

PRINT VERSION

Support Group Roundup

By Stacey Foster, Support Group Coordinator

In my final Support Group round up for the year, I'd like to start by saying thank you to everyone who has welcomed us to your Support Group this year. We really enjoy going out into community and meeting you all, hearing your stories, and witnessing how you all support one another.

Since the last edition of *InTouch*, Parkinson's NSW Board Chair, Rachel Tanny visited Eastern Suburbs Young Onset Support Group for a meet and greet. There are also plans for Rachel to guest speak at one of their meetings early next year.

In early November, John Back and I visited Bega Valley Support Group. We were sorry to miss leader, Jody Collins, but thank group Secretary, Keith Pitchford, and all of the participants for your warm welcome and interest in Parkinson's NSW. We look forward to working with you to boost awareness of Parkinson's and the Support Group in the Bega Valley region in 2025.

Mirelle Brockett, Digital and Marketing Manager, visited the mid-north coast Support Groups also in November, covering Kempsey, Grafton, Coffs Harbour North and Nambucca Valley!

Word from Mirelle is that Kempsey Support Group leader, the always energetic Garth Fatnowna, led the group in song to open the meeting – a fabulous activity to keep those voices strong. Thank you, Garth, for your dedication and commitment to the participants of the Support Group and the wider Parkinson's community.

Next up was Grafton Support Group, led by Terry Shinn, supported by his wife Evelyn Shinn and Catherine Eggins. The Support Group meet for brunch and enjoy the socialisation and friendship, interspersed with discussing the latest *InTouch* and *Research Round Up*.

A big thank you to Terry and Evelyn's daughter who held a Parkinson's Tea Party and raised almost \$600. Despite the challenges that come with running a support group, Terry has encouraged a friendly atmosphere for people to gather, and we look forward to working with the group next year to further boost awareness of Parkinson's and the Support Group in the local area.

Coffs Harbour North, well led by Graham Saxby, welcomed Mirelle next. Mirelle was left very impressed by the meeting venue and all the excellent facilities available.

Whilst there, Mirelle, Graham and a few of the participants visited Bailey Centre Liberty Service Station and PK Express Transport to thank them in person for their

wonderful fundraising efforts in their ongoing support of Parkinson's NSW and our Specialist Nurse, Vince Carroll.

A huge thanks to Graham for his commitment to the local Parkinson's community, stretching himself across a few support groups and generously sharing his knowledge about leading a group and the pitfalls to avoid to newly established groups.

Lastly (but definitely not least!), Mirelle visited Nambucca Valley Support Group, which has been led for many years by Jenny Zirkler. She has excellent support from the group participants as well as Parkinson's nurse, Vince Carroll. My sincere thanks to Jenny for her long-term dedication and commitment.

In November, I had the pleasure of visiting Nepean Blue Mountains Support Group to share information on Parkinson's NSW and spend some time with the group. Vivienne Ross is the long-time leader of the group, and in a year which has had many challenges and setbacks, Vivienne has shown great resilience and courage to keep going. Participants of the support group have stepped up to support Vivienne, a testament to the strong bonds, support and commitment from everyone.

December is upon us and that means Christmas parties! We look forward to joining Southern Highlands, Eastern Suburbs, Blacktown, Central Coast and Nepean Blue Mountains at their festivities in the coming weeks.

Wishing you all a very merry and safe Christmas and a Happy New Year!

Side-to-side eye movement can improve stability in Parkinson's

Side-to-side eye movements can help reduce body sway and improve postural stability in people with Parkinson's disease, even though Parkinson's patients generally have difficulty coordinating their eye movements, a new study reports.

The study, "[People with Parkinson's Disease Are Able to Couple Eye Movements and Postural Sway to Improve Stability](#)," was published in the journal *Biomechanics*.

People living with Parkinson's have a higher risk of falls. One of the reasons is that they tend to sway more when standing than people without the disease. This can increase the risk of them losing their balance and falling over.

It's been proven that side-to-side and up-and-down (saccadic) eye movements can help reduce body sway in adults who don't have a neurological disease. Parkinson's patients have a difficult time fine-tuning their eye movements, so it's not been known if this technique could apply to them.

Scientists in Brazil studied 10 people with Parkinson's and 11 similarly aged people without the disease and recorded how much they swayed when their gaze was fixed on one point over when they moved their eyes side to side or up and down.

Side to side, and up and down

The experiments were conducted while Parkinson's patients were under the influence of medications to help manage their disease symptoms, but the researchers expected that eye movements would have less benefit for them than for people without the disease.

But that wasn't the case. Side-to-side eye movements reduced body sway in the people with Parkinson's to a similar extent as they did those without the disease. This was true even though patients generally scored worse on measures of how well they coordinated their eye movements, which was expected.

"Individuals with [Parkinson's] can reduce postural sway as efficiently as neurologically healthy people when performing horizontal saccades [side-to-side eye movements]," the researchers wrote.

Moving the eyes up and down did not improve body sway in Parkinson's patients, however, but it did in people without the disease. The findings were consistent no matter how the participants were standing — with their feet side by side or one in front of the other.

The results suggest integrating side-to-side eye movements into postural training for Parkinson's patients could be beneficial, said the researchers, who cautioned that their study was aimed at basic research rather than toward designing an intervention.

"It's not an automatic strategy to avoid losing balance and falling, since routinely moving the eyes rapidly from side to side is difficult," Fabio Barbieri, PhD, co-author of the study at São Paulo State University in Brazil, said.

"You can train horizontal saccadic eye movement, but this study was aimed at basic research rather than practical recommendations. Our findings furnish new knowledge of the disease, and of its motor and cognitive consequences."

Source:

Original article by Marisa Wexler, MS

[Parkinson's News Today](#)

Balance Impairment Leading to Falls in Parkinson's

One of the most challenging symptoms of Parkinson's disease that fundamentally affects quality of life is balance impairment that can lead to falls.

Falls are one of the major causes of emergency room visits and hospitalisations for people living with Parkinson's, so finding ways to prevent as many falls as possible is a high priority. Thankfully there are things you can do to improve your stability and decrease the likelihood of falling, and we'll share some helpful tips and advice below.

Causes of falls in people with Parkinson's

The most important first step to prevent falls is to identify the cause or causes of the falls. It may seem that everyone living with Parkinson's falls for the same reason, but in fact, there are multiple factors that need to be assessed.

- *Postural instability* – this is often referred to as one of the four cardinal features of Parkinson's (along with resting tremor, bradykinesia or slowness of movements, and rigidity or stiffness). Postural instability refers to the inability to right oneself after being thrown off balance. It is typically tested in the doctor's office when the neurologist tugs backward on your shoulders to see if you are able to prevent yourself from falling. A person living with Parkinson's with postural instability may fall if they are jostled. This symptom is not typically present early in the disease and tends to develop as the disease progresses.
- *Freezing of gait* – This is an abnormal gait pattern that can accompany Parkinson's in which you experience sudden, short, and temporary episodes during which you cannot move your feet forward despite the intention to walk. In a sense, you're stuck. This results in the characteristic appearance of the feet making quick-stepping movements in place. However, while the feet remain in place, the torso still has forward momentum which makes falls common in the context of freezing of gait.

- *Festinating gait* – this is another abnormal pattern of walking that can occur in some people living with Parkinson's. In this gait, the person takes short steps which get smaller and faster, until it looks like they are almost running. The person may not be able to stop this pattern of walking and may end up hitting up against barriers in order to stop. Festination can lead to falls.
- *Dyskinesias* – These are extra, involuntary movements that occur in some people as a side effect of Levodopa ingestion. When severe, dyskinesias can throw a person off-balance and cause falls.
- *Visuospatial dysfunction* – One of the typical cognitive challenges that can affect people living with Parkinson's is deficits in visuospatial thinking. Deficits in this cognitive area lead to an inability to navigate oneself in three dimensions. A person may have difficulty manoeuvring around obstacles in a room or backing up to sit down in a chair. This difficulty can also lead to falls.
- *Orthostatic hypotension* – A common non-motor feature of Parkinson's is drops in blood pressure upon changing head position. This can lead to dizziness and even passing out, which can be interpreted by the bystander as a fall.
- *Posture problems* – Parkinson's can be associated with stooped or tilted posture which can contribute to imbalance.

Falls prevention

Understanding which factors are contributing to falls is important since each is treated in a different way:

- Postural instability may be responsive to increases in Parkinson's medications.

- Sometimes episodes of freezing of gait and gait festination can be reduced with increases in medication as well.
- Botherome dyskinesias can be treated by adjusting Parkinson's medications.
- A number of strategies can be used to manage orthostatic hypotension including increased fluids and dietary salt as well as compression stockings. If necessary, medications to increase blood pressure can also be considered.

Another important step in falls prevention – which is necessary to consider whatever the cause of falls – is modification of the home environment, such as:

- Remove rugs and potential obstacles.
- Install grab bars in key areas in which falls are more likely, such as the bathroom.
- Choose the right shoes for you. Some people like rubber soles and some do better with leather soles. Check that shoes are not loose-fitting and provide support. Wear shoes with a slight heel to reduce falling in the backward direction, but no high heels.
- Wear a medical alert bracelet or pendant in case a fall does occur.

A very important part of managing someone who tends to fall, which is often overlooked, is assessing *bone density*. If thinning of the bones or osteoporosis is detected, medications can be prescribed to improve this, which can prevent a fracture should a fall occur. Your GP can arrange for bone density testing, which is done via a quick and painless x-ray scan.

More Ways to Help Manage Balance

Physical therapy

Once medications are optimised and the home environment is as safe as possible, the next step in the treatment of falls in Parkinson's is a comprehensive rehabilitative assessment by a trained physical therapist.

A physical therapist will then design a program that can address postural instability, freezing of gait, festination of gait, visuospatial dysfunction, and problems with posture, depending on the active problems that are identified.

Assistive devices

Sometimes, the balance is affected to the point that an assistive device for walking becomes necessary.

The use of a cane is often discouraged by physical therapists who are experienced with Parkinson's. With only one side of the body using the cane, this creates an additional imbalance that is not present when using a walker. In addition, the cane itself can get caught up in furniture or other obstacles and contribute to falls.

Because of these concerns, walkers are often suggested as the assistive device of choice for people living with Parkinson's. There are many types of walkers that are available for people with walking difficulties:

- Basic walker – this is usually just a metal frame without wheels
- Wheeled walker – a metal frame with wheels. The wheels may be on two or four legs and the wheels may swivel or be fixed
- Rollator – a walker with swivel wheels on all four legs and hand brakes. The brakes typically need to be engaged for the walker to stop. Often the rollator has a seat and a basket for convenience.

- U-step walker – designed specifically with the concerns of people with PD in mind, particularly freezing of gait. The U-step walker has a reverse braking system which means that without engaging anything, the walker is in the braked position and the wheels will not turn. A lever must be gripped or pressed in order for the wheels to turn. Therefore, if freezing of gait occurs, the walker should stay stable.

Your physical therapist can help you determine the walking aid that is best suited for your specific situation.

Should I be using a walker?

This is a critical question that many people living with Parkinson's grapple with and is best answered for each individual by their neurologist or physical therapist.

People are often concerned that that if they start to use a walker, they may become 'dependent' on it, and they won't be able to walk without one in the future. If your balance is impaired and falling is a concern for you, talk with your neurologist about the potential steps that could improve your situation and prevent falls.

If all adjustments have been made and poor balance is still present, the reality is that it will likely remain that way and will not be worsened or perpetuated unnecessarily by the use of a walker.

At that point, a walker becomes essential for you to maintain your independence. Embracing its use is the best way to maximise your quality of life.

Taming Parkinson's Disease with Intelligent Brain Pacemakers

Two new studies from University of California (UC) San Francisco are pointing the way toward round-the-clock personalised care for people living with Parkinson's disease through an implanted device that can treat movement problems during the day and insomnia at night.

The approach – called adaptive Deep Brain Stimulation, or aDBS – uses methods derived from Artificial Intelligence (AI) to monitor a patient's brain activity for changes in symptoms.

When it spots them, it intervenes with precisely calibrated pulses of electricity. The therapy complements the medications that Parkinson's patients take to manage their symptoms, giving less stimulation when the drug is active (to ward off excess movements) and more stimulation as the drug wears off (to prevent stiffness).

It is the first time a so-called 'closed loop' brain implant technology has been shown to work in Parkinson's patients as they go about their daily lives. The device picks up brain signals to create a continuous feedback mechanism that can curtail symptoms as they arise. Users can switch out of the adaptive mode or turn the treatment off entirely with a hand-held device.

For the first study, researchers conducted a clinical trial with four people to test how well the approach worked during the day, comparing it to an earlier brain implant DBS technology known as constant or cDBS.

To ensure the treatment provided the maximum relief to each participant, the researchers asked them to identify their most bothersome symptom. The new technology reduced them by 50%.

The future of Deep Brain Stimulation

"This is the future of Deep Brain Stimulation for Parkinson's disease," said Philip Starr, MD, PhD, the Dolores Cakebread Professor of Neurological Surgery and Co-Director of the UC San Francisco Movement Disorders and Neuromodulation Clinic and one of the senior authors of the study.

Starr has been laying the groundwork for this technology for more than a decade. In 2013, he developed a way to detect and then record the abnormal brain rhythms associated with Parkinson's. In 2021, his team identified specific patterns in those brain rhythms that correspond to motor symptoms.

"There's been a great deal of interest in improving DBS therapy by making it adaptive and self-regulating, but it's only been recently that the right tools and methods have been available to allow people to use this long-term in their homes," said Starr.

Earlier this year, UC San Francisco researchers led by Simon Little, MBBS, PhD, demonstrated that adaptive DBS has the potential to alleviate the insomnia that plagues many patients with Parkinson's.

"The big shift we've made with adaptive DBS is that we're able to detect, in real time, where a patient is on the symptom spectrum and match it with the exact amount of stimulation they need," said Little, Associate Professor of Neurology and a senior author of both studies.

Restoring movement

Parkinson's disease affects about 10 million people around the world. It arises from the loss of dopamine-producing neurons in deep regions of the brain that are responsible for controlling movement. The lack of those cells can also cause non-motor symptoms, affecting mood, motivation, and sleep.

Treatment usually begins with levodopa, a drug that replaces the dopamine these cells are no longer able to make. However, excess dopamine in the brain as the drug takes effect can cause uncontrolled movements, called dyskinesia. As the medication wears off, tremor and stiffness set in again.

Some patients then opt to have a standard cDBS device implanted, which provides a constant level of electrical stimulation. Constant DBS may reduce the amount of medication needed and partially reduce swings in symptoms. But the device also can over- or under-compensate, causing symptoms to veer from one extreme to the other during the day.

Closing the loop

To develop a DBS system that could adapt to a person's changing dopamine levels, Starr and Little needed to make the DBS capable of recognising the brain signals that accompany different symptoms.

Previous research had identified patterns of brain activity related to those symptoms in the subthalamic nucleus, or STN, the deep brain region that coordinates movement. This is the same area that cDBS stimulates, and Starr suspected that stimulation would mute the signals they needed to pick up.

So, he found alternative signals in a different region of the brain, called the motor cortex, that wouldn't be weakened by the DBS stimulation.

The next challenge was to work out how to develop a system that could use these dynamic signals to control DBS in an environment outside the lab.

Building on findings from adaptive DBS studies that he had run at Oxford University a decade earlier, Little worked with Starr and the team to develop an approach for detecting these highly variable signals across different medication and stimulation levels.

A better night's sleep

Continuous DBS is aimed at mitigating daytime movement symptoms and doesn't usually alleviate insomnia.

But in the last decade, there has been a growing recognition of the impact that insomnia, mood disorders and memory problems have on Parkinson's patients. To help fill that gap, Little conducted a separate trial that included four patients with Parkinson's and one patient with dystonia, a related movement disorder.

In their paper published in *Nature Communications*, first author Fahim Anjum, PhD, a postdoctoral scholar in the Department of Neurology at UC San Francisco, demonstrated that the device could recognise brain activity associated with various states of sleep. He also showed it could recognise other patterns that indicate a person is likely to wake up in the middle of the night.

Little and Starr's research teams have started testing new algorithms to help people sleep.

Scientists are now developing similar closed-loop DBS treatments for a range of neurological disorders.

“We see that it has a profound impact on patients, with potential not just in Parkinson's but probably for psychiatric conditions like depression and obsessive-compulsive disorder as well,” Starr said. “We're at the beginning of a new era of neurostimulation therapies.”

Sources

Original article by [Robin Marks](#)
[University of California San Francisco](#)

Partnering through Parkinson's: Louisa and Frank Feltracco

Frank Feltracco, now 77, arrived in Griffith from Italy with his family as a three-year-old, while his wife, Louisa, 73, was born in the town.

Frank and Louisa married in 1970 in the little village of Yoogali outside Griffith and have lived in the area all their lives. Louisa now leads the Griffith Parkinson's Support Group while Frank still works part time driving a bus for a local aged-care centre.

Back in 2008, Frank, who then worked for a winery, had started to be troubled by a tremor in his left hand.

"He was finding that it was shaking, and he was losing strength when doing woodwork and things," recalls Louisa. "He went to the doctor to get it checked out, but she didn't take too much notice and said it was essential tremor.

"However, it was slowly getting worse, and Frank was becoming more anxious. Eventually I checked 'Dr Google', and the more I read, the more I thought it was Parkinson's."

In 2012, Louisa accompanied Frank back to see their doctor.

"I said that it was getting to Frank and he was always getting cranky with himself, and that I was thinking it was Parkinson's," explains Louisa. "The doctor said yes, and that he needed to see a neurologist."

After discovering that there was a six-month wait to see their nearest neurologist in Wagga, Louisa managed to get an appointment in a couple of weeks in Albury.

"The doctor told Frank straight away he had Parkinson's," says Louisa. "He put him on medication for the tremor and we stayed with this neurologist until we heard a talk in Griffith by a Sydney-based professor and changed to seeing him from 2016."

Louisa and Frank first heard about Parkinson's seminars early 2012 when friends told them about one taking place in Wodonga, Victoria, which they all attended.

“We learned a lot there,” says Louisa. “A lady there had been through Deep Brain Stimulation surgery and was a great speaker. She showed us videos of how she was before and after. I thought that at least Frank wasn’t that bad.

“In 2013 we’d go to occasional seminars at Wagga which is where I got to know Kate, the local Parkinson’s nurse.

“A couple of years after attending Griffith Support Group meetings, Kate and another woman who was running yoga programs asked me to take over the Support Group. I became the leader and coordinator and later exercise supervisor. We have meetings once a month, alternating meetings with carers’ meetings.

“It’s very important for carers to take time out for themselves and be able to get support as well through meeting up with other carers who know what it’s like.

“We also have a special, gentle sitting-and-standing balance exercises group meeting fortnightly and on the alternate fortnight we have cardio at a gym. The exercise classes are very social with laughter and funny comments to egg each other on, with lunch a must afterwards.

“I organise guest speakers for our meetings too. There are a lot of people with Parkinson’s in the Griffith area. We send out emails and post mail about the meetings. While not everyone comes along, at least they know there are meetings if they want to come sometimes.”

Because Frank’s Parkinson’s has not progressed much and his medications still manage his symptoms, he is able to also continue a busy social life with Louisa.

“We go dancing once a week and bingo once a week,” says Louisa. “We go out for dinner sometimes with people and out for morning coffee and other things.

“Frank walks a bit slower now but mind-wise he’s very good. He enjoys doing the bus run once a fortnight, getting out and meeting different people. At home he does gardening and work outside.

“Frank also keeps his mind active every day by doing Sudoku in books and also word fit puzzles, which he found in the *Daily Telegraph*.”

Louisa puts a lot of time and energy into running the local Support Group and says her experiences early on with other groups gave her both information and encouragement.

“Frank has never been one to sit at home and think ‘poor me’; I really like to encourage other people not to sit back either,” she says.

“The way to deal with Parkinson’s is not to stress out – but take medication on time, exercise daily, socialise and take each day as it comes. If you have a problem, there is always an answer how to deal with it. I’ve always been one to read further on anything, and there is lots of information there if you need it.

“Support from family and friends is very important to us. We have a son and daughter who are both married, and we have four grandchildren. We have Saturday night dinners at our place with them all and they are very supportive in everything we

A monthly review of the top five issues raised in calls to the Parkinson's NSW InfoLine team.

The InfoLine (call 1800 644 189) is the single point of contact for people living with Parkinson's, care partners, health professionals, and family members who require evidence-based advice, information, and connection with essential services.

This service gives you easy access to experienced Registered Nurses, an Allied Health professional with 20 years of prior experience in community pharmacy, counsellors, a qualified social worker, a specialised NDIS Advocate, connections to Support Groups and access to education seminars – all free of charge to the consumer.

1. Carer Stress

The holiday season can increase stress for carers, making it vital to prioritize self-care and seek support. Engaging with carer support groups, talking to a counsellor, or using respite care services can help to alleviate the pressure.

Tips to manage carer stress can be found on our website:

www.parkinsonsnsw.org.au/tips-for-managing-carer-stress/

2. Diet and Nutrition

A well-balanced diet can aid in managing Parkinson's symptoms – including energy levels, digestion, and medication effectiveness. For tailored advice, consulting a dietitian experienced in Parkinson's is highly recommended. Our InfoLine also has a nutrition guide that we can supply as a starting point.

Diets to boost the body against Parkinson's can be found on our website: www.parkinsonsnsw.org.au/diets-boost-body-against-parkinsons/

3. MRI-Guided Focused Ultrasound Treatment

This emerging treatment uses advanced imaging to target areas of the brain, offering potential benefits for managing certain symptoms of Parkinson's. For more information on eligibility and availability, consult with a neurologist or Parkinson's specialist.

4. Hallucinations

Hallucinations can be linked to medication or disease progression. To address this, it's important to speak with your Movement Disorder Neurologist or a Parkinson's nurse who can assess medications and suggest strategies for management.

Information on Hallucinations can be found on our website:

www.parkinsonsnsw.org.au/hallucinations-in-parkinsons/

5. Falls

Falls are a major concern due to balance issues or freezing episodes. A physiotherapist with expertise in Parkinson's can assist with exercises to improve balance and mobility, while occupational therapists can advise on home modifications or aids to reduce risks.

Tips on preventing falls can be found on our website:

www.parkinsonsnsw.org.au/tips-on-preventing-falls/

HAVE A HAPPY AND SAFE CHRISTMAS & NEW YEAR!



Get in touch with us

InfoLine 1800 644 189 (9AM-5PM MON-FRI)

Email: pnsw@parkinsonsnsw.org.au

We are here for you

Parkinson's NSW is here to support, enable and advocate for and with people living with Parkinson's and their communities. We are here for you and your loved ones every step of the way!

We provide essential services and programs which include:

- Counselling
- A network of online and in-person Support Groups across the state
- An InfoLine which provides access to a Parkinson's Registered Nurse, pharmacist, counsellors, NDIS Advocacy and Support Groups
- Education and information programs
- Parkinson's Specialist Nurses in regional and rural areas of NSW

All our support services are provided at no charge, enabled by generous donations. Every donation makes a difference and if you can make a contribution, we thank you for your support.

Easy ways to donate have been listed over page...

To donate to our Christmas appeal you can securely donate online at:

www.pitchinforparkinsons.org.au/dani

Or phone us on 1800 644 189 during business hours
(note: our Xmas closing period is from 20 Dec until 6 January 2025)

