

Issue 1 Autumn 2024

InMotion

A magazine for the Parkinson's community



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**Fight
Parkinson's**TM

Together we can

In this issue:

Join us for A Walk in the Park 2024
Relationships, intimacy and Parkinson's
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CEO update

As Parkinson's Awareness Month approaches in April, it's time to champion our community and gear up for all the exciting action to come.

Fight Parkinson's works with many organisations to deliver support and raise awareness at a national, statewide and local level.

Around the state, Peer Support Groups, volunteers and the Fight Parkinson's Team are preparing for A Walk in the Park. This annual event provides an opportunity for community connection and serves as a chance for everyone – friends, family and supporters – to come together once again to raise vital awareness and funds to support people with Parkinson's, PSP, MSA and CBS.

Melbourne's A Walk in the Park will be held on Sunday 21 April at Federation Square. In addition, many of our regional community members are hosting an A Walk in the Park in their local areas, including Geelong, Swan Hill, Echuca, Colac, Lakes Entrance, Moorabbin and Hastings. If you would like to participate in a walk near you, details will be available on the Fight Parkinson's website.

We extend an invitation to everyone to join us for A Walk in the Park this year. Awareness of Parkinson's, PSP, MSA and CBS is steadily growing and we need to build on this momentum to make this walk our biggest one yet. Please help us build strength in numbers by bringing yourself, family, friends and people who have never attended before. Each person you inspire to participate in A Walk in the Park brings us one step closer to ensuring greater access to services and support for the community.

A Walk in the Park brings people together for different reasons. Some participate to celebrate the inspiring people in our lives, while others walk to raise awareness of the challenges they face living with the condition. It is a time to show our collective strength, amplify the voices of those living with Parkinson's and galvanise the support we need to fight Parkinson's.

Our ambassadors for A Walk in the Park are doing their bit to help lift the lid off Parkinson's. You can meet the new ambassadors and find further details about A Walk in the Park on pages 8-11.

In this issue of InMotion, we are privileged to have many community members share their personal stories so generously. The lived experience of Parkinson's is unique for each individual, but the wisdom of how each person manages day-to-day is something we can all learn from.

The stories showcase the experiences of people living with Young Onset Parkinson's, the unique perspective of a carer and stories of heartwarming fundraisers and local Peer Support Groups, including the individuals who lead them.

Each year, we recognise outstanding individuals and honour others for their long-term commitment through the Fight Parkinson's Recognition Awards. Isa Adams was named the Sir Zelman Cowen Award recipient and Jill Price received the Harold Waldron Carer's Award stories. You can read about Isa and Jill's achievements on pages 4-5.

As a collaborative leader, Fight Parkinson's continues to focus on building a national response and advocacy to address better and equitable support for people living with Parkinson's. One of these developments is the formation of the National Parkinson's Alliance (page 3), comprising key stakeholders living with Parkinson's and leaders who are working towards aligned outcomes for the Parkinson's community.

The Alliance embraces visionary and impactful leadership that will drive change. By pooling our knowledge, resources and expertise, we will achieve greater impact, address complex challenges and create transformative solutions to enhance the lives of people with Parkinson's in Australia.



Fight Parkinson's CEO
Emma Collin

The National Parkinson's Alliance includes a diverse range of organisations, regions and disciplines that are working together to prioritise research, inclusivity and health equity. This approach ensures that our work benefits all people affected by Parkinson's, acknowledging their respective experiences and circumstances.

There are significant barriers to support, and Fight Parkinson's is committed to addressing them systematically. While the National Parkinson's Alliance will lead national advocacy efforts, work is also being done at a local level as well.

In this edition of InMotion, we hope to shed light on topics not often discussed. We've taken some insights from an Ask the Expert Session on Relationships, Intimacy and Parkinson's. In addition, we have provided a glossary of Parkinson's symptoms and taken a closer look at Progressive Supranuclear Palsy (PSP) to explore how it differs from Parkinson's.

We extend our gratitude to everyone who has openly shared their stories with others to help raise the profile of Parkinson's in the community. We hope to see you in person at A Walk in the Park.

Emma Collin
CEO
Fight Parkinson's

News & highlights

Introducing the National Parkinson's Alliance

Fight Parkinson's has joined forces to establish the National Parkinson's Alliance, a new national collaboration of leaders in the Parkinson's community created for the community.

The National Parkinson's Alliance was created to inform and shape policies, strategies and initiatives to enhance the lives of people affected by Parkinson's across Australia.

Member organisations of the Alliance include Fight Parkinson's, Parkinson's NSW and Parkinson's Tasmania, all of which provide vital services and support to individuals and communities affected by Parkinson's. Additionally, the Shake It Up Australia Foundation is the primary supporter of Parkinson's research in Australia.

In addition, Alliance members include representatives from institutions such as Neuroscience Research Australia (NeuRA), Walter and Eliza Hall Institute of Medical Research (WEHI), Menzies Institute of Medical Research, the University of Tasmania and Queensland University of Technology. These members are key leaders from the Movement Disorder and Parkinson's research fields, both nationally and internationally.

By working across various organisations, sectors and professional disciplines, the Alliance is harnessing its combined strength to accelerate support for the Parkinson's community.

The Alliance is working with and for the Parkinson's community across various regions and populations to address the multifaceted challenges posed by Parkinson's. Focus areas include earlier detection and diagnosis of Parkinson's and improving access to healthcare, resources, support and treatments. Furthermore, the Alliance is committed to advancing research to better understand causes, mechanisms, new and improved treatments and prevention.



Her Excellency Linda Hurley, Dr Harley Stanton, A/Prof Richard Gordon, Mike Whitehouse, Mary Kay Walker, His Excellency General the Honourable David John Hurley AC DSC (Retd), Vicki Miller, A/Prof Grant Dewson, Emma Collin and Miranda Woodward.

Together, the Alliance will lead nationwide advocacy efforts for the Parkinson's community. To ensure the sustainability of this work, the Alliance is committed to establishing an inclusive network of people with Parkinson's, like-minded organisations, institutions, clinical professionals and government. This network will be dedicated to supporting the development, implementation and assessment of the National Parkinson's Action Plan.

Developed with and for the community, the National Parkinson's Action Plan will inform community, government and key stakeholders across the sector of the priorities, strategies and actions necessary to deliver real impact and change for people living with Parkinson's in Australia.

The National Parkinson's Alliance is committed to visionary and impactful leadership that will drive change and achieve greater impact for the Parkinson's community. Stay tuned for all the exciting action to come!

ParKanDo receive the Grassroots Volunteering Award

Volunteering Victoria announced the winners during a special ceremony held at Government House on February 27.

The Grassroots Volunteering Award recognises the remarkable contributions of small community-led organisations that have played pivotal roles in providing essential local services, driving positive change and fostering social and community cohesion.

ParKanDo was founded in February 2020 and has since become a beacon of hope and support for individuals and families affected by Parkinson's. ParKanDo is run by a dedicated team of four volunteers, including individuals living with Parkinson's and one carer. Together, they have worked to expand the scope and diversity of activities for participants, their families and carers.

Under the guidance of Carmel and Peter Wall, Mimi Morgan and Pam West, ParKanDo has driven inclusive initiatives tailored to meet the diverse needs of its participants. These initiatives range from emotional and social support programs to educational seminars and information-sharing sessions.

ParKanDo has actively worked to combat isolation and enhance general well-being within the local Parkinson's community.



Carmel Wall, Peter Wall, Her Excellency Professor the Honourable Margaret Gardner AC, Mimi Morgan and Pam West.

In addition, ParKanDo has established a Young and Early Onset group to serve all demographics within the Parkinson's community located in the western suburbs of Melbourne.

The Grassroots Volunteering Award from Volunteering Victoria is a well-deserved recognition of ParKanDo's dedication to improving the lives of local community members and we wish to congratulate them.

Recognition awards

Creating a legacy of positive change

Isa Adams has transformed her experience living with Parkinson's into a powerful force for change.

At age 49, Isa Adams began to notice the tremor in her right hand intensifying. Having seen both of her in-laws live with Parkinson's, she had a strong feeling that she could have Parkinson's too.

Isa received her Parkinson's diagnosis 15 years ago. Keeping this news mostly to herself, she quietly and proactively managed her condition. "I constantly told myself to keep moving as the option of lying on the bed is much easier, but the outcome would have been much worse".

She tentatively stepped into the Parkinson's spotlight in 2017 when she publicly disclosed her diagnosis with friends and family at A Walk in the Park. After seeing the positive response to her fundraising efforts, she was motivated to become even more involved in supporting the community.

"My husband Alan and my two boys set up a fundraising page for my first A Walk in the Park event and within a few hours, we saw the amount quickly climb. There was so much excitement, kindness and most of all, generosity. I knew I needed to keep doing this."

Since then, Isa has fully immersed herself in the Parkinson's community, participating in various fundraisers for Fight Parkinson's. She has inspired her loved ones and her network to get involved with a range of initiatives, including fundraising breakfasts and dance evenings and facilitating grants and donations from family celebrations. Thanks to Isa's passion and dedication, she has helped to raise more than \$180,000 for the community.

In 2023, Isa took on a crucial role as an ambassador in the Lift the Lid off Parkinson's campaign. With courage and grace, she shared her personal journey of living with Parkinson's, shedding light on the difficult challenges she has faced.

Isa's commitment to staying active has been remarkable. For the past 15 years, she has been attending regular dance classes which have had a significant impact on her physical and mental health. After witnessing the benefits she's experienced, Isa was determined to make dance more accessible to the rest of the Parkinson's community.

Fight Parkinson's connected her with Professor Meg Morris, a physio and world-leading researcher in Parkinson's. Together, they discussed advancing research into the benefits of ParkinDance, a dance program created for the Parkinson's community.

Over three years, two research trials were conducted and the findings from ParkinDance research are now accessible worldwide. With Isa's support, Professor Morris' publication has provided the international community with a solid evidence base, facilitating global access to the ParkinDance program.

"These weekly classes are something people can look forward to, where they can have fun and know they will benefit from the exercises. I consider myself a very lucky person that I can try to help Fight Parkinson's."

In recognition of her achievements, Isa was awarded the prestigious Sir Zelman Cowen Award, named after Sir Zelman Cowen for his outstanding services to the Parkinson's community over two decades. Kate Cowen presented the award to Isa on behalf of the Cowen Family at Fight Parkinson's Annual General Meeting in November 2023.

She accepted her award with a moving speech. "I know I am not telling you anything new when I say there is no cure for Parkinson's and each day presents itself with new and extremely difficult challenges. We need to find a cure for this dreadful disease. It just creeps up on you and changes your life forever. My life is so different than how I imagined it would have been, but I feel blessed to have the opportunity to make a difference and to try to help others."

Isa's story is marked by courage and a deep commitment to making a positive difference. Her actions and achievements are a powerful reminder that one person's warmth and strength can have a significant impact on countless lives.



Isa and her husband, Alan.

A guiding light in the Parkinson's community

Jill Price has been an active member of the Parkinson's community for more than 17 years, caring for her husband and the wider community.

Her dedication and generosity have been acknowledged with the Harold Waldron Carer's Award, named after Harold Waldron, who spent 38 years caring for his wife Margaret and leading the Geelong Peer Support Group.

The award recognises a family member who has been touched by Parkinson's and has made significant contributions to the community through their voluntary leadership.

Jill's involvement with Fight Parkinson's began when her husband David was diagnosed with Parkinson's. She reflected on this time when she graciously received her award at Fight Parkinson's Annual General Meeting in November. She expressed her gratitude towards the community for providing support over the years.

"When Dave was diagnosed, I can remember thinking it felt like we had joined a club that we hadn't applied for and didn't want to be part of. I am so grateful that back then, someone pointed us in Fight Parkinson's direction and over the years, you have always been there when we needed you."

Now we find ourselves in a big, caring Parkinson's family that you have helped to build and I am so proud and thankful to belong to this community and to play my part in it as well as to be able to continue to care for the man I love."

Jill has given back to the community tenfold; she has led the Ashwood ParkinSong group for many years, fostering a supportive and inclusive environment for her local community. Coming out of the pandemic, she played a pivotal role in ensuring a safe and successful reopening for the group and continues to lead with empathy and compassion.

In addition to her work with Ashwood ParkinSong, Jill has volunteered her time at Fight Parkinson's, providing crucial administrative support and assisting in the development of a program to train new volunteer leaders. Her extraordinary contributions have ensured community members receive the care and support they need.

During her Harold Waldron Carer's Award acceptance speech, she received the award on behalf of all the carers in the community who are quietly backing up their loved ones and living with and constantly adapting to the changes Parkinson's brings.

"Caring is something we all do under the radar, out of love and commitment, not for any recognition - but when someone notices and cheers you on, it is worth a million dollars."

Throughout her years of service, Jill has been a beacon of hope and a source of comfort for numerous individuals and families navigating Parkinson's. Her commitment to uplifting the community has had a profound impact, resulting in a stronger network of support for people who need it.

Jill's resilience and caring nature continue to inspire those around her and her unwavering compassion has earned her the admiration of all those who have had the pleasure of working with her.



Jill and her husband, David.

Award recipients

Without the contributions of volunteers who generously dedicate their time and experience, the Parkinson's community would not be what it is today.

15-year Service Award

Christine Gladwell (Berwick Painting with Parkinson's),

Mick Dee Prose (Berwick Painting with Parkinson's)

10-year Service Award

Franz and Sue Schnellmann (Essendon), **John and Jenny Wilson** (Bentleigh/Bayside), **Lynne Blake** (Mildura)

5-year Service Award

Geoff Serpell (Essendon), **Geoff Constable** (ambassador and fundraiser)

Community Recognition Awards

Dr Kelly Bertram - physiotherapist, research grant awardee and regular guest speaker for patient and professional forums

Grant Dewson (WEHI) - longstanding supporter and collaborator, contributor to Ask the Expert sessions

Mary Danoudis - physiotherapist and researcher who has been active in the Parkinson's space for decades

Dr Sanjay Raghav - longstanding supporter and regular guest speaker at community seminars and Ask the Expert sessions

Lift the Lid off Parkinson's campaign ambassadors -

Belinda Zipper, Bill Mackintosh, Jennie Wood, Matt Pettifer, Michelle Mendes, Peter Wylie, Stephen Dunn, Russell Joyce

Longstanding ambassadors - John Young, Lorena Bazzano, Mandy Baker, Patty Mayne, Pauline Wiltshire, Shona Cross, Sue Normington

Longstanding fundraisers - Alan Adams, Damian Rann, Florence Morrow, Ian McFarlane, Janette Cannizzaro, Mimi Morgan, The Hicks Family

Longstanding commitment to Peer Support Groups - Dennis Williams (Werribee), Kate McCormack (Lancefield), Marlene Hamilton (Corryong), Suzy Quinn (Monash), Tom Jambrich (Eltham)

Certificates of Appreciation

Retiring Board Members - Orlando Viola, Mark McAuley

Support of Bequest Program - Ian Phelan

Outstanding service supporting the Parkinson's community - Gateway Community Services

A Walk in the Park and 27forParkinson's fundraisers - Amy Chung, Anne Cox, Anne Paterson, Avi Koth and Nikky Gandel, David Rosenberg, David Smith, Delia McPherson, Elyse Cripps, Eng Lee, Garry Manning, George Doucas, Jeannette Branch, John McBride, Julie Wardle, Libby Young, Lottie Peters, Luke Grundy, Matt Perkins, Marcos Amado, Michael Tomasoni, Mick De Graaf, Mirella Yoho, Paul Kreutzer, Ron Keilar, Rose Doolan, Samantha Layton, Sean Anderson, Shane Buzza, Steph Mulcahy, Tessa Botheras, Ian Temme, Nadine Cripps, Vicki Thomas

Community fundraisers - Brett Frenkel, David Ball, Leon and Marlena Argent, Hugh Creamer, Ian Pratt, Jackie Unwin, Jacqueline Rose, Josephine Hale, Judith Greenwood, Katheesh Kandasamy, Kelly Bogunovic, Melissa Ferabend, Parker Tilley, Paul Coniglio, Paul Reeves, Renee Lancaster, Stephen Lake, Suzanne Conway, Matthew Pettman, Menaka Friend, Tamara Burba, Teagan Parker, Tony Forster

Managing symptoms

Parkinson's symptoms explained

Parkinson's is more than a tremor. In fact, there are around 40 motor and non-motor symptoms that can be experienced.

The following list can help you identify and articulate the symptoms you may be experiencing so that you can feel more confident discussing them with your health team.

Fight Parkinson's provides Parkinson's education, information and support for navigating these symptoms. To learn more about how to manage these symptoms, you can call our free health information line at 1800 644 189. They can also refer you to various free information sheets, webinars and online courses that are available to you.

Glossary of symptoms

Altered gait

Taking small, shuffling steps. Little or no swinging of arms and a tendency to lean forward.

Anosmia

Loss of a sense of smell, which impacts the sense of taste and enjoyment of food. Similar to Hyposmia (reduced sense of smell) which can also be experienced.

Apathy

A general disinterest or indifference towards certain activities or people.

Anxiety

A feeling of fear, nervousness or unease that may stop you from doing the things you enjoy.

Balance problems

Increases the likelihood of falls. This can be related to changes in posture, blood pressure or both.

Blurred or double vision

Caused by difficulties focusing.

Bradykinesia

Slowness of movement. Daily tasks take more time and effort, which can result in fatigue.

Cognitive changes

Changes to thinking and memory, causing difficulty with multi-tasking or planning.

Constipation

Infrequent passage of dry, hard-to-pass bowel movements.

Delusions and psychosis

Unusual thoughts, fixed beliefs or worries that aren't based on reality.

Dementia

A decline in cognitive functioning significant enough to interfere with daily activities.

Depression

Intense feelings of sadness or low mood for long periods (weeks, months or years).

Diminished or reduced libido

Loss of sexual interest or desire. It can occur for both men and women.

Dry mouth

Decreased saliva production. Often a side effect of medication.

Dysphagia

Difficulties chewing and swallowing.

Excessive sweating

Often unpredictable and may occur during "wearing off" periods.

Eyelid apraxia

Involuntary closure of eyelids in advanced Parkinson's.

Fatigue

Physical or mental exhaustion, causing a deep sense of tiredness.

Freezing

Stopping suddenly while moving. Usually triggered by a visual or auditory distraction.

Drooling

Caused by swallowing difficulties and changes to saliva production. Saliva may become thicker and stickier and sometimes extra saliva is produced.

Dystonia

Painful muscle cramps caused by low levels of dopamine. It often affects the feet.

Hallucinations

Seeing, feeling, hearing, smelling or even tasting something that is not there.

Hypomimia

Loss of ability to make facial expressions. It is also known as the "Parkinson's mask".

Hypophonia

Quiet voice. Caused by reduced movement of the larynx or the brain affecting perception of speaking volume.

Hypotension

Low blood pressure causing dizziness. Blood pressure may fluctuate or drop while moving. It can also be a Parkinson's medication side effect.

Impulsive/compulsive behaviour

An overwhelming drive to act in a certain way or carry out certain activities. It is a side effect of a group of medications called dopamine agonists, used in Parkinson's and for restless legs.

Micrographia

Small, cramped handwriting.

Nocturia

The urge to pass urine often at frequent intervals during the night.

Pain

Sharp, shooting sensations in the body. Includes nerve, musculoskeletal and radicular pain.

Postural imbalance

Stooped posture, including rounded shoulders, decreased low back curve and forward lean.

Reduced pain threshold

Decreased sensitivity to pain.

REM sleep disorder

Acting out dreams. Caused by the brain pathways that suppress muscle activity during sleep not working effectively. This may be a symptom occurring several years before any motor symptoms.

Resting tremor

Shaking, which is more likely to occur when a limb is relaxed and resting.

Restless legs

An overwhelming urge to move your legs which commonly occurs in the evening or in bed. It can also lead to burning, tingling, itching or throbbing in your legs.

Rigidity

Stiffness and tension in the muscles. It is often most noticeable when you move a joint through a circular movement.

Skin changes

Increased oil production, making the skin appear greasy and shiny.

Sleep difficulties

Includes disrupted sleep, daytime sleepiness, vivid dreams and difficulty in moving in bed.

Slurred speech

Caused by the muscles not moving with enough strength and speed to make all the quick, precise movements needed for speech.

Urinary urgency

Having little warning that you need to pass urine.

Weight loss

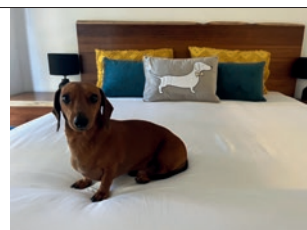
Unintended weight loss, which can occur in advanced Parkinson's.

It's important to remember that not everyone with Parkinson's will experience each of these symptoms. It can take many years for symptoms to progress to a point where they cause significant impairment. If they do, many of these symptoms can be managed with treatment and support.

If you are experiencing symptoms, it's important to discuss them with your GP or neurologist to establish the best symptom management plan.

The Fight Parkinson's Health Team can also help you to navigate symptoms as they arise. You can contact us by calling 03 8809 0400 email us at info@fightparkinsons.org.au.

Parkinson's Iceberg



Satin Panel Fitted Sheets

For help with movement in bed

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Poly-cotton fitted sheet with satin insert across the bed at torso level. The satin portion facilitates ease of movement and the top and bottom sections allow grip when turning. The satin insert covers the full width of the mattress finishing on the side of the mattress

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A Walk in the Park

A Fight Parkinson's community event

Join us for A Walk in the Park 2024

Get ready for Australia's largest community event supporting the Parkinson's community.

A Walk in the Park has been bringing together thousands of people every year since 2009 to raise awareness and crucial funds to support the Parkinson's community.

This year, A Walk in the Park Melbourne will be held on April 21, during Parkinson's Awareness Month.

In addition, there will be walks throughout the year in areas across Victoria, including Geelong, Horsham, Swan Hill, Bairnsdale, Eltham, Colac, Lakes Entrance and more.

A Walk in the Park is an inclusive and accessible event that invites people from all walks of life, including those living with Parkinson's, Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Corticobasal Syndrome (CBS). We also encourage families, friends, carers and health care professionals working in the field to attend.

A Walk in the Park creates a sense of belonging, brings the community closer and is a crucial fundraiser for Fight Parkinson's health education and support services.

This year, we're asking you to help build strength in numbers by inviting one more new person to join your A Walk in the Park Team. Every person you bring to A Walk in the Park has the potential to inspire someone else, creating a ripple effect that starts with you.

Your fundraising efforts help improve the quality of life for people living with Parkinson's. Together, we can ensure access to better care, support and resources for the Parkinson's community.



Why walk?

By participating in A Walk in the Park, you can:

- Show your support for the community, including those living with Parkinson's, PSP, MSA and CBS and their loved ones
- Pay tribute to those special to us and those no longer with us
- Spread awareness to friends, colleagues and the wider public
- Connect with other people who understand the impacts of Parkinson's
- Illustrate the size of the community and how many people are impacted by movement disorders
- Remind others that they are not alone – they have the support of a whole community

Important info for Melbourne A Walk in the Park

When: Sunday 21 April 2024

Where: Federation Square, Melbourne

Times: Arrive from 8.30am

Pre-walk entertainment from 9.30am

Walk begins at 10.30am

Official event activities will conclude at 1pm

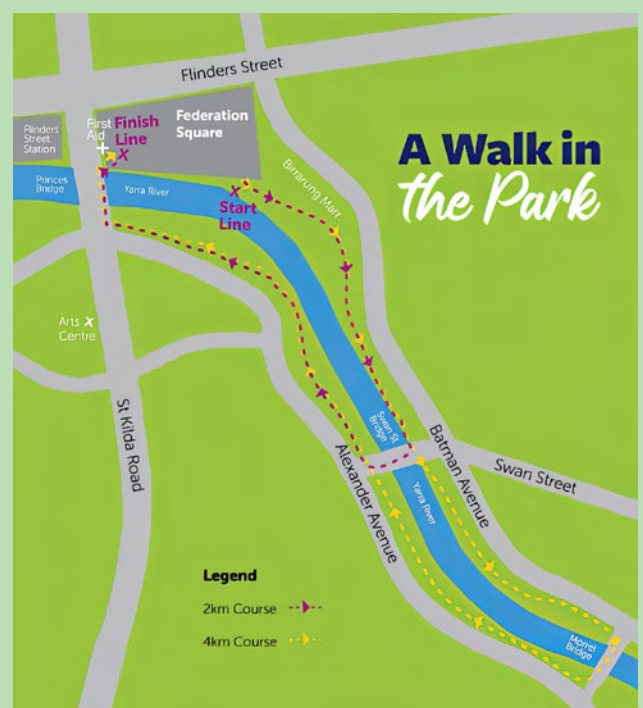
To ensure that the day is as fun and safe as possible, we kindly request that everyone follows these steps:

1. Register for the event beforehand to avoid any delays
2. Enter the event via the registration marquee located on the St Kilda Rd side
3. After pre-walk entertainment and the warm-up, head down to the start line and complete the walk
4. Following the walk, you are welcome to continue the celebrations with our fantastic entertainment or make your way back home

Remember to wear flat comfortable shoes and dress for the weather.

If you feel unwell on the day of the event, we ask that you prioritise your health and not attend. The well-being and safety of the community is our top priority.

For further information and event details, you can visit www.awalkinthepark.org.au or call Fight Parkinson's on 03 8809 0400.



FAQs

How do I register?

Visit www.awalkinthepark.org.au and click the "Register" button. You will have the option to register for Federation Square or to walk in your local area. Select your ticket option and follow the prompts. If you need help with registration, you can call the Fight Parkinson's office on 03 8809 0400.

How much are tickets?

Senior/Concession	\$30
Child (under 18)	\$30
Adult	\$50
Family (2 adults, 2 kids)	\$140
Dog	\$10

To ensure the best possible price, please register prior to the event. Higher rates will apply for same-day registration.

Can I register on the day?

Yes - on the day registrations open at 8:30am.

Is there entertainment?

A Walk in the Park is not just a walk, it's a day of celebration and fun for the whole family. We have organised a great line-up of entertainment before and after the walk, including a fantastic MC and live performances.

Is merchandise available?

Each person who signs up will receive a 2024 A Walk in the Park t-shirt to wear on the event day.

In addition, there are exciting rewards for your fundraising efforts. Raise \$500 and you'll get a free drink bottle and cap to go with your A Walk in the Park t-shirt. If you raise \$1000, you'll be part of the exclusive \$1K Club and receive a special \$1k Club t-shirt to go with your drink bottle and cap.

A Walk in the Park merchandise will also be available to purchase on the day or via our online shop, www.awalkinthepark.org.au/shop. All orders must be received by 11 April to ensure delivery prior to the event. You can also pick up your order at Federation Square on the day if you need. Please note that ticket prices for dogs do not include a free t-shirt. However, you can purchase extra t-shirts for your furry friends online or at the venue on the day.

Will there be food and drinks available on the day?

There will be water stations at Federation Square and along the walking routes. Coffee, cold drinks and snacks will be available to purchase at nearby shops, however, we recommend packing a lunch if you or any family members would like to refuel after the walk.

Is Federation Square accessible?

Federation Square has a number of wheelchair and pram-friendly ramps and lifts, in addition to an onsite carpark. The entire route, which includes a 4km and 2km shortcut, is located on footpaths and is accessible for wheelchairs and prams.

To ensure full accessibility for everyone, we will be utilising the toilets at Federation Square. For more information about accessibility at Federation Square, please visit www.fedsquare.com/accessibility.

Fisher Lane Mobility is providing free mobility equipment hire for participants on the day. This will include manual and some motorised wheelchairs.

Traveller's Aid Australia will also offer hire services nearby at Flinders Street Station. To book ahead, please call Traveller's Aid at 03 9068 8187 or book online at www.travellersaid.org.au/our-services/mobility-equipment-hire. Traveller's Aid will also offer a shuttle buggy from Federation Square after the walk to assist anyone getting to and from the car park.

For more details, please get in touch with us on 03 8809 0400 or email fundraising@fightparkinsons.org.au.

Do I have to walk at Federation Square?

If you can't make it to Federation Square or one of the many regional walks, you can walk in your local area at a time that best suits you. Don't forget to snap some photos with your team while wearing your A Walk in the Park t-shirts and share them on social media using the hashtags #FightParkinsons and #AWalkinthePark. We would love to see your amazing efforts!



Creating a team

Make the day even more fun by building your team

It's a beautiful way for family and friends to come together and show strength in numbers. If you already bring a team every year, see if you can add a new person to your team.

You can sign up a team online during the registration process or after signing up via your fundraising dashboard. Simply click "Create Team" and follow the prompts. If you need help creating your team, you can call Fight Parkinson's on 03 8809 0400.

Our top fundraising tips

1. Add a profile picture to your fundraising page
2. Include a personal story. What inspired you to do this challenge? Why have you chosen to support Fight Parkinson's? What are you asking your supporters to do?
3. Set yourself a target to work towards
4. Share your page. Email your fundraising page link to your friends, family and colleagues and spread the word on social media
5. Thank your supporters. Along the way and at the end of your fundraising journey, remember to thank everyone who donated



A Walk in the Park

A Fight Parkinson's community event

Find a regional A Walk in the Park near you

If you live in a regional or rural area, this is your chance to be part of a meaningful day of connection and support.

This year, we want to unite as much of our Parkinson's community as possible. If you can't make it to Federation Square or if you would prefer to walk in your local area, regional walks are a great way to get involved and provide strength in numbers.



A Walk in the Park Warrnambool.

Regional A Walk in the Parks are organised by Fight Parkinson's Peer Support Groups and community members across Victoria. Each regional walk is unique in its location and activities, but they all contribute to a shared cause. Together, we can ensure that vital information and support are available for people who need it most.

A Walk in the Park is accessible to people of all ages and abilities. It's the perfect opportunity to get outside, get active and make unforgettable memories with your friends and family. By participating in a local walk and asking other people to join you, you are sending a message of solidarity and support that extends to the whole Parkinson's community. By doing so, you can also help raise awareness and educate those who may not be familiar with the realities of living with Parkinson's.

Upcoming regional walks

Echuca	– Thursday 11 April
Bairnsdale	– Sunday 21 April
Lakes Entrance	– Sunday 21 April
Moorabbin	– Sunday 21 April
Hastings	– Sunday 21 April
Colac	– Friday 26 April
Swan Hill	– Sunday 28 April
Geelong	– Sunday 5 May

A Walk in the Park is a testament to the power of community and what we can achieve when we come together. Thanks to our community's dedication, we are excited to announce that more regional locations and dates are being confirmed. Keep an eye on our online events calendar for news of upcoming walks and additional event information at www.fightparkinsons.org.au/support-for-you/events.



A Walk in the Park Mildura.

If you're interested in having A Walk in a Park in your local area, it can be organised with the support of Fight Parkinson's year-round. Every walk counts and helps to increase awareness and improve outcomes for the Parkinson's community. For more information about regional walks, please visit awalkinthepark.org.au/regionalwalks. You can also contact our Fundraising Team at fundraising@fightparkinsons.org.au.

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MEET OUR A WALK IN THE PARK AMBASSADORS

These community members are inspiring others to join them for A Walk in the Park and sharing their personal stories to help lift the lid off Parkinson's.

Damian Rann

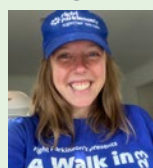


Damian Rann has been supporting A Walk in the Park for over a decade. It's been a family tradition since he began walking in support of his dad, who had Parkinson's.

Even after his father's death, Damian has continued to walk in his honour. His motivation to support the community has since been intensified after learning his cousin has been diagnosed with Young Onset Parkinson's. Witnessing the impact of Parkinson's on both sides of his family, Damian believes that no one should have to go through this.

Damian sees A Walk in the Park as an opportunity to drive important conversations about Parkinson's, promote physical activity and raise awareness to hopefully one day find a cure.

Georgy Hicks

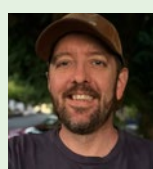


Georgy Hicks is determined to raise the profile of Parkinson's on behalf of her family. Her dad, Andrew, was diagnosed with Parkinson's in 2018 and her great-aunt was diagnosed with Progressive Supranuclear Palsy (PSP).

Georgy was an ambassador for A Walk in the Park 2023 and has been amazed by the support she and her family have received. She's also had the opportunity to build a network of support for people who have reached out to her with their own personal connection to Parkinson's.

Georgy is grateful for the strong sense of community that A Walk in the Park brings and the connections made during previous walks have been invaluable to her family. Through these connections, her father has discovered a range of classes and support groups that he is now actively involved in.

Iain McLean



Iain McLean was diagnosed with Young Onset Parkinson's in 2019 after struggling with symptoms for a decade. His personal experience with Parkinson's, including the impact it has had on his professional career and family, is what drives him to advocate for the Parkinson's community.

Iain strongly believes that increased awareness and funding are key to advancing research and ultimately finding a cure for Parkinson's. He is also passionate about mental health and peer support.

As an ambassador for A Walk in the Park, Iain is committed to raising awareness and inspiring the wider community to get involved. Through sharing his story, he wants to increase representation for the Parkinson's community and offer support to people who share similar experiences.

Jeannette Branch



Jeannette Branch has been living with Parkinson's for 17 years. Despite being diagnosed at 49 and experiencing many symptoms and setbacks since then, she hasn't let Parkinson's dampen her energetic spirit.

She is a devoted mum, grandma, wife and friend. Living in Echuca, she is an active member of her community and is involved in her local Parkinson's Peer Support Group. Over the years, she has participated in A Walk in the Park and 27forParkinson's and has organised several fundraisers of her own. This year, Jeannette and her team are making the trip from Echuca for A Walk in the Park Melbourne.

As an ambassador, Jeannette hopes to foster support for the Parkinson's community. She is also motivated by her personal goal of improving her voice and believes that the opportunity to speak up and share her story will help her reach that goal.

John Wijsma

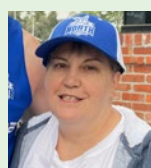


John Wijsma was diagnosed with Parkinson's in 2016, while he was running his landscaping business and raising his two sons with his wife. At 48, he has had to retire from his career and adjust to a new family dynamic as a full-time dad. In the midst of confronting the physical, emotional and financial impacts of Parkinson's, he recognises the importance of sharing his story.

As a dad who is in the thick of raising a young family, he wants to showcase the diversity of people living with Parkinson's and break down the misconceptions and stigma associated with it.

John is looking forward to A Walk in the Park as he wants to support Fight Parkinson's and enjoys the sense of community. He believes that by having more open conversations about Parkinson's and its complexities, people can gain a better understanding and provide more support to those affected.

Michelle Mendes



Michelle Mendes was diagnosed with Parkinson's in 2012 while she was working as a primary school teacher. Now retired at 55, she is determined to raise awareness about the realities of living with Parkinson's and to provide support to other people in the community.

Michelle is passionate about raising funds for improving support and services for people with Parkinson's. After countless experiences with long wait times in hospitals, lack of proper care and difficulties accessing allied health services, she is very aware of the systemic issues and barriers to funding. She also strongly advocates for improved training for health care professionals to ensure that everyone living with Parkinson's receives the best care and support possible.

Sean Anderson



Sean Anderson was diagnosed with Parkinson's at 43 after noticing tremors while riding his mountain bike. Seven years later, Parkinson's has presented him with challenges, but it doesn't define him.

Sean is grateful for the support of his friends, wife, health care professionals and his medication, which has helped him continue working and pursuing his hobbies.

Sean's motivation for participating in A Walk in the Park is to give back to Fight Parkinson's after receiving a great level of support during his diagnosis and ever since. He wants to shed light on the lesser-known symptoms of Parkinson's, including anxiety, pain and cognitive changes. He also wants to support the community, including friends with loved ones living with Parkinson's.

Sheenagh Bottrell



Sheenagh Bottrell was diagnosed with Parkinson's in 2011 at age 47. Since then, she has immersed herself in the Parkinson's community through volunteering, fundraising and taking leadership roles. She is currently a Fight Parkinson's board member and the Peer Support Group leader of Young@Park.

She has also shared her experiences in the media and community events to help others navigate similar challenges and to spread hope among the community.

Sheenagh aims to challenge the stereotypes surrounding Parkinson's. She wants people to know that this condition is not just a condition that affects older people but can impact anyone at any age. Through her work, she wants to amplify the community's voice, especially for women diagnosed at a younger age.

Ask the Expert

Relationships, Intimacy and Parkinson's

Parkinson's presents unique challenges to intimacy and relationships.

In a recent Ask the Expert session, social worker and counsellor Amanda Spillare explored these challenges and shared some helpful tips for navigating them.

Everyone knows that healthy relationships are fundamental to our social and emotional well-being. However, Parkinson's adds extra layers of complexity that can make it feel like there's a third person in the relationship.

Difficulties can arise at different stages of Parkinson's, although these challenges are often subtle and can sneak up due to the condition's slow and progressive nature.

Navigating diagnosis

It's not easy for couples to adjust to a Parkinson's diagnosis and it can be one of the most challenging experiences they face together. The diagnosis can trigger feelings of grief, loss, sadness, anger and frustration.

Couples may feel a sense of loss about how they envisioned their future together and dynamics may change. All of a sudden, the roles in the relationship shift, or one person has to take on more or less.

For the person diagnosed, loved ones may not know how to support them, leaving them feeling alone in their experience with Parkinson's. This may cause feelings of frustration and resentment if not properly negotiated.

Learning about Parkinson's together, including its symptoms and treatments or management strategies together can be a good way to begin navigating the journey together.

Communication challenges

Good communication is at the heart of any healthy relationship, but Parkinson's symptoms can sometimes make communicating difficult.

Soft or slurred speech, facial masking and trouble multitasking are just a few barriers that can make one partner feel ignored and the other misunderstood.

That is why communication requires extra care and patience with Parkinson's. It's important to understand each other's perspectives and encourage open communication. Listen without interruption and don't rely on a partner to guess what the other person is thinking.

If one partner feels hurt or alone, it's important to discuss it safely and avoid attacking each other during conflict.

Checking in regularly is also important. A great way to strengthen communication is taking at least five minutes every day to reconnect and talk about feelings and dreams for the future together.

Intimacy challenges

Living with Parkinson's can affect intimacy in relationships for many reasons.

Firstly, grief, emotional challenges and symptoms like depression and anxiety can reduce the desire to be intimate with a partner.

Secondly, dopamine affects arousal and pleasure. Low dopamine levels might result in problems like trouble maintaining erections or reduced vaginal secretions. Some people may even lose interest in sex altogether.

Some dopamine agonist medications can have side effects such as an unnatural increase in libido, which can potentially damage relationships if not addressed.

REM sleep cycle disruption or mobility requirement may also lead to separate sleeping arrangements, which can result in



fewer opportunities for physical touch and pillow talk, both of which are important for a healthy relationship.

While medication, fatigue and motor issues can create hurdles to intimacy, there are practical ways to overcome them.

For instance, if a partner with Parkinson's is most fatigued in the evening, try being intimate in the morning instead when their medication is at its most effective.

It's easy to get stuck in a routine, so introducing new activities, positions and toys can help ignite intimacy. Embrace spontaneity when the mood is right and always communicate with a partner before trying new things to ensure they are comfortable with it.

Seeking support

Seeking support from health care professionals can help address potential concerns and take pressure off a relationship.

Understandably, discussing issues around intimacy with others can feel uncomfortable. A helpful way to open this kind of conversation with a health care professional is to ask if they are comfortable speaking about sex and intimacy issues. If they say no, they can suggest or refer clients to an appropriate service.

Building healthy foundations

Remember that healthy relationships are built on a foundation of respect, trust, open communication, honesty and shared values. If there are already some cracks in these foundations, it can begin to feel like a chasm only exacerbated by Parkinson's.

It's important to recognise the impact of Parkinson's on relationships and discuss them openly.

When couples navigate Parkinson's together, it can bring a new and profound depth to the relationship; some people might even appreciate their partner more.

If you have concerns related to relationships, sex and intimacy, you can seek assistance from a counsellor who is trained in sexual health. You can also see your doctor for information, advice and referral on any sexual difficulty.

For more information or help with finding counselling services, you can call the Fight Parkinson's Health Team on 03 8809 0400.

Atypical Parkinson's

Progressive Supranuclear Palsy (PSP)

PSP is a unique condition with its own set of challenges. However, its early symptoms can overlap with Parkinson's, often leading to an initial diagnosis of Parkinson's which changes when treatments are not effective.

What is PSP?

Progressive Supranuclear Palsy (PSP) is a rare brain disorder that impacts balance, speech, vision, mood and thinking.

To break down the term:

'Progressive' means that symptoms worsen over time.

'Supranuclear' refers to the part of the brain that is affected.

'Palsy' refers to a weakness or paralysis in a part of the body.

In the context of PSP, the progressive nature of the condition often leads to a significant decline within three to five years of the first symptoms. The supranuclear aspect refers to the slowing of eye movements, leading to a fixed gaze.

The underlying cause of PSP is an overproduction of a protein called 'tau' in certain parts of the brain. This leads to the formation of tau tangles that damage nerve cells in the brain.

Understanding PSP is crucial for those living with or caring for someone with PSP to ensure they get the right help and support.

Parkinson's vs PSP

It's important to note that PSP and Parkinson's share some similarities, but they also have distinct differences.

PSP can be easily mistaken for Parkinson's in the early stages. The symptoms of PSP usually don't respond to medications used in Parkinson's which may be the first clue the diagnosis is not Parkinson's.

PSP also affects speech and swallowing more significantly than Parkinson's and may cause problems moving the eyes, particularly when looking downwards. Additionally, people with PSP are more likely to fall backwards than forwards.

When compared to Parkinson's, PSP generally progresses at a faster rate. These symptoms, if not properly managed, can result in serious complications. These complications include pneumonia, choking, head injuries and fractures, all of which can be fatal.

On average, the life expectancy after PSP diagnosis is around seven years, but some people with PSP can live a decade or more after the first symptoms appear.

This is why consulting with a specialist who can recognise these differences is important. A neurologist with expertise in movement disorders may be better equipped with the latest advances in PSP treatment and management and can provide individualised care.

PSP symptoms

Typically, people with PSP begin to experience symptoms between the ages of 60 and 70.

Early symptoms of PSP may include problems with walking (stiffness or problems with balance and unexplained falls), feeling dizzy, slow movements, facial stiffness, problems with eyesight, problems with thinking and personality changes, apathy, irritability, depression, heightened emotional responses, slurred speech, clumsiness, mild shaking of hands and small handwriting.

Later symptoms of PSP may include worsening movement problems that make walking very difficult or impossible, recurrent falls that can lead to bruises and fractures, involuntary closure of eyelids, difficulty looking up, down or to the side, difficulties swallowing, communication difficulties and increased difficulty with thinking.

PSP can be difficult to diagnose since there are no specific tests to confirm it. However, doctors may use certain tests and scans to rule out other conditions with similar symptoms.

Early diagnosis is key to helping people manage these symptoms and achieve the best possible independence and quality of life.

PSP management

While there is currently no cure for PSP, there are a range of treatments and therapies to manage its symptoms.

A multidisciplinary team, including neurologists, physiotherapists, occupational therapists and speech pathologists, can help address specific challenges related to PSP. They can assist with things like mobility, difficulties with swallowing and communication issues.

PSP support

Navigating PSP can be overwhelming, but it's important to remember that no one has to face it alone.

If you or someone you know is coming to terms with a PSP diagnosis, getting information and support can help adjust to the diagnosis and begin to navigate PSP's complexities.

The Fight Parkinson's Health Team offers national specialist support, including information on symptom management, services, health-related benefits, entitlements and everyday living.

If you need further support, the Health Team can provide specific information for (and advocate on your behalf to) medical and healthcare professionals who may not have a lot of knowledge about PSP.

Tailored information and resources are also available for you at fightparkinsons.org.au/living-with-psp/.

If you would like to connect with other community members living with PSP, Fight Parkinson's holds a bi-monthly online support group for people living with PSP, MSA and CBS. If you're interested in attending or want to know more, you can contact us at 03 8809 0400 or email info@fightparkinsons.org.au.



Personal Story



Laura and her husband, Laurence.

Laura Power Davies

Parkinson's affects more than just the person who has been diagnosed. Laura's honest account of being a carer highlights the importance of finding support to cope with its challenges.

Laura Power Davies is a Melbourne-based artist. She has been married to her husband, Laurence, for 35 years and describes their partnership as "one of the love stories for the ages".

Their relationship began in Alaska in 1987 and they continued their lives in Melbourne, where Laura worked as a psychologist and Laurence worked as a chiropractor. Together they ran a chiropractic clinic until the early 2000s when Laura returned to the fine arts. Laurence was diagnosed with Parkinson's in 2016, however, continued to work as a chiropractor until 2018.

Navigating Parkinson's together

"You're dropped into a landscape and you have to learn a whole new world. And what I've learned about Parkinson's has been profound; everybody with Parkinson's has their own version."

Navigating Laurence's diagnosis together was challenging, but Laura made a point of reminding him that Parkinson's is something they would tackle as a team.

Over the years, as Laurence's symptoms progressed, Laura gradually took on more of a carer's role. She says it was the hardest thing she's ever done. "In between all that caring, you're dealing with all the feelings of grief because you're watching the person you love decline by degrees. I call it the long goodbye."

Obstacles and challenges

Now at age 70, she reflects on her traumatic experiences navigating the aged care system. "It's not fair to get to our age and have to go to battle for just services. It's so unjust and it's so much for anyone to take on, especially when you're older and have to take care of someone else while trying to take care of yourself".

"I basically broke. It's taken me four years to get to the point where I am now, looking after my own health as well. I went back to counselling and I finally was able to make the decision for him to go into care because I had to start to look after my own health."

The importance of self-care

During this time, Laura was able to find solace in her art. She used repetitive practices like crochet as a form of self-care. Even in her art practice today, she's been able to explore the themes and feelings associated with living with and caring for someone with Parkinson's.

One of her textile projects has incorporated one of Laurence's dress shirts that he would wear on their trips to the opera and the ballet. Through her pieces, Laura is not only creating something visually beautiful but also raising awareness about Parkinson's and its impact on those it affects.

As well as her art, Laura has fallen in love with exercise as part of her self-care. "I'm so grateful that I persisted and prioritised exercise because it's one of the things that has gotten me through a very difficult time". With regular physiotherapy and strength training, she is becoming physically and mentally stronger, which has been beneficial in her role as a carer for Laurence.

Seeking support

Laura is also grateful for her local Fight Parkinson's Peer Support Group in Newport. She attended her first meeting in March 2022, where she met people who were also caring for their loved one with Parkinson's. "There were two other women in my age group and because we were all stressed to the max and at the point of breakdown, we formed a triffecta of three amazing women and it has saved our lives."

It can be easy to overlook your own needs when you're focused on taking care of someone else, but neglecting yourself can lead to carer burnout and other issues.

Thankfully, Laura's art and her network of support have been a source of strength for her. She encourages other carers to prioritise their own well-being so that they can provide the best care possible for their loved one.

If you are caring for someone living with Parkinson's, support is available. Call Fight Parkinson's on 03 8809 0400 for details of your local Fight Parkinson's Peer Support Group, or to confidentially discuss the challenges you are facing with our Health Team. They can also advise on other counselling services in your area.

Young Onset Parkinson's

Richard Grimmett

Richard's Parkinson's story provides a glimpse into his strength of character and the life lessons he has learned along the way.

At 60, Richard Grimmett refuses to let Parkinson's dampen his positivity and love of life. Around the age of 47, he began noticing the subtle signs of Parkinson's beginning to surface. His arms stopped swinging, he would struggle to get cards out of his wallet and his sense of smell and memory were being affected. At the time, he was working as a funeral director in Ocean Grove.

Given that Richard's father, uncle and brother had previously been diagnosed with Parkinson's, he and his wife Heather were able to spot the symptoms early. Since Parkinson's was already familiar to them, they found some degree of comfort in knowing that Parkinson's wasn't a death sentence and it was possible to continue living a full and active life. But equally, they understood what lay ahead.

Richard was certain that he had Parkinson's and took the proactive steps to get an official diagnosis. However, this process proved to be more difficult than expected when his GP was hesitant to refer him to a neurologist.

The GP was concerned that dealing with medication and its side effects could be worse than his symptoms at the time. He recalls being asked, "Do you really want to know if you've got Parkinson's?"

Richard sat on this question for a while, but he eventually decided that medication and treatment would be the best way forward to ensure his ongoing quality of life.

For the first five years of living with Parkinson's, he was able to carry on with work and life as usual. Understanding that Parkinson's is a progressive condition, Richard and Heather made a conscious decision. They would go on all the overseas trips they had always dreamt of going on before his symptoms began impacting daily life. Both Richard and Heather strongly believe in living life to the fullest and not putting off the things you want to do.

One year into his Parkinson's diagnosis, his adventurous spirit led him to embark on a solo hike along the Great Ocean Walk. He documented his experience through photos and diary entries, which he later turned into a book titled "Great Ocean Walk with Parkinson's Disease: Apollo Bay to the Twelve Apostles in Eight Days."

In the book, he recounts his adventures, which include encounters with wild creatures and friendly people he met along the way. Passages include personal reflections, poems and words of wisdom. His book isn't just a travel diary but an ode to reconnecting with nature and the human spirit.

He shares his optimistic approach to life, reminding readers that "With courage and determination, every hill can be climbed".



The people in Richard's life know him as someone who faces adversity with a positive and proactive attitude. Being a community-minded person, he became actively involved in the Parkinson's community and is passionate about raising awareness and funds for improved treatments and support for people living with Parkinson's and related conditions.

Along with running various events and fundraisers, he hosted a radio show on a network broadcasted for and by the international Parkinson's community, using his love for music to connect and empower people.

Seven years ago, Richard underwent Deep Brain Stimulation (DBS), which had helped a lot with his movement. Over time, his fatigue and cognitive symptoms became too significant and he had to make the tough decision to sell his business and eventually medically retire.

Despite having to constantly adapt to new symptoms and realities, resilience and positivity have defined Richard's approach to living with Parkinson's. He chooses to find happiness and joy in the small things and wants to inspire others to seize the day.

Richard and Heather are incredibly grateful for the love and support of family, friends and their community. They are excited to welcome their first grandchild in June and look forward to the next chapter of their lives together.

We express our gratitude to Richard and Heather for sharing their story. If you are interested in reading "Great Ocean Walk with Parkinson's Disease: Apollo Bay to the Twelve Apostles in Eight Days," please send an email to info@fightparkinsons.org.au.



An excerpt from Richard's book, "Great Ocean Walk with Parkinson's Disease: Apollo Bay to the Twelve Apostles in Eight Days".

Young Onset Parkinson's

Ian McFarlane

Ian McFarlane is a fighter and tireless advocate for the collective wellbeing of his local Parkinson's community.

Ian was just 52 when he was diagnosed with Parkinson's. As a father of two who maintained an active lifestyle, his concerns first began when he found that he was having trouble keeping up with his running group. Over the course of a year and seeing several GPs, he finally got a referral to a neurologist and he was diagnosed within five minutes of the appointment.

Shortly after receiving his diagnosis, he began meeting with Patrick Cahill who was running the Fight Parkinson's Peer Support Group in Lysterfield. "His knowledge of the disease was a great help to me", Ian said. "We would meet in various cafés and chat for hours."

One of Ian's major concerns about Parkinson's was its impact on his fitness, as he was an avid runner. "I was running at the time and I was running up to 20 km in a session. By the time I got diagnosed, I was running less and less. I actually got down to 0 km and I didn't think I'd be able to run again."

However, with the right medication and his passion for exercise, he has continued running and has recently ran 10 km again. He also regularly attends pilates and boxing classes to maintain his health and well-being.

Boxing, in particular, is a growing passion of Ian's. In late 2018, he met with Fitlife Boxing gym founder Tommy Hopkins and asked if he ran sessions for people with Parkinson's. Within days, Tommy and Ian were meeting at the Boxing Gym regularly to talk about the different issues, capabilities and approaches associated with Parkinson's.

Since its inception in February 2019, there have been about 300 boxing classes conducted at Tommy's gym. Ian says the classes are catered for all stages of Parkinson's. Some participants still run, while others arrive in wheelchairs. There is a mixture of men and women attending and there is an ever-changing mixture of fun and fitness involved.

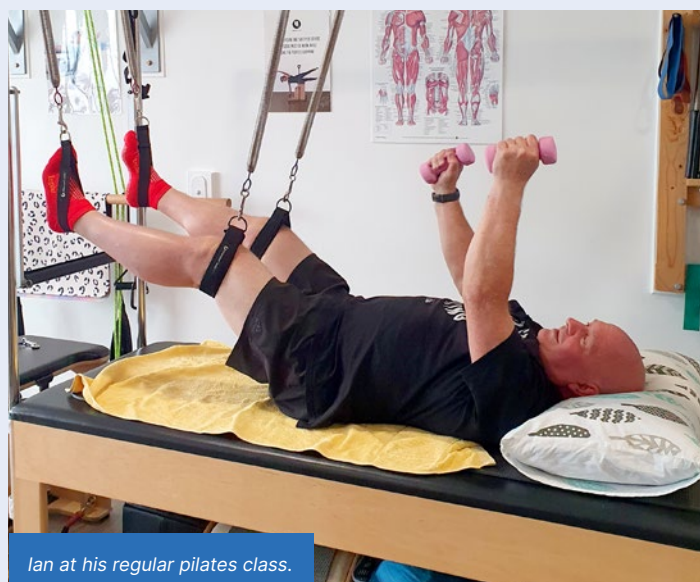
Class activities include boxing, stretching, balance work, falls training, light weights, multi-tasking, dancing, singing and laughter training. Following the boxing sessions, participants often have lunch together at a local café.

"Each session is just a friendly get together of like minded people dealing with the same condition. Often for participants, it was the first time that they had met someone else with Parkinson's or talked to someone else who was living and understanding Parkinson's."

Ian was seeing the success of these get-togethers and seeing its benefits to the community. However, he understood that not everyone boxes, so the informal boxing support groups did not make sense for everyone. He identified a wider need among his local Parkinson's community, so he initiated a more formal Peer Support Group.

The Knox & District Parkinson's Support Group began meeting in 2023. With the support of community members Stephen Dunn and Steve Smith, they held the first meeting in August 2023 with five attendees at Boronia Library. "We were happy with that as we really were not sure that anyone would turn up on the day. I'm happy if we just have one person that gets some benefit."

Ian notes that his Peer Support Group was due to start in 2022 but unfortunately had to be delayed for a year.



Ian at his regular pilates class.

"I was diagnosed with Lymphoma in April 2022 and started my chemotherapy and radiation the same week that the group was due to start. Finally, following successful treatment, I was able to start thinking about getting the group up and running."

Since his recovery, the Peer Support Group has conducted five monthly meetings and membership is steadily growing. They have drawn from the experiences of members of the boxing group to provide a topic for discussion each month. Topics so far have included Pickle Ball, Block therapy and personal accounts of Parkinson's journeys and DBS.

It's inspiring to see how Ian stays optimistic and committed to maintaining an active and healthy lifestyle despite his challenges. In addition to creating a supportive community for others living with Parkinson's, he is also extremely passionate about Parkinson's research.

Ian's involvement in the Consumer Advisory Committee at the Walter and Eliza Hall Institute (WEHI) and events like the World Parkinson's Congress is yet another testament to his dedication towards making a difference.

Anyone diagnosed with Parkinson's before the age of 65 is eligible for support under the NDIS (National Disability Insurance Scheme). The NDIS is better placed than the Aged Care System to respond to some of the disability changes Parkinson's might bring.

Fight Parkinson's encourages anyone diagnosed before this age to lodge an application so they are in the system before turning 65. If you would like more information about Parkinson's and the NDIS, you can access the Community Learning Hub free course called "The NDIS and Parkinson's: How to Apply" via www.fightparkinsons.org.au/communitylearning.



The Rock Steady Boxing Cohort in action.

Support for you

Meet the Mildura Peer Support Group

Learn about Fight Parkinson's Peer Support Group leader Cheryl Barnes and her journey with the Mildura group.

How it began

Cheryl, a Mildura resident, was diagnosed with Parkinson's at age 56. At this time, she says there was very little information on Parkinson's and most GPs in the area didn't know very much on the subject either.

In 2007, Cheryl met with Amanda Spillare, who was working at Fight Parkinson's (then known as Parkinson's Victoria). After their discussion together, they realised the need for a Peer Support Group in Mildura. This led to the formation of a community that would later become a crucial support for people navigating Parkinson's.

Initially, Cheryl and Don MacKellin were asked to chair the first few meetings, with the support of Sunraysia Community Health and occupational therapists, Renée Kelly and Leanne Wright.

Through word of mouth and a range of other networks, the group gained momentum quickly, with up to 50 members attending the meeting. It wasn't long before they had to find a new venue to accommodate growing numbers. The Rose Lifestyle Village in Central Mildura provided a welcoming space for their monthly meetings and gatherings.

When Don became ill and stepped back from chairing meetings, Cheryl continued on and she's very glad she did. She thinks of everyone she has encountered at the meetings as remarkable, each with a unique story.

"The people I have met since are so amazing. Finding out about their lives and their families is so refreshing and interesting. We were learning all together about Parkinson's Disease as a family."

The group today

Over the years, the Mildura Peer Support Group has held many fundraising events to raise money for Parkinson's research.

The group has embedded themselves in their local community and they are proud to say that the Sunraysia region now has a greater understanding of Parkinson's thanks to their presence and awareness-raising activities.

After the very first Melbourne A Walk in the Park in 2009, the Mildura Support Group started running their own regional A Walk in the Park. These regional walks are great for bringing the community together and everyone looks forward to it every year.



Cheryl and the cohort at their regional walk in 2022.

Parkinson's education is an important part of the Mildura Peer Support Group's meetings. At least once a year they meet with a Health Team member from Fight Parkinson's and have had a range of guest speakers visit, covering a range of specific topics.

One of the group's major highlights is when they were asked to be part of research in a cognitive study conducted by La Trobe University. Members were thrilled as it's rare for regional Parkinson's communities to have the opportunity to participate in such studies.

Other memorable moments include regular dance lessons and a visit from artist Anne Atkins, who presented on "Art in Parkinson's". Since then, some of the group members have even gone on to produce some lovely art of their own.

Connection is at the heart of the Mildura Peer Support Group and Cheryl says the group loves to be social. They try to have a coffee morning once a month and they meet at a different venue each time. They also have Christmas in July and end-of-year lunches to celebrate their achievements together.

Cheryl is proud to say that various Peer Support Group members have received many awards for their outstanding work in the community. She herself received Fight Parkinson's Sir Zelman Cowen Award in 2017 and then the following year, she was named Senior Citizen of the Year in Mildura.

Looking ahead

Going into 2024, the Fight Parkinson's Mildura Peer Support Group hopes to continue making a positive impact, promoting more inclusivity, awareness and education together.

If you are interested in attending a Fight Parkinson's Peer Support Group near you, you can contact the Fight Parkinson's office. Call us on 03 8809 0400 or email info@fightparkinsons.org.au.

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The advertisement for TabTimer features a collection of various electronic devices designed to help people manage their medication. These include several smartwatches in different colors (black, white, purple, yellow), a digital clock with a large display, a small digital timer, and an electronic pill box. The background is white with a blue and red color scheme. The TabTimer logo is prominently displayed in the top right corner, with the tagline "helping to keep people on-time". A small inset image shows a smartphone displaying a medication reminder.

Fundraising



Yackmembers out on the course

Yackandandah Charity Day

"It was a natural choice for us to choose Fight Parkinson's for the Charity Day as it was so important to Pam".

The Yackandandah Golf Club held a Charity Day in loving memory of Pam Crosthwaite.

Pam was a passionate advocate for Fight for Parkinson's during the 15 years of being diagnosed with Parkinson's. She believed strongly in educating health care professionals and those diagnosed with Parkinson's to ensure they could get the best health advice and quality of life.

After retiring from her Director of Nursing role, Pam was involved in educating others through speaking to support groups and health care workers.

"She was a bit of a go-to in Yackandandah as far as Parkinson's was concerned," said Pam's Husband, Donald. "She had a great rapport at the hospital. Even doctors referred people to her."

Pam was also a long-standing member of the Yackandandah Golf Club, a small country 9-hole sand scrape golf course managed entirely by volunteers.

Libby, the Club's Women's Captain, recalls Pam as a respected and much-loved member and says her passing was felt deeply within the community.

The Charity Day was an absolute success with 14 teams playing from clubs in the region, including Beechworth, Howlong, Thurgoona and Albury, along with Yackandandah's own members and nearly three teams from the Crosthwaite family and friends.

The participation of 56 members and their dedication to honouring Pam's legacy exemplified the power of their community.

The winning scramble team included Pam and Donald's son, Stuart Crosthwaite, his friend Scott, James (Pam and Donald's nephew) and Glenda Stacey, a long-time friend of Pam's.

There were also many members who couldn't play but helped in the background by putting on lunch and running the raffle. The raffle alone raised over \$700 for the first donated prize.

"From the day, our small Club raised \$2372 for Fight Parkinson's, which we think is an outstanding effort and the support, attendance and atmosphere are a testament to how much we all loved Pam," said Libby.

We extend our appreciation to Donald and Libby for sharing their story and to all Yackmembers who participated and honoured Pam's legacy.

If you are interested in fundraising for Fight Parkinson's, please contact the Fundraising Team at fundraising@fightparkinsons.org.au.



The winning team: Stuart, Scott, James and Glenda.

Swan Hill Trivia Night

The Swan Hill Parkinson's Peer Support Group held a series of fundraisers to entertain and educate their local community about Parkinson's.

Following the success of A Walk in the Park 2023, members of Fight Parkinson's Swan Hill Peer Support Group were eager to continue the positive momentum and have a fundraising goal to work towards together.

To help gather support from their local community, they decided to run two trivia nights at the Swan Hill Club. The first night, held in November, attracted a full house of 100 people. The second trivia night, held in December, attracted about 65 people.

To prepare for the event, Peer Support Group member Russell Wardle wrote the trivia questions. They covered a range of general knowledge topics and even included some questions related to Parkinson's to foster extra awareness and understanding among the attendees.

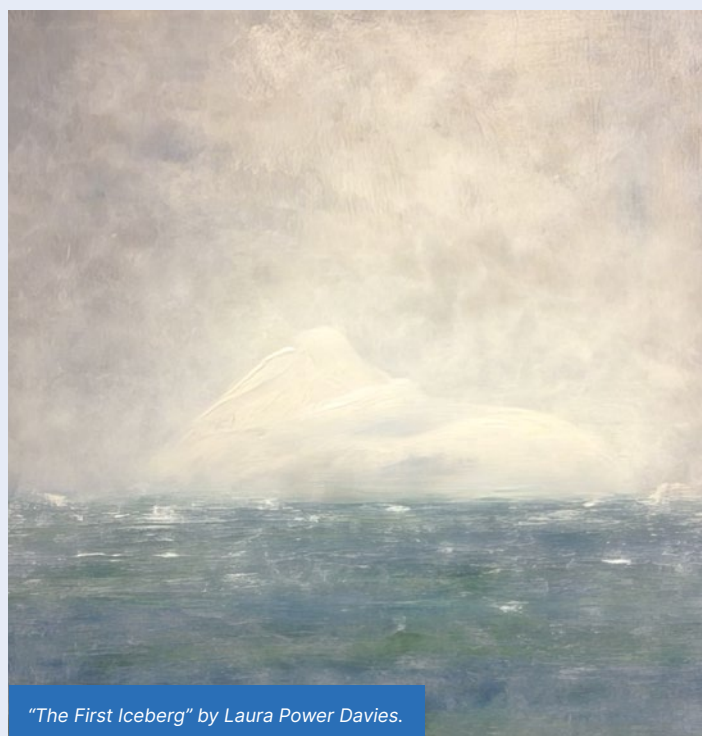
To spread the word and gather some support, the events were promoted through social media, word of mouth and local media. On the day of the event, attendees were charged \$10 per head and there was also a raffle to boost fundraising efforts.

Across both trivia nights, the group raised \$2,513. Russell says the group plans to run more trivia nights throughout 2024.

Our special thanks to the Swan Hill Peer Support Group for their fantastic fundraising efforts.

Russell would like to extend his gratitude to all the local businesses that generously provided lucky door prizes, event host Daryl Billing and raffle organisers Judy Mitchell and Christine Schang.

If you are interested in connecting with a Peer Support Group or hosting a fundraiser of your own, you can contact the Fight Parkinson's Team on 03 8809 0400.



Spring into Summer art show

Running for its second year in a row, an online art show supporting Fight Parkinson's attracted 276 submissions and raised over \$2,500.

The Spring into Summer online art show was held throughout December 2023. The show aimed to showcase Australian original artworks.

Submitted works spanned a range of mediums, including paintings, photographs and digital art. Selected works were judged by Melbourne artist Faye De Pasquale and standout pieces were awarded titles such as "Best Painting" and "Best Photograph", while others received commendations. All artworks were then featured online and available for the public to purchase. 100% of the profits from the art show were donated to Fight Parkinson's.

Stephen Lake, owner of Gallery 247 and City of Yarra Peer Support Group leader, organised the Spring into Summer art show. Some of the featured artists included members of the Parkinson's community, such as Laura Power Davies, who generously donated her art for the cause.

Laura's painting, titled "The First Iceberg" was inspired by a special trip to Antarctica with her husband Laurence, who is now living with Parkinson's.

As Laura explained, the iceberg in the painting has a double meaning. It represents the visible symptoms of Parkinson's, like freezing, that people often associate with Parkinson's. It also symbolises the countless other symptoms that people experience beneath the surface, which others may not always see.

The Spring into Summer online art show has been an excellent platform supporting Fight Parkinson's. It gave people an opportunity to express their creativity and highlighted the role that art can play in providing self-care when living with Parkinson's.

Fight Parkinson's thanks Stephen Lake, Laura Power Davies and everyone who contributed to this wonderful initiative.

If you would like to browse the featured artwork or learn more about the art show, you can visit www.springintosummerartshow.com.au or email us at fundraising@fightparkinsons.org.au.

About Fight Parkinson's



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All submissions are subject to the publisher's
editorial guidelines and may be edited for space
or clarity.

Upcoming events

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

DATE	NAME	EVENT DETAILS
Thursday 21 March, 10-11am	Positive Life: Sleep and Parkinson's	Join Victor McConvey as he explores how living with Parkinson's can affect sleep and ways to overcome sleep difficulties.
Friday 22 March, 10:30-11:30am	Online Singing	Join our online singing community and get ready to belt out some tunes in the comfort and security of your own home.
Thursday 4 & 5 April, 4-5.30pm	Recently Diagnosed Seminar	Gain a better understanding of living with Parkinson's and have your questions answered by a clinical Parkinson's Nurse.
Thursday 11 April	World Parkinson's Day	An international day of reflection and recognition for people living with Parkinson's.
Monday 29 April, 10:30-5:30pm	Research Seminar	Exploring the latest in Parkinson's research at The Florey Institute. Further details will be available on our website.
Tuesday 14 May, 5:30-6:15pm	Ask the Expert: Early Onset Parkinson's	This Ask the Expert session will discuss practical advice for men and women living with Young Onset Parkinson's.
Thursday 23 May, 5:30-6:15pm	Positive Life: Navigating the National Disability Insurance Scheme (NDIS)	Explore how the NDIS can support people living with Parkinson's and Atypical Parkinson's conditions and learn practical tips for navigating the NDIS.



COMMUNITY

Learning Hub

The Learning Hub provides evidence-based Parkinson's education, which anyone can access at any time. The courses are free and cover topics such as:

- What is Parkinson's?
- Parkinson's diagnosis
- Motor symptoms
- Non-motor symptoms
- Treatment options
- Planning ahead
- Building your health team
- Managing your symptoms
- Keeping healthy and living well
- Supporting someone with Parkinson's.



To access the Learning Hub, scan the QR code below:

1. Open the camera on your smartphone
2. Point the camera at the QR code
3. Follow the link that appears on your smartphone screen

Access code is: **Welcome**

Fight Parkinson's
Together we can