulties they've been experiencing after searching so long for answers.

If you have received an MSA diagnosis, it's important to have a safe space to navigate through these complex emotions, knowing that those around you are likely feeling the same way. Speaking with a counsellor can offer valuable support in coming to terms with these feelings and make meaning of the situation.

Getting information and support can help you adjust to the diagnosis. Investigating what is available early can provide some peace of mind and seeking out health professionals who understand MSA can assist. Please remember that you are not alone and there is help available for you.

Fight Parkinson's has a comprehensive information guide to MSA and the Health team can assist with information, support and navigation to services. Free telephone interpreter services are available for people who speak a language other than English. We also hold a bi-monthly online Peer Support group for people with MSA and Atypical Parkinson's.

If you are interested in attending an online meeting or would like to know more, please call us on 03 8809 0400 or email us at info@fightparkinsons.org.au.

# Young Onset Parkinson's

## Young Onset Parkinson's Conference

**Young@Park, a Fight Parkinson's Peer Support Group, is dedicated to raising awareness and providing support for individuals living with Young Onset Parkinson's. With the support of a Government grant from the Department of Families, Fairness and Housing, the Young Onset Parkinson's Conference was made possible, serving as a regional hub for tailored support.**

Young Onset Parkinson's presents distinct challenges, including managing symptoms while maintaining a career, raising a family and navigating the stigmas associated with Parkinson's.

The free conference was organised in Geelong to bring together community members from across Victoria who share similar experiences. It also brought a wide range of experts who shared practical tools to live well despite the unique challenges.

### The presentations

Neuropsychologist Dr Luke Smith's presentation delved into how Parkinson's affects cognition - one of many "invisible" symptoms of Parkinson's. Cognitive symptoms of Parkinson's can be particularly challenging, especially when you are still of working age. His presentation also included valuable strategies for managing cognitive symptoms, which participants could incorporate into their busy lives.

Movement disorder neurologist Associate Professor Sanjay Raghav shared his holistic approach to managing Parkinson's while young, incorporating evidence-based therapies, yoga and mindfulness strategies. The session was especially interactive, with Associate Professor Raghav leading a yoga session where he demonstrated a range of postures and breathing techniques.

For attendees interested in the latest research updates, Professor Michael Lazarou, a leading neuroscientist from the Walter and Eliza Hall Institute, shared a comprehensive overview of the latest advances in Parkinson's research, making complex scientific information more accessible to everyone.

Movement Disorder Specialist and Social Worker Amanda Spillare led a dedicated session for partners and carers, which was both helpful and validating. The session recognised the vital role that carers play and acknowledged the complex journey they undertake in supporting a loved one with Young Onset Parkinson's.

Since many people with Young Onset Parkinson's are still employed or have retired early, issues like employment, superannuation and insurance are often top of mind. Craig Parrish from Maurice Blackburn led a highly interactive session, addressing audience questions and equipping attendees with the tools to understand their entitlements, know their rights and effectively manage financial uncertainties.

Professor Meg Morris, best known for her groundbreaking studies on falls prevention, physiotherapy and dancing for Parkinson's, shared her latest research on powerlifting. She also highlighted a clinical trial investigating the benefits of powerlifting exercises for people with Early Onset Parkinson's (aged under 50).

The final presentation of the day was a discussion on sex and intimacy, led by Fight Parkinson's Director Health Service Victor McConvey OAM. During the session, Victor created a safe environment to explore the subject, which is often shied away from. His empathetic approach helped break down barriers and foster an open dialogue.

After the presentations wrapped up, conversations continued over lunch, where attendees shared their reflections and experiences, fostering new connections.

The Young Onset Parkinson's Conference highlighted the value of connecting with people who understand the complexities of Parkinson's. The sessions provided a toolbox of strategies and tailored resources, while the camaraderie served as a reminder that no one has to fight Parkinson's alone.

We extend our heartfelt thanks to Young@Park for organising the event and we hope that everyone left the conference feeling informed, connected and uplifted.


*Conference MC and Young@Park Group Leader, Sheenagh Bottrell.*


*Professor Michael Lazarou discussing mitochondrial dysfunction in Parkinson's.*


*Victor McConvey OAM sharing how Parkinson's affects men and women differently.*

# Support for you

*Warrnambool Parkinson's Support Group Leader Liz Morse (left) and Betty Suggett (right).*

## A legacy of community care

**The Warrnambool Parkinson's Support Group has been a pillar of support and hope for people living with Parkinson's in the region. As Liz Morse steps into her role as Group Leader, she brings enthusiasm and a deep commitment to continuing the legacy of her predecessor, Andrew Suggett OAM.**

### Continuing a legacy

Andrew Suggett, former Peer Support Group Leader, was a cornerstone of the Warrnambool community. His dedication and passion, alongside his wife Betty, left a profound impact on everyone involved.

"Andrew was just one in a million," Liz reflects. He was always proactive, visiting people in their homes and hospitals and spreading awareness about Parkinson's. His work was instrumental in making our group what it is today."

### New leadership, same commitment

Taking over the Peer Support Group is no small task, but Liz is up to the challenge. With a background in nursing and personal experience caring for her husband, John, who lives with Parkinson's, she brings both professional and personal insights to the role.

Having witnessed firsthand the positive impact the support group had on herself and John over many years, she is deeply committed to continuing this vital work. "I want to ensure that people do not feel isolated," Liz emphasises. "For my husband, realising he wasn't alone and that there were other people he could talk to was really important. And I've made some lovely friends, too."

### Group activities

The Warrnambool Parkinson's Support Group meets on the first Wednesday of every month. The meetings provide a space for members to share their experiences, discuss challenges and offer mutual support. Additionally, they host guest speakers who provide valuable information on living well with Parkinson's. The meetings often include raffles and luncheons, where everyone can unwind. Several group members also attend ParkinSong™, which meets every fortnight.

### Looking to the future

As Liz settles into her role, she is focused on supporting the group through this new chapter. With the support of group Treasurer Lynn Gardner and fellow members, Liz hopes to increase community awareness and participation, ensuring that everyone affected by Parkinson's knows there is a supportive network available to them.

Liz and the group are planning their regional A Walk in the Park event, happening later in the year. "We're going to name it the Andrew Suggett Warrnambool Parkinson's Walk. It's a fitting tribute to recognise his efforts and the awareness he promoted."

Reflecting on her leadership, Liz says, "I'm just hoping to do even a fraction as well as Andrew did. It's been very rewarding so far. I've had really positive feedback and people are thankful for the support."

Despite the challenges that come with Parkinson's, Liz believes in maintaining a lighthearted spirit.

*"You got to have a bit of humour in life, particularly when you've been diagnosed with Parkinson's. You don't die from it, but you die with it and you'd like to think that everybody can still have a good quality of life if they've got the right care and support."*

For anyone considering attending a Peer Support Group meeting for the first time, Liz's advice is to just come along and see what happens. "We'll make you feel welcome and there will be no pressure. You can take what you need and leave the rest. But just come along and if it doesn't suit, it doesn't suit. If it does, you'll meet some wonderful people."

Fight Parkinson's has an extensive network of Peer Support Groups across Victoria. If you would like to get involved or learn more, please call the Fight Parkinson's Team on 03 8809 0400.

*Members of the Warrnambool Parkinson's Support Group catching up at their recent luncheon.*

# Support for you


*Local community member Charles Gilbert and Fight Parkinson's Director Health Service Victor McConvey OAM discussing the benefits of Peer Support.*


*Neurologist Dr Daniel Barber debunking misconceptions about Parkinson's during his keynote address in Benalla.*

## Community seminars

**Fight Parkinson's is pleased to continue delivering community seminars across Victoria, providing vital access to Parkinson's information and education, especially in regions that have limited access to specialists. These seminars not only raise awareness but also offer an essential opportunity for people to learn more about Parkinson's and connect with others in their area.**

Experts, including Professor Grant Dewson and neurologist Dr Daniel Barber, shared invaluable insights into the latest research and treatments. Their presentations made technical information more accessible, empowering attendees with the knowledge and tools to advocate for the best possible care and stay informed about potential new treatments.

As always, members from Fight Parkinson's Health Team were available to answer frequently asked questions and dispel myths and misconceptions about living with Parkinson's.

The personal stories shared during the seminars were powerful testaments to the resilience and support found within our community. In particular, the personal accounts from members like Shona Cross in Horsham and Charles Gilbert in Benalla deeply struck a chord with audience members.

The seminars have also led to new initiatives, particularly in Benalla. One of the main objectives was to highlight the importance of Peer Support. The discussion revolved around establishing a new group in Benalla as the previous one couldn't reconvene after the easing of COVID-19 restrictions. Several community members showed interest in joining a Peer Support Group and the Fight Parkinson's Team will be working with them in the upcoming months to set up a new group.

If you are interested in participating in our new Benalla Peer Support group or would like to join a Peer Support Group in your area, please call Fight Parkinson's on 03 8809 0400.

# Fundraising

## Brothers' bike trek for Parkinson's

**In a remarkable display of endurance, determination and love, three brothers—Steve, Ian and Mark Binks—have completed an epic cycle ride through the UK in memory of their parents.**

The Binks brothers embarked on their journey, named B'LEJoG (Binks's Land's End to John o'Groats), to raise funds for Parkinson's research. The funds raised are being split between Parkinson's UK and Fight Parkinson's, as Mark and Ian live in England and Steve now lives in Australia.

Over 16 days, they covered an astonishing 1650 km, pedalling approximately 100 km each day through diverse terrain. Despite the physical demands, their drive was fuelled by a purpose much greater than the ride itself.

### Honouring their parents' memory

The brothers' motivation to undertake the ride comes from a deeply personal place. Explaining the purpose of the ride, the brothers stated, "Both of our parents had Parkinson's and we learnt a lot from them on how to deal with adversity in life. However, a cure for the condition would be better. The challenge of riding from Land's End to John o'Groats is a big one, but adding a purpose beyond a ride makes it all the more fulfilling."

To make the ride even more meaningful, the brothers adjusted their planned route to pass through Clive, the village where they learned to ride bikes as kids and created cherished memories together.

### Planning the ride

The idea began with inspiration from a workmate's ride in 2022, discussed during one of the brothers' virtual catchups. By June 2023, the brothers had crafted a plan with the help of their Tour Director, Ian.

With their route finalised and accommodation booked by January 2024, they launched a website to spread awareness and start fundraising. Local media attention grew and by May, the brothers were packed and ready, and their journey was finally set to begin.

### The journey

Throughout the ride, the brothers kept a daily blog to update supporters on their progress and share stories from the road.

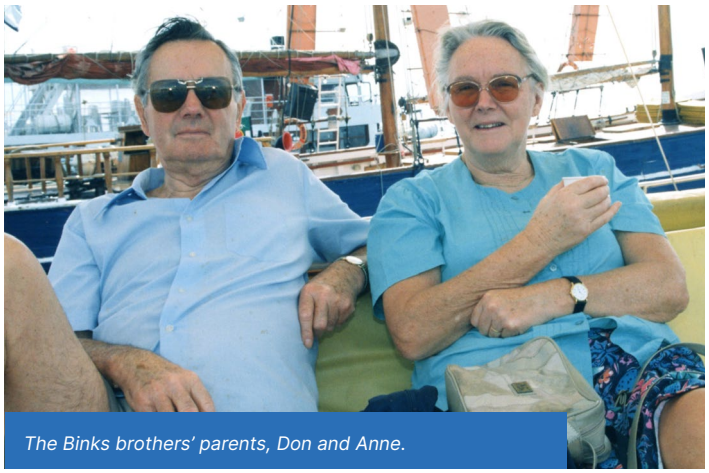
Early highlights of the journey included scenic stops in St Ives and Perranporth, coupled with spontaneous donations from generous strangers. The riders encountered varying landscapes, from the brutal climbs of Bodmin Moor and Exmoor to the scenic beauty of Cairngorms National Park.

They faced challenges like relentless rain, difficult climbs and technical issues, but these were offset by heartwarming reunions with old friends and family, generous hospitality from locals and breathtaking views across moors and national parks. Significant stops included a visit to their late uncle's house, the house they grew up in and many bridges. The ride was predominantly on minor roads, including a climb up Cheddar Gorge in pouring rain, passing through ski fields in Scotland, and seemingly endless bike trails through Edinburgh.

Emotional moments were plentiful, especially as they revisited their childhood haunts, the town of Shrewsbury and Clive village, rekindling memories and reconnecting with old friends.

The journey was filled with communal meals and poignant memories, underscored by the spectacular landscapes and the kindness of those they met along the way. It was a journey of resilience, joy and a deep connection to both the past and present.

For more details on the Binks brothers' journey from Land's End to John o'Groats, you can visit their blog at blejog.com.



*The Binks brothers' parents, Don and Anne.*


*Ian Binks, Tour Director Ian, Mark Binks and Steve Binks on Day 1, starting at Land's End.*

*They passed through Shropshire, joined by their fourth brother, Andrew, and former classmate, Graham, who rode with them for the day.*

*Mark riding up Cheddar Gorge.*

# Fundraising

## A story of legacy and impact – meet Sharon

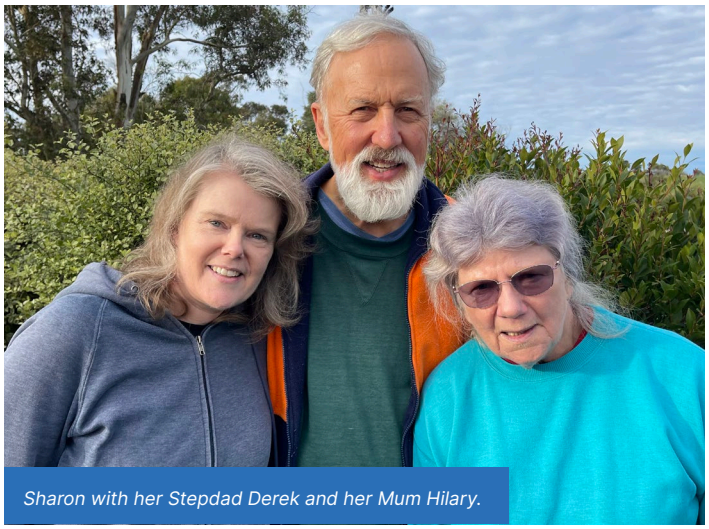
**Sharon, a devoted member and supporter of Fight Parkinson's, recently made a heartfelt decision to include Fight Parkinson's in her Will, which will leave a lasting impact.**

Her inspiring story is a perfect example of the powerful legacy we can all leave behind.

Include a Charity Week is a heartwarming campaign that aims to educate everyone on the importance of having a Will and the incredible impact of leaving a gift in your Will to a charity.

Gifts in Wills, also known as bequests, create a meaningful difference in our communities, contributing to around a quarter of all charity revenue in Australia.

Many Australians are eager to support their favourite causes, yet only half have a Will.



*Sharon with her Stepdad Derek and her Mum Hilary.*

## How writing my Will allows me to live in the present

**"The thought that my bequest can support others living with Parkinson's and their families brings me a sense of hope and fulfillment."**

Sharon has always had a close relationship with her Mum, Hilary. After noticing hand tremors for a while, Hilary was officially diagnosed with Parkinson's in 2020.

Soon, Sharon and her parents came to understand that Parkinson's was more complex than a tremor.

As an individual who has experienced her own health challenges and has recently completed a Master of Public Health, Sharon has played an integral role in her Mum's Parkinson's journey.

"Due to my own health challenges and the invaluable support I received from similar organisations in the past, I promptly joined Fight Parkinson's when Mum was diagnosed.

Given my parents live in Gippsland, I attended a Recently Diagnosed Seminar on their behalf and shared the valuable information and insights I gained with them. I regularly share the InMotion magazine, Fight Parkinson's events, webinars and information I've obtained from the Information Line with my parents."

When she is able, Sharon travels to Gippsland to spend quality time with her parents. Checking out the local op shops with Mum and having a family lunch at the local country RSL, followed by a walk with their beloved family dog, Minnie, are always special moments.

Recently, Sharon made the decision to write up her Will, after several reminders from her Mum.

"I knew it was something I should have done earlier but I kept postponing it until I realised, especially after Mum's diagnosis, that none of us can predict when health issues might arise."

She also appointed a Power of Attorney and Medical Treatment Decision Maker in case she is unable to make decisions for herself in the future.

*"It dawned on me that it's crucial for loved ones to understand your wishes, making things easier after you're gone.*

"I also realised I had freedom to allocate more of my estate to charities that are close to my heart; including Fight Parkinson's."

Sharon shared how she worries about the future but knows all we can do is strive to live in the present and create lasting memories for the years ahead.

She continues to get more involved in Fight Parkinson's activities and events including her local A Walk in the Park.

"It has been comforting to feel part of a community that supports those living with Parkinson's and their families."

By nominating Fight Parkinson's in her Will, Sharon is hoping to contribute towards a future where other families, just like hers, won't have to experience the challenges of life with Parkinson's.

"Ideally, I hope for a preventative medication or cure for Parkinson's. Alternatively, I would love to see advancements in early diagnosis methods and more effective treatment options that minimise side effects for patients."

Individuals who choose to leave a gift in their Will make a significant contribution to the Parkinson's community. Their gifts allow investment in key areas such as research, advocacy and program development, enabling us to reach more people seeking help, explore innovative approaches and maximise our impact to fight Parkinson's. When you decide to leave a gift in your Will to Fight Parkinson's, you are joining a community of people who are choosing to create a better future for those impacted by Parkinson's. Your legacy will live on well after you're gone.

If you're interested in leaving a gift to Fight Parkinson's in your Will or would like to learn more about the process, please don't hesitate to contact Fight Parkinson's by phone at 03 8809 0400 or email bequests@fightparkinsons.org.au.


*Sharon and family dog, Minnie.*

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

## About Fight Parkinson's


Office: Suite 6, Waterman Business Suites, Level 1, 793 Burke Road, Camberwell VIC 3124
Phone: (03) 8809 0400
Free call: 1800 644 189
Email: info@fightparkinsons.org.au
ABN: 59 604 001 176
Website: fightparkinsons.org.au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## About InMotion

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**Membership enquiries:**
T: (03) 8809 0400
E: info@fightparkinsons.org.au

**Advertising enquiries:**
T: (03) 8809 0400
E: info@fightparkinsons.org.au



**Editorial policy:**
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.

**COMMUNITY CALLOUT**

# Share your story

InMotion magazine features real-life stories and experiences from people living with or caring for someone with Parkinson's, PSP, MSA or CBS.

Every story shared helps lift the lid off Parkinson's and reminds others facing similar experiences that they are not alone.

**If you have a story to share, we want to hear from you**

**Email us at marketing@fightparkinsons.org.au**

**SUPPORT FOR YOU**

# Peer Support

**Peer Support Groups offer information, social connection, hope and support to people living with Parkinson's, PSP, MSA and CBS.**

There are more than 60 Fight Parkinson's Peer Support Groups meeting regularly throughout Victoria, including a number of specialist and activity-based groups.

People living with Parkinson's, their carers, friends and family are all welcome.

If you are considering attending a Peer Support Group or setting up a new group in your area:

**Call Fight Parkinson's on 03 8809 0400 or email info@fightparkinsons.org.au**