IN THIS TOGETHER
parkinson's
TASMANIA

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Subarus Crossing the Simpson Desert – Pressing on for Parkinson's

Following 18 months of planning and just over 4 weeks driving some 8,500 kms we have now returned back to Tassie.

Back to normality.

I am very pleased to confirm the trip was certainly very successful.

We set out to "Raise awareness of Parkinson's Tasmania" and we had a multitude of conversations with people. It still amazes me how often people would say a friend of mine has been advised they have been diagnosed with Parkinson's, or they have it.

We wanted to promote the function of Parkinson's Tasmania and the support services available. We also wanted to raise awareness of this debilitating disease. While exact records weren't recorded I estimate we spoke one on one, to in excess of 450 people.

I am very appreciative of the willingness of the Management Committee of Parkinson's Tasmania to support this program, in both word and action.

We met the wife of the man who cut in the track from Ceduna for some 250kms north, very sandy and very, very tough.

The team of ten had one member who became ill at Coober Pedy and needed to be taken 686kms to Alice Springs so he could fly home to Melbourne unexpectedly due to health issues. Thankfully the team rallied together to ensure we had enough members to share the driving amongst the members that were still participating.

We then proceeded on to Mt Dare at the western end of the Simpson desert. We confirmed the huge extent of flooding towards the eastern end and the depth of one of the creeks was in excess of 700mm.

Way too deep for small petrol driven cars. We had to change plans and leave crossing the Simpson to another year.

We altered the route home and visited Oodnadatta, William Creek and spent a couple of days at Farina, looking at the ruins and the under-ground bakery. As is always the way with trips like this, some very strong friendships have been fostered and developed.

I am pleased to report that cash donations are still coming in and we have not only raised awareness of this disease but also raised in excess of $20,000.00

A truly remarkable month on the road.

Malcolm McGinn

from the

NURSES DESK

The ABCs of FOG

What is FOG?

Freezing Of Gait – or FOG – in relation to people with Parkinson's disease refers to "a brief, episodic absence or marked reduction of forward progression of the feet despite the intention to walk" (Gao, 2020). About half of people living with Parkinson's experience FOG at some point.

Most people who experience FOG report that their legs don't stop moving completely. Rather you may experience trembling in place, shuffling forward or rapid weight transfer between legs when attempting to force forward movement. You might feel like you're trying to move though mud, have your feet stuck in place, or like someone has pushed the pause button on your legs.

Typically, episodes of FOG are brief, lasting a few seconds, however people living with FOG may find it frustrating or embarrassing. It also impacts daily life, increasing falls risks and near misses.

Common experiences people experiencing FOG include;

- **Sudden immobility** – feel like feet are "glued", "stuck" to the floor making it impossible to take a step.
- **Fear of falling** – FOG is unpredictable increasing risk of falls
- **Frustration and loss of independence** – impacts ability to perform activities of daily life and maintain independence.
- Impacts on ability to go shopping, see friends or walk around home.
- **Emotional impact:** FOG may lead to anxiety, depression and social isolation.
- **Medication effects:**
- FOG may occur more often during medication "OFF" or wearing off periods

People living with FOG report episodes occur more often when:

- **Initiating Movement** – going sit to standing or standing to walking
- **Walking through a doorway** or narrowing
- **Turning a corner** or around
- **Environmental Factors** – changed floor patterns or textures, cluttered spaces or obstacles
- Experiencing a **stressful** situation or anxiety
- Attempting to **multitask** or dual task

What causes FOG?
Walking is complicated!

Locomotion involves several areas of the brain and the exact cause of FOG is still being researched. Our current understanding is that FOG is caused due to a breakdown in brain circuitry. The wiring or communication between several areas of the brain involved in movement initiation, balance, processing and feedback.

The areas of the brain thought to be involved in FOG are the:

- Cerebral cortex - which plans and initiates movement;
- Basal ganglia - (where the dopaminergic neurons live) responsible for fine tuning and exerting control over movement;
- Brainstem responsible for movement refinement and wakefulness; and
- Cerebellum which receives sensory feedback from the body.

There are several studies currently in the research phase and not yet available for clinical use. Such as a neuro-rehabilitation program, known as *StandingTall-PD* involves "rewiring" parts of the brain involved in walking control via audio, visual and haptic sensory cues. Also, an ADHD medication atomoxetine which has been shown to reduce "cross-talk" which occurs during a FOG episode.

Since FOG involves several parts of the brain one could call it complicated, therefore techniques to respond to FOG require a personalised and multi-pronged approach.

How to help FOG

In general, the best advice is don't fight the FOG – work around it! Different techniques work for different people. Experiment with techniques to find which help you the most. Work with a physio and OT with experience in Parkinson's to tailor techniques to suit you the best.

Some suggestions for overcoming episodes of FOG are:

- **Use music to provide a rhythm to step in time** with,
- Use your phone to play music in your pocket
- Try humming, singing or counting; out loud or in your head
- **Try another movement** rather than trying to force your legs forward:
- Move or **lift an arm** or hand if your legs are "stuck"
- **Shift the weight of your body** from one leg to the other. Then exaggerate a large shift to one side while you step with the other foot.
- **March or goose step** (swing your leg high and parallel to the ground with knees locked).
- Use a visual cue – **imagine a line to step** over or use a laser pointer to create a line to step over
- Use verbal cues – try **counting** out loud or inside your head "123, GO!"
- Take up space – **Turn by walking in a semi-circle** or square rather than pivoting
- **Try the 4 S strategy: STOP, SIGH, SHIFT, STEP.** When you feel an episode of freezing starting try to **STOP** your movements, **SIGH** and take an audible breath, **SHIFT** your weight back and forth, and finally take an exaggerated first **STEP** to resume walking.

The best thing you can do to help your FOG is to develop a personalised rehabilitation/ treatment programme and team.

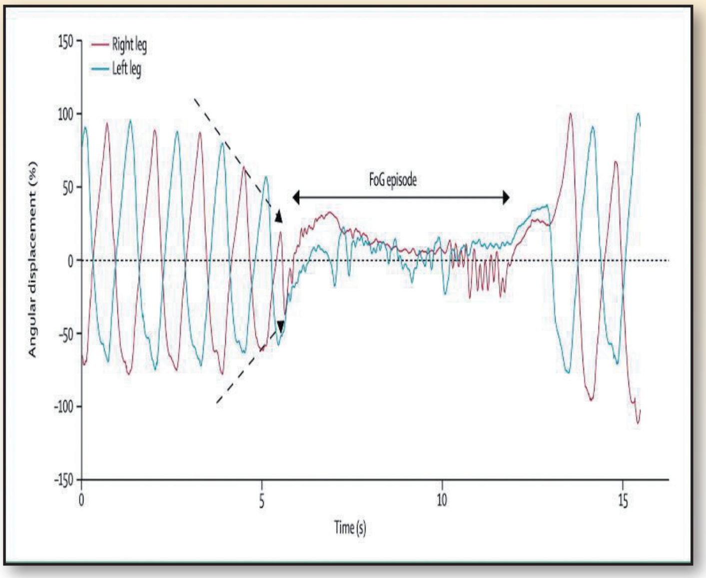
Your team may include a physiotherapist, occupational therapist, exercise physiologist, PD nurse, psychiatrist, specialists, or support groups. They can educate you and your support network about your FOG symptoms and discuss treatment options. Treatment options apart from medication include:

- Gait training on a treadmill which will improve walking patterns aiming to reduce FOG
- Robotic-assisted walking
- Dual task training
- Mind-body exercise such as dance, Tai Chi, yoga, or Pilates.
- General stretching, resistance and balance training to build leg and core strength to improve stability and confidence when walking.
- Cognitive training to improve mental strategies for overcoming FOG

Freezing of gait can be difficult and impact on your daily life, but you have choice in working to overcome it!

Article from Parkinson's Nurses South

Illustration of FoG in a patient with Parkinson's



Physical Therapy – A Fairness Factor

By Dunlap-Shohl, N/W Parkinson's Foundation

Physical therapy can be many things, tiresome, taxing, tedious, terrifying, and time consuming, to name just a few—Terrific and toughening, to name a few more. But it is also something else, something you wouldn't expect. It is, unlike so many aspects of Parkinson's, fair.

Much of Parkinson's Disease is galling in its indifference to basic fairness: the falling, the drooling, the freezing gait, the sleep problems, the choking, the constipation, the dystonic spasms— should I go on? What's more, any one of these common Parkinson's complaints would be considered a disease in its own right, but with Parkinson's they are reduced to mere symptoms, hinting at the forbidding bigger picture. At best, they help define the problem. At worst they are an unruly group of thugs ready to gang up on you without provocation or warning. Unfair!

Physical therapy can address some of these PD complaints and the outcome of that therapy depends on what you put into the effort every day. This is where the fairness of physical therapy comes in. If you decide that you're going to coast, the only one it hurts is you. If you elect to skip a day, you will pay for it by losing a day's progress. No arguments, no appeals. No referee to enforce the rules. It's all on you.

The flip side? If you are faithful to the routine, you can influence the severity of some symptoms and maintain a less problematic day-to-day existence, a better quality of life. You will be rewarded over the long run with a postponement and/or reduction of the mayhem those symptoms can wreak.

That reward can take different forms. It may be the restoration of your ability to walk without freezing, or perhaps a reduction in falling episodes. Or it may be the taming of pain brought on by Parkinson's-impaired posture, or bad ergonomic practices.

It depends on the particular form your case of PD takes. Your physical therapist is there to custom design a program of exercises to address your particular constellation of symptoms. The therapist serves as your coach or personal trainer, demonstrating the exercises and looking over your shoulder, judging and correcting your performance. They will keep notes and track your progress or lack of it, but they are not able to do the hard part. Only you can follow through on the commitment to a therapy regime. This is not that easy.

Our natural inclination to avoid exercise is compounded by a body that is stiff and slow, a body that needs to move, but rebels at that need. Still, progress will be proportional to how faithful you are to executing the program despite the inclination to take the easier route.

There are compensations. By accepting the responsibility to commit to the program designed by your therapist, you reject the role of helpless victim. Instead, you do what you can to have a positive impact on your disease. In addition to the softening of your symptoms, you can get a good feeling for standing up to that bully, PD.

The downside? The sweat equity and consistent discipline you must put into the effort. And that seems fair, you do the hard work, you reap the reward.

This is a rare opportunity in Parkinson's Land, where much of the disease process is beyond anyone's control. Physical therapy gives you traction on the muddy fields and steep climbs of your path through Parkinson's Disease. It will enable you to stand up straighter, metaphorically and actually.

Weekly injection could be life changing for Parkinson’s patients

14 July 2025

UniSA PhD candidate Deepa Nakmode and Professor Sanjay Garg in the lab.

A new weekly injectable drug could transform the lives of more than eight million people living with Parkinson’s disease, potentially replacing the need for multiple daily tablets.

Scientists from the University of South Australia (UniSA) have developed a long-acting injectable formulation that delivers a steady dose of levodopa and carbidopa – two key medications for Parkinson’s – over an entire week.

Their findings have been reported in the journal Drug Delivery and Translational Research.

The biodegradable formulation is injected under the skin or into muscle tissue, where it gradually releases the medication over seven days.

Currently the symptoms – tremors, rigidity and slow movement – are managed with oral medications that must be taken several times a day.

The frequent dosing is a burden, especially for elderly patients or those with swallowing difficulties, leading to inconsistent medication levels, more side effects, and reduced effectiveness.

Lead researcher Professor Sanjay Garg, from UniSA’s Centre for Pharmaceutical Innovation, says the newly developed injectable could significantly improve treatment outcomes and patient adherence.

“Our goal was to create a formulation that simplifies treatment, improves patient compliance, and maintains consistent therapeutic levels of medication. This weekly injection could be a game-changer for Parkinson’s care,” Prof Garg says.

“Levodopa is the gold-standard therapy for Parkinson’s, but its short life span means it must be taken several times a day.”

UniSA PhD student Deepa Nakmode says the in-situ implant is designed to release both levodopa and carbidopa steadily over one week, maintaining consistent plasma levels and reducing the risks associated with fluctuating drug concentrations.

“After years of focused research, it’s incredibly rewarding to see our innovation in long-acting injectables for Parkinson’s disease reach this stage. Our invention has now been filed for an Australian patent,” Nakmode says.

The formulation can be easily administered through a fine 22-gauge needle, minimising discomfort and eliminating the need for surgical implant.

“The implications of this research are profound,” Prof Garg says. “By reducing the frequency of dosing from multiple times a day to a weekly injection is a major step forward in Parkinson’s therapy. We’re not just improving how the drug is delivered; we’re improving patients’ lives.”

UniSA scientists hope to start clinical trials in the near future and are exploring commercialisation opportunities.

The study, titled “Development of an in-situ forming implant system for levodopa and carbidopa for the treatment of Parkinson’s disease,” is authored by Professor Sanjay Garg, Deepa Nakmode, Dr Sadik Abdella and Dr Yunmei Song. DOI: 10.1007/s13346-025-01892-y

Diet & Nutrition

(Parkinson's Foundation) Studies show that making targeted nutrition the mainstay of your meals may slow Parkinson's disease (PD) advancement. Eating a whole-food, plant-based diet has many benefits.

While there is no prescription for a PD-specific diet, one that includes a variety of whole grains, vegetables, fruits and protein-rich foods can improve health. Also consider including nuts, olive oil, fish and eggs to your diet, for their beneficial fats.

Maintain Health

Avoid "fad" diets. Eat food from all food groups.

Eating a variety of foods will help you get the energy, protein, vitamins, minerals and fiber you need for good health.

Ease PD Symptoms

The right foods will also optimize your medications, keep your bones strong, fight constipation and weight loss and maintain general health and fitness.

Challenges

Diet and Parkinson's medications can impact each other. Carbidopa/levodopa medications work best on an empty stomach. However, some people experience nausea as a side effect of these medications, and taking them on an empty stomach may not be their best option.

For some, taking certain PD medications close to a protein-rich meal — like meat, fish, eggs, dairy products, nuts and beans — may interfere with the absorption of the drug in the blood, causing it to work more slowly or less effectively. Talk to your doctor about the right option for you, such as taking the drug on an empty stomach or with a small snack, such as crackers or apple sauce.

Tips for Getting Started

Changing your diet can be difficult. Try making one change at a time, like eating a handful of nuts a few times a week or avoiding white bread. Small changes can add up to big benefits.

Consult with a registered dietician, who can help you plan menus and make shopping lists for preparing nutritious meals that you like and that account for your individual needs and the timing of your medications.

An occupational therapist can help you explore assistive devices to make eating and drinking easier.

If you experience anxiety or depression, talk to your doctor. These symptoms can suppress appetite.

If swallowing issues are causing problems eating, a speech pathologist may be able to help.

Salmon Recipe for a Parkinson's-Friendly Diet

July 2025

Kathrynne Holden, former National Parkinson Foundation dietitian says, "I love this easy-to-chew recipe because it features salmon, a valuable source of heart-protective fats, as well as excellent protein.

The vegetables make it almost a one-pot meal, while the creamy sauce mixed with the baked potato makes each bite much easier to swallow.

Ingredients

350ml milk or milk alternative
230g thinly sliced carrots, cooked and drained
230g canned salmon, drained
90g grated Cheddar cheese or vegan cheese
4 tbsp minced onion
4 tbsp minced bell peppers
2 tbsp unsalted butter
1 1/2 tbsp whole wheat flour
1/4 teaspoon garlic powder
1/8 teaspoon ground thyme
ground marjoram
pre-baked potatoes

Method

In a medium-sized saucepan, sauté the onion and bell peppers in butter for five minutes or until vegetables are tender.

Combine the flour, garlic powder, thyme and marjoram. Stir into onion mixture. Heat and stir for one or two minutes.

Remove from heat. Slowly stir in the milk.

Return to heat and stir until the sauce becomes thickened and reaches the boil.

Stir in the cheese, cooked carrots and salmon and heat through.

Split the baked potatoes and fluff the insides with a fork. Discard the potato skins.

Spoon the salmon mixture over potatoes and stir lightly to blend with and moisten the potato.

St Andrew's War Memorial Hospital implants the smallest rechargeable, remotely programmable deep brain stimulator in an Australian first

(Extract - 26th June 2025)

St Andrew's neurologist, Professor Peter Silburn, and neurosurgeon, Dr Terry Coyne, have become the first team in the Asia Pacific region to implant the latest deep brain stimulation (DBS) technology which enables patients to access care remotely from anywhere in the world.

The system's NeuroSphere™ Digital Care platform allows clinicians to adjust therapy settings remotely and push software updates directly to the implanted device.

The bring-your-own-device model also means patients do not need to carry a separate programmer or go into the clinic for every adjustment.

Professor Peter Silburn said this about giving patients more freedom, control, and peace of mind. "For people with Parkinson's, movement disorders and other neurological disorders, it's life-changing to know their therapy can be managed from home or even while travelling overseas," Professor Silburn said.

"This isn't just a smaller device, it's a smarter system designed for the next decade of care."

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Dates to Remember

SUPPORT GROUP MEETINGS

SOUTH
2.00pm Senior Citizens Club Rooms
Lambert Ave., Sandy Bay
27th August, 24th September, 29th October 2025

NORTH
2.00pm Launceston Conference Centre,
Door of Hope Church, 50 Glen Dhu St., Launceston
9th September, 14th October, 11th November 2025

NORTH WEST
2.00pm Gnomon Pavilion, 3 Wharf Road, Ulverstone
10th September, 8th October, 12th November 2025

CARERS GET-TOGETHER

SOUTH
10.00am 12 Adelie Place, Kingston
18th September, 20th November 2025

NORTH
2.00pm Launceston Conference Centre,
Door of Hope Church, 50 Glen Dhu St.,
Launceston
12th September, 5th December 2025

NORTH WEST
2.00pm Willaway Apartments,
2 Tucker Street Ulverstone
11th September, 4th December 2025

Disclaimer

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Nor is it to be construed that other material on any of the subject matter is unavailable.
Further, Parkinson's Tas. takes no responsibility for the persons who may rely on this information for whatever purpose.
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Contact Details

Mike Whitehouse President
42 Auburn Road, Kingston, TAS 7050
Mobile: 0448 710 882
Email: mike.whitehouse@bigpond.com

Pauline Domeney Secretary/Treasurer
12 Adelie Place, Kingston, TAS 7050
Phone: (03) 6229 2509 Mobile: 0407 314 933
Email: pdomeney@netspace.net.au

Business Address
PO BOX 608, Kingston, Tasmania 7051