Issue 3 Spring 2026

InMotion

A magazine for the Parkinson's community



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Together we can

In this issue:

- *Every Victory Counts*® coming in 2027
- Determining the safety of clinical trials
- Managing sleep difficulties

CEO update

Even as the seasons change, meeting people in our community remains one of the most valuable parts of our work. At seminars in Ballarat, Bendigo, Horsham and on the Mornington Peninsula, we connected with community, sharing practical information and hearing directly about the challenges they face. Those conversations help shape our services and advocacy.

We have also continued to unite and provide services and support online, including sessions like 'Online Singing', and offering new resources via the Community Learning Hub and our Health Information Line. Whether someone has recently been diagnosed or has lived with Parkinson's for many years, we are proud to provide accessible and reliable information and support to our community.

The feedback we learn from our community also reinforces the need for coordinated action across Australia. In August, I joined colleagues at the Neurological Alliance Australia (NAA) 2026 Neurological Summit at Parliament House in Canberra. Listening to people with lived experience alongside clinicians, researchers and parliamentarians brought that need into focus. We will continue working with the neurological and neuromuscular communities as the 'National Action Plan for Neurological Conditions' develops and ensure the experiences of people with Parkinson's are acknowledged.

Research offers another way for our community to help shape the future of Parkinson's care. The Fight Parkinson's Research Committee reviewed studies and clinical trials that we have since shared as opportunities for people who wish to participate. These include the University of Melbourne's 'Deep Brain Stimulation (DBS) CURIOUS study' and The Alfred's 'Longevity Biotech Australia' clinical trial. We will share further opportunities as they become available.

We are also supporting research directly through our Seed Funding Grants Program. Dr Sarah Davies and her team, recipients of the Clinical Seed Grant announced at the 2026 Fight Parkinson's Research Symposium, have moved into the next stage of 'Mapping Real-World Stigma to Support Victorians with Parkinson's'. We are pleased to fund this work and help the team invite people to participate. Better understanding the stigma that people with Parkinson's encounter can help us respond to their experiences.

In July, Fight Parkinson's was honoured to receive the Victoria Day Award for Community and Public Service by a Victorian Not-For-Profit Organisation. Acknowledging our work in community support and education, awareness raising and advocacy and research towards better treatments, care and prevention, we were privileged to accept the award on behalf of the more than 57,000 people across Victoria who are living with Parkinson's.

Peer support is another important way our community finds connection and understanding. I want to congratulate every Fight Parkinson's peer support group that applied for a grant through the Department of Families, Fairness and Housing. Every group that applied was successful, reflecting the commitment of the people who give their time and energy to bring others together.

The Victorian Government grants will help groups meet practical costs, including room hire, catering and support for community events, such as the Young@Park Conference in Bendigo.



Fight Parkinson's CEO Emma Collin

The meaningful support these groups provide, reminds us why equitable access to care and community connection must remain a priority for government. As Victoria approaches the state election, Fight Parkinson's will continue to bring the experiences of people living with Parkinson's, their loved ones and carers to decision makers. We will advocate for the services and supports people need across Victoria, including continued funding for our Health Information Line.

In case you missed our latest updates, we are progressing on the localisation of *Every Victory Counts®* – Australian Edition (EVC). This manual has been written by over 50 international and local expert contributors and covers aspects from medication and therapies to exercise, nutrition and emotional health. Distribution is planned for early 2027, and the publication will be available free of charge.

Thank you for the many ways you contribute to this community, whether by sharing your experience, supporting someone else or taking part in our programs. Together, we will keep working towards our vision of 'Freedom from Parkinson's'. No one has to face Parkinson's alone.



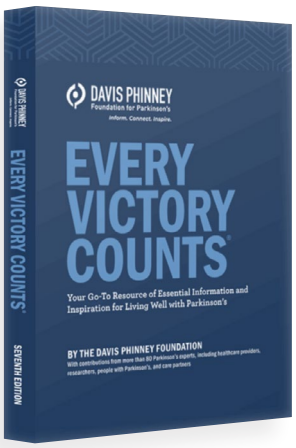
Emma Collin
CEO
Fight Parkinson's

Cover: Gaby and his family hiking in Tanzania

News and highlights

Every Victory Counts® – Available in 2027

Following our announcement of *Every Victory Counts*® in the previous edition of this magazine, we are excited to share that Fight Parkinson's is currently in the final stages of development and will complete the first Australian version ready for 2027.



In case you missed it, *Every Victory Counts*® Manual: An Australian Guide to Living Well with Parkinson's (EVC) is a practical, evidence-based manual that helps people living with Parkinson's and their carers understand the condition, navigate the Australian healthcare system, access appropriate supports, and take an active role in their wellbeing through informed day-to-day decisions.

First developed and published by the Davis Phinney Foundation in the United States in 2010, Fight Parkinson's is adapting the manual for an Australian audience and will make it available nationally for people living with Parkinson's and those that care for them, free of charge.

Written by over 50 international and local expert contributors, the manual provides practical guidance for developing a holistic approach to living well, with a focus on proactive self-care – covering all aspects from medication and therapies to exercise, nutrition and emotional health.

The Australian edition of EVC translates complex medical knowledge into clear, usable guidance that supports people to not just understand Parkinson's, but how to take an active role in their wellbeing. It advises on how to work with a range of specialists and combine clinical care with strengthened community-based support.

Fight Parkinson's has collaborated with Australian multidisciplinary clinicians, including neurologists, occupational therapists, physiotherapists, speech pathologists, nurses, and Parkinson's specialists to co-design, review and edit the manual to ensure its accuracy, relevance and alignment with the Australian healthcare landscape. The content has also been reviewed by a Consumer Advisory Committee, made up of people living with Parkinson's, ensuring that the resource reflects lived experience and practical day-to-day challenges.

Stay up to date and register your interest in *Every Victory Counts*®

Scan the QR code with your phone to receive the latest news from Fight Parkinson's, including updates about EVC.

Neurological Alliance Australia 2026 Neurological Summit

Fight Parkinson's was proud to join colleagues from across Australia at the Neurological Alliance Australia (NAA) 2026 Neurological Summit at Parliament House in Canberra.

Neurological and neuromuscular conditions affect more than one in four Australians. While our communities represent many different conditions, we share common challenges – and a powerful collective voice.

The Summit reinforced the need for coordinated national action, including:

- A National Action Plan for Neurological Conditions
- A dedicated Neurological Nursing Workforce Strategy with stronger training, career pathways and advanced practice roles
- Better national data, equitable access to care and services and genuine involvement of people with lived experience.

We welcomed the strong parliamentary engagement throughout the day, including contributions from parliamentary hosts – Senator Deborah O'Neill, Dr Anne Webster MP, Dr Trish Cook MP, Dr Helen Haines MP and Joe Kelly MP on strengthening the neurological nursing workforce, and Dr Gordon Reid MP and Dr Monique Ryan MP on clinical leadership and health reform.

We also appreciated the perspectives of Senator the Hon Anne Ruston and the many people with lived experience, clinicians, researchers and sector leaders who contributed to the discussion.

For Fight Parkinson's, collaboration across the neurological and neuromuscular community is essential. Together, we can advocate more effectively for the national leadership, skilled workforce and coordinated systems needed to deliver better outcomes for millions of Australians – and for the families and carers who support them.

Community Callout

Be a positive voice

We're looking for community members who want to provide mentorship and share their Parkinson's journey with the community through our 'Positive Life' sessions, which offer practical tips and valuable insights from our health team and community members.

From medication management, to emotional well-being, sleep, and more, your personal experience could help others to feel connected and understood.
If you would like to be a voice in our 'Positive Life' sessions and inspire others to live confidently with Parkinson's, contact us today.

Email us at marketing@fightparkinsons.org.au

Managing symptoms



Managing sleep difficulties

Tips for a good night's rest

Changes to sleep and sleep difficulties are the most early, common and frustrating symptoms of Parkinson's – reported by 84% of people who live with the condition.

When talking about 'sleep difficulties', this includes problems like:

- Rapid Eye Movement (REM) sleep behaviour disorder
- Insomnia and sleep fragmentation
- Restless legs syndrome
- Urinary frequency, urgency and nocturia
- Obstructive sleep apnoea.

While sleep difficulties have multiple causes and can impact on relationships, mood and quality of life, it's important to remember that they can be managed through a comprehensive assessment and management plan from your neurologist.

REM sleep behaviour disorder (RBD)

RBD refers to physically acting out dreams, i.e. talking, punching, kicking, etc. due to loss of normal muscle paralysis during REM sleep. RBD is one of the strongest known predictors of Parkinson's and may occur several years before motor onset.

Management:

- Speak with your neurologist, who may consider medication to assist reducing the movement
- Make your environment safe to reduce injury if you are moving about in your sleep
- Beware that sleep difficulties have an impact on your bedpartner.

Insomnia and sleep fragmentation

Insomnia refers to difficulty falling asleep, staying asleep or both. Fragmented sleep is when sleep lacks continuity, repeatedly broken by brief awakenings or shifts to lighter stages. This sleep difficulty is caused by motor and non-motor symptoms. Reduced medication in the evening and overnight may make it hard to get comfortable and often when this occurs, can result in overthinking and worrying, which can also hinder sleep.

Management:

- Manage both motor and non-motor symptoms
- Long-acting medications for motor and some non-motor symptoms
- Cognitive Behavioural Therapy (CBT) to address anxiety and mood.

Restless legs syndrome (RLS)

RLS refers to the urge to move your legs to relieve unpleasant sensations and can make it difficult to get comfortable and settle whilst trying to fall asleep. RLS can be a symptom of medication wearing off and is also a separate neurological condition. People living with Parkinson's are more likely to report experiencing RLS than the general community. Other than the wearing off of medication, RLS may be triggered by pregnancy, confinement (such as long-haul air travel) and low iron levels.

Management:

- Satin sheets may assist with bed mobility
- Long-acting medications can reduce the impact of 'wearing off' and improve sleep
- Deep Brain Stimulation (DBS) – some evidence reports that DBS can improve comfort and RLS
- Foslevodopa infusion (Vyalev) – case reports suggest RLS, bed mobility and comfort can improve on this medication.

Urinary frequency, urgency and nocturia

Nocturia refers to getting out of bed at night to urinate more than once. It can also be called nocturnal urinary frequency. This can occur commonly in Parkinson's, which changes the communication between the bladder and the brain, causing a sudden urge to urinate. Parkinson's can also cause a lowering of blood pressure over time. This may lead to fluid retention, which the body will reabsorb and can lead to producing more urine at nighttime.

Management:

- Reduce fluid intake, especially alcohol, stimulants and acidic fluids in the evening
- Long-acting Parkinson's medication may reduce urgency
- Medication to reduce bladder spasms
- Positioning your bed with the head elevated can also reduce nocturia.

Obstructive sleep apnoea (OSA)

OSA refers to repeated interruptions to breathing, causing poor and disrupted sleep. While many people have obstructive sleep apnoea, research suggests that it is more prevalent in people living with Parkinson's. OSA can contribute to daytime sleepiness and fatigue.

Management:

- A sleep study may be able to identify OSA
- Non-invasive ventilation, e.g. Bi/CPAP.

Medication side effects

Unfortunately, many medications can impact on sleep, including those commonly used to treat Parkinson's. Commencing levodopa or dose adjustments can cause some sleepiness after taking medication for a couple of weeks afterwards. Dopamine agonist medication can cause the sudden onset of sleep (or sleep attack). Conversely, some medications commonly used for Parkinson's can cause wakefulness. Amantadine (Symmetrel), which may be used to assist with Parkinson's can have a stimulatory effect as it is metabolised, and some anti-depressants can cause insomnia.

Management:

- If persistent sleepiness occurs after taking levodopa-based medication, let your neurologist know
- Slow and supervised reduction of dopamine agonist medication may be required if sudden onset of sleep occurs
- Review anti-depressant treatments
- Avoid taking amantadine after midday.

Improving your sleep habits

- Practice good sleep hygiene
- Reduce visual stimulation, such as screen, TV and magazines in the hour before bed
- Keep the bedroom cooler
- Try to go to bed and rise at the same time every day
- Look after your psychological health
- Listen to and share concerns with your carer, partner or trusted healthcare professional
- Wear a smart watch that tracks your sleep, so you can share the data with your neurologist
- When travelling on long haul flights or overnight stays, bring some information about your sleep difficulty to share with crew, accommodation providers, etc.



Satin Panel Fitted Sheets

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Positive Living

Navigating nutrition and Parkinson's

Addressing challenges and solutions to managing brain and body

> **Please note:** The nutritional issues faced by people with Parkinson's are complex and diverse and therefore need to be reviewed by an accredited practising dietician on a case-by-case basis.

Many people with Parkinson's experience symptoms that can impact their nutritional health, including constipation, fatigue and nausea. This can impact significantly on everyday functioning and quality of life.



Below are some examples

Parkinson's symptom	Impact on nutrition
Olfactory impairment, i.e. reduced sense of smell and taste	Reduction of appetite and interest in food preparation
Low mood or apathy	Reduction of appetite and motivation to prepare food
Fatigue	Can increase interest in sugary foods and make it harder to prepare healthier snacks that take more time
Constipation and slowed gastric emptying	Can impact appetite and produce a feeling of fullness
Medication	Can cause side effects, i.e. nausea or dry mouth. B12 levels can be impacted by levodopa.
Swallowing issues	Can impact on the enjoyment or effort of eating and can result in different food choices with nutritional ramifications, e.g. swapping a steak and salad that might be difficult to chew for a pasta that is softer but has less iron/protein and fibre.
Motor symptoms, i.e. changes to posture or movement	Can impact energy expenditure and independence

Despite the examples listed above, please remember that there are many steps you can take to manage and improve your nutrition, which are detailed throughout this article. And as always, no one has to face these challenges alone – if you need support, please check the list at the end of this article, or contact Fight Parkinson's.

Impact of nutritional challenges

Unplanned weight loss appears more commonly in the Parkinson's community. This not only depletes your body fat stores but also your nutrient and protein stores, which make up your lean muscle tissue. The adverse effects of losing lean muscle mass can make daily tasks and activities very difficult, like walking and maintaining balance.

Physical activity of any form is encouraged to help maintain muscle mass. Where permitted, include some exercise into your daily routine. There are many types of exercise that are particularly well suited to people with Parkinson's, including brisk walking, swimming, dancing and more.

It's recommended to speak with a physiotherapist before you start exercising, especially if you have had Parkinson's for many years or if your movement is substantially impaired. Your GP or specialist can also suggest suitable fitness activities or guide you through any possible restrictions on your ability to undertake an activity or exercise.

Medications and supplements

Foods containing protein are important for nutritional health, providing a valuable source of iron, magnesium, calcium, zinc and Vitamin B12. These foods support the immune system, help the body repair and grow cells, assist in wound healing and maintaining lean muscle mass. However, the amino acids from high-protein foods can reduce levodopa absorption.

Instead of removing high-protein foods from your diet, it may be more beneficial to take levodopa 30-60 minutes before meals or 1-2 hours afterwards, for best absorption. If nausea occurs, speak to your GP or pharmacist about eating a low-protein snack, e.g. crackers or toast, with your medication.

Supplements suggested by your GP for demonstrated deficiencies, e.g. Calcium, Vitamin D, Vitamin B11 and B12, etc. can also interact with your Parkinson's medication, so please consult your GP or pharmacist before commencing a new supplement or medication.

Diet

While no one food is seen as 'neuroprotective', i.e. serving to protect nerve cells against damage, degeneration or impairment of function, the Mediterranean diet, has the strongest evidence for Parkinson's symptoms, including cognition. This diet focuses on vegetables, fruits, whole grains, legumes, i.e. beans, peas and lentils, nuts, low-fat proteins, such as fish and poultry, and olive oil.

Other foods that can help combat nutritional challenges include fermented foods, such as yoghurt and kefir, which can improve constipation and support microbiome. Calcium-rich foods, like milk, cheese, yoghurt and custard, plus exposure to sunlight can also prove helpful due to the increased risk of reduced bone density and associated risk of fractures for people with Parkinson's.

Hydration

Balancing hydration with some other symptoms of Parkinson's can be tricky and require an individualised plan, e.g. for those experiencing frequent urination overnight, it may be better to consume more fluids in the morning, rather than the afternoon. Remaining well-hydrated is important for numerous reasons, like assisting with constipation, reducing the risk of urinary tract infections (UTIs) and regulating blood pressure. It's also important to note that dehydration can also impact levodopa absorption.

Some tips to stay well-hydrated include setting reminders or downloading a 'water-minder' app on your phone, using a water bottle, adding a dash of cordial or some fresh fruit to your water, and implementing routines like drinking a glass of water before meals or snacks.

Keep in mind that beverages like coffee and alcohol can also have a dehydrating effect. Moderate coffee consumption, i.e. 2-4 cups per day (200-400 mg caffeine) appears safe for most people, preferably consumed earlier in the day. And if you are someone who lives with Parkinson's, and you have decided to consume alcohol, limit your drinks to 1-2 standard glasses per day.

Learn more about living well with Parkinson's

Visit https://tr.ee/hQZoXs or scan the QR code with your phone to learn more practical advice for everyday life with Parkinson's.

Where to go for help

Nutritional challenge or Parkinson's symptom	Specialist or Team
Exercise guidance	Physiotherapist
General queries about diet and nutrition	Your general practitioner (GP)
Full nutritional assessment and individualised strategies and plans	Dietician
Medication advice	Pharmacist
Mealtime aids and postural supports	Occupational therapist
Swallowing and saliva control issues	Speech pathologist
Any of the above	Fight Parkinson's Multidisciplinary Health Team

Support for you

Funding granted by the Victoria State Government

Financial support for our peer support groups

Fight Parkinson's would like to congratulate each of the peer support groups that applied for a Department of Families, Fairness and Housing (DFFH) grant through the Victoria State Government.

We acknowledge that applications such as these can take a lot of time and energy, however your efforts proved fruitful as all who applied were successful in securing a grant. Well done to the following peer support groups:

- Albury, Beechworth, Wodonga
- Ashwood ParkinSong™
- Ballarat
- Echuca
- Eltham Park
- Essendon
- Geelong
- Latrobe Valley
- North East
- Pakenham
- ParKanDo
- Werribee
- Wimmera
- Young@Park

Over 2 years – the second round occurring in 2027 – these peer support groups are scheduled to receive over $80,000 in total.

Whether the funding was to help provide catering at meetings, to help cover room or venue rental fees or for the delivery of exercise and wellbeing programs, these DFFH grants will enable groups across Victoria to remain operating as essential pillars of support in the Parkinson's community.



Garry (left) and Jennie (right) with their new Fight Parkinson's Latrobe Valley Peer Support Group banner, purchased thanks to their grant from the DFFH

A community comes together

Fight Parkinson's Moorabbin Peer Support Group

Following her Parkinson's diagnosis in 2017, Helen attended a Fight Parkinson's community seminar and met others of all ages who had lived with Parkinson's. Together a group of those people decided to form a support group to create a safe space for people with lived experience to come together for community and shared understanding.

Fight Parkinson's Moorabbin Peer Support Group is fascilitated by Helen and her husband, David, and involves a wide community, including volunteers from the local Rotary Club. People living with Parkinson's, and carers, come together each month and everyone shares their ideas about how the group is run to provide the best support and resources everyone needs. What started in 2018 with 20 attendees, has grown into a monthly meeting in the Saint Nicholas Anglican Church Hall in Mordialloc with over 50 group members.

Whether it's getting creative with some paint, singing along to some tunes, or sharing light-hearted stories amongst one another, the group fosters connection in a multitude of ways – mostly, it's about "having fun" and finding "tools that enable people to open up."

The environment is relaxed and welcoming for all. Together, the group decides on a program of activities, including guest speakers who share information and the kind of supports available in the community for people living with Parkinson's.

From local pharmacists, physiotherapists and counsellors, to families, friends and carers, many individuals from the Bayside area have attended the group meetings to share their knowledge, experiences and personal stories.

Reflecting on shared moments from the past, Helen said that certain memories still stuck with her, like the time she caught "the light in everyone's faces" as they listened to a poem that was written by one member's son. Or the wedding photos that featured four generations of women in one member's family, which she practiced smiling for, in fear of "ruining" them.

Support group member, Frank says that the group is a "sanctuary" for him, because he's "surrounded by people who get it."

"When things feel overwhelming or chaotic, walking into that room feels like I'm finally stepping into a safe harbour. When no one truly understands what I am experiencing, physically or emotionally, the group understands. Without having to explain a single thing, there is a beautiful silent bond of shared experiences."

"Parkinson's is all-encompassing and so complicated that some people end up not talking about it to their loved ones. Some people lose their jobs because of it, others feel like their identity disappears," said Helen, "But the experience of community makes you stronger."

Although the Group maintains an element of 'fun', the members also acknowledge the complexities of Parkinson's and the "continuity of support" from Fight Parkinson's.

"Fight Parkinson's is serious about being there for the long term," said Helen, "Their commitment to people is very moving and that makes a real difference."

Interested in joining?

Helen and Trina have both explained Fight Parkinson's Moorabbin Peer Support Group as a "non-confronting, no-pressure environment" where people are free to come, sit and listen without participating if they choose not to.

Contact Fight Parkinson's to learn more

Phone: 1800 931 031

Email: info@fightparkinsons.org.au

Please note: Although a Parkinson's peer support group may provide opportunities for emotional and social connections, these meetings should not replace the medical care you receive from your GP, Parkinson's specialist or healthcare professional.







Group members participating in a boxing class (left), with their 'feelings board' (top right) and during an art class (bottom right)



Fight Parkinson's Moorabbin Peer Support Group at A Walk in the Park 2026

Research

In the age of Parkinson's

A study into Parkinson's and residential aged care

In September of 2026, an observational study titled, 'Care Needs of Australians with Parkinson's Disease Living in Residential Aged Care', was published in the Journal of the American Medical Directors Association.

Professor of Physiotherapy at the University of Melbourne and Fight Parkinson's Board Member, Professor Jennifer McGinley, and team, used a decade of national aged care data from 2012 to 2022 to examine the care needs and profile of the growing population of Australians with Parkinson's living in residential aged care facilities (RACFs). Their findings highlighted the need for workforce training, evolving care models and sustained access to specialist medical and allied health supports.

The following is a simple breakdown of the study findings:

The Parkinson's "pandemic"

Parkinson's is the fastest-growing neurodegenerative disorder globally, affecting over 12 million people. The World Health Organization (WHO) has called for an urgent public health response to address the health and social needs of people with Parkinson's, to improve functioning and quality of life and to prevent disability as global longevity increases. The escalating burden has been described as a noncommunicable, or non-transmittable "pandemic" requiring heightened advocacy and planning.

Parkinson's and residential aged care facilities

Due to numerous influences, like cultural factors and differences in study settings, national registries and population-based estimates, this study states that reports of people with Parkinson's within RACFs range widely. However, a prior review did suggest that 20% to 48% of people with Parkinson's will spend time in an RACF. And what we do know for certain, is that as disability progresses and care needs escalate, many individuals with advanced Parkinson's will require accommodation in a RACF.

As all numbers continue rising

Planning for the health care needs of older people with Parkinson's requires consideration of both population-based and disease-based calculations. Australia's population is aging rapidly, with the proportion of those aged over 65 predicted to double in the next 40 years. In parallel, the number of people with Parkinson's is anticipated to increase by 77% by 2050. Furthermore, recent data suggests a rise in the prevalence of Atypical Parkinson's (including PSP, MSA and CBS), which typically produces greater complexity. Although government policy has increasingly prioritised supporting aging at home, most aged care expenditure remains directed toward RACFs, which is forecast to rise substantially. Care costs for people with advanced Parkinson's are over 4 times higher than those in early disease stages, with RACF costs estimated to be between 17% and 31% of all Parkinson's-related costs.

The complexity of care

The available data about the characteristics and care needs of Australian RACF residents with Parkinson's is very limited, with prevalence estimates from 3% to 7% of all people living permanently in RACF. Residents with advanced Parkinson's have complex care needs, including high assistance needs for activities of daily living and a high prevalence of cognitive, psychological and behavioural symptoms. Accumulating evidence suggests that non-motor symptoms, such as depression are common and may affect care needs and quality of life. Compared with other RACF residents, individuals with Parkinson's are also more likely to experience a rapid functional decline after admission. Understanding longitudinal trends, i.e. studies that observe the same subjects repeatedly over long periods, and the profile of care complexity of residents with Parkinson's is important to inform RACF resource provisions, service planning and workforce training and allow data-informed future projections.

Future considerations

Without major advances in treatments to slow progression, the prevalence of Parkinson's in the Australian community is anticipated to increase by 77% by 2050. It is probable that the number of people with Parkinson's in RACFs will also rise, despite policies supporting aging at home. Over the last decade, the size of residential care services has increased, with more larger services (100+ beds) and fewer small services (≤60 beds). The within-RACF Parkinson's prevalence data of 5.5% in 2022 suggests all services are likely to have at least 3 to 5 or more residents with Parkinson's at any time. Planning for high-quality RACF care therefore requires consideration of the complex needs of people with advanced Parkinson's.

Conclusions and implications

This study provided an Australian national profile of individuals with Parkinson's in RACFs. We found that over 5% of residents had Parkinson's and had higher care needs compared with the general aged care resident population. Given the rising prevalence of Parkinson's and the complex care needs of this population, the following actions or policies should be considered urgently:

- Preventing RACF admission through expert support at home
- Workforce education to enable high-quality evidence–based care in RACFs
- Ongoing access to appropriate medical and allied health care
- Access to services, including specialist neuropalliative care.

Read the full study online

Visit https://tr.ee/jxDIpa or scan the QR code with your phone to read the full study online.

Scrutinise, contemplate and weigh

Navigating the benefits, motivations and risks of clinical trials

Clinical trials are an important part of developing new medical and other interventions that may improve the health and wellbeing of people who live with Parkinson's (including Young Onset) and Atypical Parkinson's (including PSP, MSA and CBS). But choosing a clinical trial can pose many questions. Trusted voice in the community and Chair of the Fight Parkinson's Research Committee for over 12 years, Professor David I Finkelstein, provides guidance on how to navigate through the decision-making process.

Before diving into specifics, Professor Finkelstein offers a note of caution: As desperation grows, so does vulnerability – opening the door to exploitation of patients who feel they have run out of options. This can include financial exploitation, e.g. scams, commercial exploitation, e.g. marketing fakes, and false claims, e.g. fake testimonials.

So how can you determine the safety, legitimacy and morality of a clinical trial? Professor Finkelstein suggests asking yourself these three important questions before making a decision:

1. **Is it legitimate?**
   Who is running it? Who approved it? Is it properly registered?
2. **What is the motivation?**
   Who stands to gain – patients, science, or someone's balance sheet?
3. **What is the benefit?**
   What do participants actually get out of taking part – and at what cost?

Let's explore some examples of trials that Professor Finkelstein deems 'safe' and 'potentially unsafe'.

Safe

ParkinsonNet Australia

The ParkinsonNet Australia Research Project aims to improve access to high-quality care for people with Parkinson's, no matter where they live. It is a model of multidisciplinary care that was first developed in the Netherlands with proven results in improved health outcomes, reduced disability, lowered hospitalisation rates and healthcare costs. Western Victoria (including Geelong and the Bellarine) and Tasmania are presently testing this model.

1. Is it legitimate?

Fight Parkinson's and The University of Tasmania made a joint $3.7million investment to bring the model to Australia. The pilot is led by Professor Michele Callisaya from The University of Tasmania's Menzies Institute for Medical Research and involves experts from over 15 universities, science centres, associations, health services and organisations.

2. What is the motivation?

Based on the positive results already shared by the Netherlands, plus the involvement of people living with Parkinson's during the design of the trial, Professor Michele Callisaya says, "We will upskill health professionals, strengthen visible networks and ultimately improve outcomes for the more than 220,000 Australians living with Parkinson's."

3. What is the benefit?

Aside from improving the quality of life for people with Parkinson's in Australia and empowering healthcare professionals and teams, the trial implements safe, clinically and proven methods. Participants are also paid for their time and any out-of-pocket expenses, and there is no potential of harm.

Potentially unsafe

Phase I/II trial of iPS-cell-derived dopaminergic cells (The Kyoto Trial)

To understand The Kyoto Trial, we first must understand 'stem cells'. Stem cells are a special type of cells that have two important properties – they are able to make more cells like themselves and they can become other cells that do different things.

The Kyoto Trial involved the transplant of cells that will become dopamine-producing cells into the brains of 7 people with Parkinson's. This trial concluded that the cells survived, produced dopamine and did not form tumours.

Professor Finkelstein acknowledges the potential of The Kyoto Trial, which may revolutionise how stem cells repair the brain, however he also wants anyone considering this trial to be aware of the potential dangers and side effects of stem cells, especially at such a large scale of implantation.

Please note: There are currently no stem cell therapies available outside of clinical trials, e.g. The Next Generation study. Similarly to The Kyoto Trial, this study also aims to regenerate brain cells lost to Parkinson's using donated stem cells and includes some of the same associated risks.

1. Is it legitimate?

The Kyoto Trial for iPS-cell-derived dopaminergic cells was conducted at Kyoto University Hospital between 2018 and April 2025. The work was peer reviewed by at least 3 people.

2. What is the motivation?

Shinya Yamanaka was awarded the 2012 Nobel Prize in Physiology or Medicine for his discovery in The Kyoto Trial.

3. What is the benefit?

Professor Finkelstein acknowledges Yamanaka's ethical source of pluripotent stem cells, as initial cell therapies used foetal tissues. Additionally, the trial states that no participants died during the trial. However, the documented scores for each participant on the Unified Parkinson's Disease Rating Scale (UPDRS) showed some affect, but not much. This posed whether the pain involved was worth the minor changes. Finally, Professor Finkelstein expressed concern around the excessive dosages that both groups (low-dose and high-dose) received. The average number of dopaminergic neuros in a healthy human brain is approximately 87,400. The low-dose group received an implantation of 2,600,000 cells per hemisphere, while the high-dose group received 5,500,000 cells per hemisphere. That's 6,000% more cells than normal. And the results show that cells are still continuing to replicate, which could result in a brain tumour in the future.

Personal Story



Gaby proudly sporting his Fight Parkinson's A Walk in the Park t-shirt at the top of Mt Kilimanjaro

Gaby reaches great heights

Taking on Parkinson's one step at a time

Important note to the community

While Fight Parkinson's maintains that exercise is one of the best ways to help manage Parkinson's symptoms, it is important to note that everyone's fitness levels and capabilities are different. Please speak to your GP or your Parkinson's specialist before considering any long-form or physically demanding hike or climb.

From the Kingdom of Bhutan to Japan, New Zealand, South America, parts of Europe, and now Africa, avid hikers, Jane and Gaby have been hiking some of the world's biggest mountains and trails for over 15 years. When Gaby was diagnosed with Parkinson's in 2024 at the age of 64, he and his family were faced with a new type of challenge.

When Gaby noticed some stiffness in his right arm and his handwriting getting smaller, his GP suggested he book an appointment with a neurologist. A few months later and following some simple movement and balance tests with his neurologist, Gaby was officially diagnosed with Parkinson's.

"It was a huge shock," recounted Gaby.

"But I was fortunate to get good support from Fight Parkinson's."

Joining the Fight Parkinson's community, which he learned about from a brochure in his neurologist's office, has enabled Gaby and his family to receive the support they need, including:

- Feeling informed, and understood from attending multiple **online seminars**
- Learning from the free online education courses available on our **Community Learning Hub** and other resources across our **website**
- Help navigating the complexities of the **NDIS system and application forms**
- Assistance locating and accessing **local allied healthcare professionals,** like a speech pathologist, occupational therapist, counsellor, etc
- Connecting with community by participating in **Fight Parkinson's community events,** e.g. A Walk in the Park.

For Jane, Gaby's wife of 26 years, accessing the Fight Parkinson's website for resources and advice, as well as attending online seminars "has been very helpful."

Contemplating the biggest challenges in managing his Parkinson's, Gaby's resilient nature shone through in his answer.

"Getting used to so many appointments, taking medication a few times a day, and setting up my supports with the NDIS was a lot to do. Even managing my diary took some getting used to. It was not easy the first year, but I feel more in a rhythm now."



Gaby (left) and Jane (right) on Safari in Africa with their son, Marcel (middle)

Since his diagnosis, Gaby now schedules an appointment with his neurologist every 6 months, and is managing his Parkinson's well with medication, ongoing support from the NDIS and Fight Parkinson's, as well as motivation from Jane.

Jane views herself more as a 'support person' for Gaby, rather than a carer, due to the fact Gaby is "good at managing his condition". She motivates him "to keep on track with his occupational therapy, physio, general diet, and exercise."

Jane and Gaby are active hikers and quite physically active. Gaby enjoys running, cycling, and boxing, which he does with a Parkinson's group in St Kilda. But the active hobby that brings him the most joy, is hiking.

Alongside the restorative effects of 'forest bathing' - the act of immersing oneself in nature using all of one's senses - Gaby also enjoys how hiking encourages him to slow down and appreciate the world around him.

"Hiking is good for the soul, as well as the body. I feel calm and content hiking. Completing a hike gives a good sense of achievement, but I more enjoy the journey of the hike, such as taking in nature, having a thermos of tea, looking at the beautiful environment, etc."

Upon the family's decision to go on safari in Tanzania, Jane, Gaby, and their son, Marcel, also decided to start training for the hiking challenge of Africa's highest mountain – Mount Kilimanjaro.

Together, with a team of 8 porters, 2 guides, and 1 chef, the family eventually set off on the 5-day route up the mountain. Through five climate zones – bushland, rainforest, heath, alpine desert, and an icy arctic landscape – the family were confronted with extreme temperature variations, high altitudes, and the many fatiguing challenges presented by 'the roof of Africa'.

While Jane reached the base camp at 5,000 metres, Gaby and Marcel continued on the final 1,000 metres to the summit. Though exhausted, Jane commented that they were "proud they did it".



Gaby and family on their hike up Mount Kilimanjaro

"The guides were very supportive, and we trained a lot before going. We took it a day at a time," reflected Gaby.

The phrase "don't look down" is often used by hikers and climbers to remind themselves, or others, to concentrate on the path ahead, rather than becoming distracted or intimidated by the height or drop below. This is the same lens through which Gaby chooses to view his Parkinson's.

"I feel it is important to keep moving and find something (can be anything) you like to do. Mine is hiking but it could be anything. Even setting small goals can be useful."

Gaby sees more hikes in his future, with Werribee Gorge on the horizon, where he plans to test his new hiking boots. And further down the track – the north of Argentina, where he was born.



Fundraising



Mirella (second from the right) and her fellow Fight Parkinson's Kyabram Peer Support Group members

A picnic for Parkinson's

Community unites for a fluffy good cause

To celebrate her 'Teddy's' 50th birthday, Mirella's grandchildren suggested a teddy bears picnic. Mirella took this opportunity to host a Fight Parkinson's fundraiser – bringing her family, friends and community together.

Mirella's Parkinson's diagnosis

When Mirella lost her sense of smell, she spent almost a year visiting allergists and ear, nose and throat (ENT) specialists. In 2015, a neurologist diagnosed her with Parkinson's.

Upon accepting her diagnosis, she contacted Fight Parkinson's for support. Mirella recalls attending a 'Recently Diagnosed' session, plus other online sessions that helped her to understand Parkinson's and how best to manage her symptoms. Fight Parkinson's also helped connect her with multiple Parkinson's Peer Support Groups in north central Victoria, until she found one that suited her social needs.

"Out here in the country, not everybody attends a Parkinson's peer support group, which is a shame because it gives you so much value," said Mirella, "You can say anything to the group and they understand, even when your family doesn't."

The Kyabram Parkinson's Peer Support Group and our Health Information Line are the main reasons why Mirella wanted to raise funds for Fight Parkinson's.

"They both made a real difference to me," Mirella stated.

Picnic time for teddy bears

Across 2 days, Mirella hosted a 'Teddy Bears Picnic', raising over $4,000 in-person and online for Fight Parkinson's.

With support that spanned across multiple generations of Mirella's family, close to 100 people turned up to her Teddy Bears Picnic, which included a garage sale, raffle, sausage sizzle and silent auction.

Mirella said that her fundraiser was a real community effort.

"It's thanks to everyone involved that we raised as much as we did," Mirella acknowledged, "I couldn't have done it without them."

From her partner, Paul, who prepared the garage and the house and ran the sausage sizzle, to her daughter, Sera, who designed promotional materials and signage, to her grandkids, who donated their own toys for the garage sale, Mirella was incredibly grateful for all the help from her own family. But the support didn't stop there.

The local community supported Mirella with many gifts to sell or use as prizes. These included: money to buy prizes, cases of wine and drinks, a portable toilet to use at the event, hand-made blankets and teddy bears. Mirella was especially moved by those who donated their time to hand-craft teddy bears for prizes, including one person who made 17 bears. She would like to thank: Macedon IGA, Rawlings Featherstone Financial Solutions, Focus IPM, Kyabram Parkinson's Peer Support Group, Shepparton Parkinson's Peer Support Group, Girgarre G.P.O and Kyabram hire.

The picnic also included a 'play area' for children, with materials for colouring in, play dough and games – all generously loaned by the local Kyabram Public Library. Mirella is also pleased of the memento book created over the weekend, which was filled with many personal stories of the adventures which people had taken with their teddy bears during their life.

Organise your own fundraising event

Visit https://tr.ee/HLhnsK or scan the QR code with your phone to learn more about fundraising for Fight Parkinson's.

Thank you for your support

Fight Parkinson's 2026 Tax Appeal

No one has to face Parkinson's alone. This is a core belief that Fight Parkinson's has remained constantly steadfast about. But we could not continue our important work in improving quality of life for people living with Parkinson's (including Young Onset) and Atypical Parkinson's (including PSP, MSA and CBS), without your support.



Peter speaking as an ambassador at Fight Parkinson's A Walk in the Park 2026

Thank you to all those who supported our 2026 Tax Appeal.

Your generosity will enable Fight Parkinson's to:

- Maintain our Health Information Line, run by our Multidisciplinary Health Team
- Remain committed to advancing research that will deliver effective therapies, treatments and prevention
- Continue providing a variety of tailored education programs to help people with Parkinson's, carers and healthcare professionals to better understand symptoms, treatment options and to improve self-management.

Fight Parkinson's would also like to give a special shout out to our 2026 Tax Appeal Hero, Peter, who so kindly shared his experience of living with Young Onset Parkinson's and allowed us to share his story with the community.

We appreciate his positive spirit and generosity of time.

From connecting Peter with a specialised speech pathologist, to helping him navigate the complexities of the NDIS, informing him of Fight Parkinson's Young@Park Peer Support Group and more, we are honoured to have helped - and to continue helping - Peter along his Parkinson's journey.

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

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

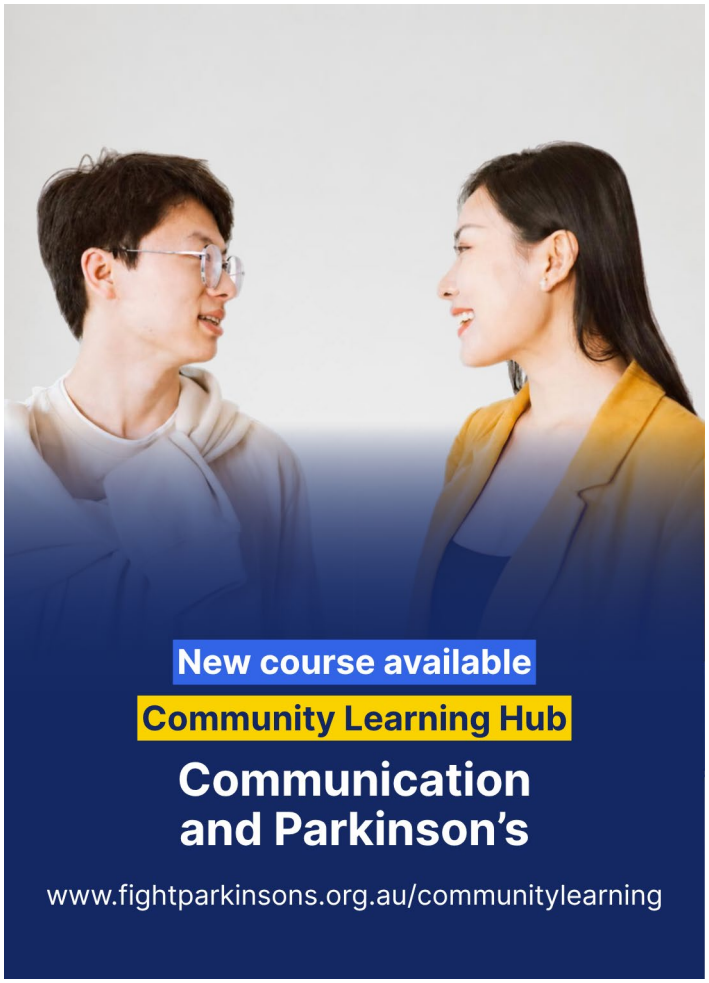
By cutting it out and keeping it in your purse or wallet, you can provide essential information to others that you are living with Parkinson's and may need their patience or assistance.

I have Parkinson's

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

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

Stressful situations can worsen my symptoms



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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.



Community Callout

Share your story

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

Every story shared 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

Cut out card

See reverse for details.

My name is:

Fight Parkinson's
Together we can

_____

With my consent or in an emergency, please call:

Name: _____

Phone: _____

Relationship: _____