



**From the
President
– Mike Whitehouse**



In the May 2024 Parkinson's Journal, detailed the need for additional Parkinson's nurses to support the existing nurses who are experiencing overwork and burnout, particularly in the Southern Region. Already, a highly experienced nurse has resigned.

A recent face to face meeting between the Minister for Health, Guy Barnett, and Dr Harley Stanton discussed, inter alia, the current staffing being extremely fragile. Staff in the south are unable to provide people living with Parkinson's, the educative and more preventative support designed to maintain function and reduce complications. In many cases this will lead to acute hospital and nursing home admissions. This must be avoided. The failure of service delivery will only see a massive increase in costs for both state and federal governments.

Parkinson's Tasmania calls upon the Minister for Health to intervene and create two new full time permanent positions in the Southern Region to enable those living with Parkinson's to remain in their own homes.

**New Blood Test for Parkinson's Could
Detect It Years Before Symptoms Appear**

Researchers have developed an AI-assisted blood test for Parkinson's which could predict the condition seven years before symptoms begin. (21 June 2024 By Laura Vickers-Green)



Researchers have developed a simple blood test for identifying Parkinson's which could predict the condition seven years before symptoms begin.

Using machine learning – a form of AI (artificial intelligence) – researchers from University College London in the UK and University Medical Centre in Goettingen, Sweden, screened blood samples from 99 people with Parkinson's and 36 people without the condition, and this led them to identify eight key proteins or "biomarkers" common to those with the condition.

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The team then analysed blood samples taken a decade ago from 72 people with a sleep condition called Rapid Eye Movement Disorder, who are known to be at higher risk of developing Parkinson's. By identifying the presence of these eight proteins, the AI tool has so far been able to correctly predict which of these people would go on to develop Parkinson's – in some cases, up to seven years before their symptoms began.

What could a blood test for Parkinson's mean for the Parkinson's community?

One of the lead researchers, Professor Kevin Mills, explains:

"As new therapies become available to treat Parkinson's, we need to diagnose patients before they have developed the symptoms. We cannot regrow our brain cells and therefore we need to protect those that we have.

"At present we are shutting the stable door after the horse has bolted and we need to start experimental treatments before patients develop symptoms. Therefore, we set out to use state-of-the-art technology to find new and better biomarkers for Parkinson's and develop them into a test."

Dr Michale Bartl at UMC Goettingen in Sweden added: "By determining eight proteins in the blood, we can identify potential Parkinson's patients several years in advance," said "This means that drug therapies could potentially be given at an earlier stage, which could possibly slow down disease progression or even prevent it from occurring."

What are the next steps for this research?

Larger trials are now needed to validate this blood tests' accuracy for predicting Parkinson's, and develop a version that could be easily used in a clinic. Prof Michele Vendruscolo from the University of Cambridge has said the blood test for Parkinson's could be performed with equipment already in major hospitals, and Kevin Mills is hopeful that this might even be possible within two years. This would replace the invasive lumbar puncture that is currently used to diagnose Parkinson's.

How Does Diet Affect Parkinson's?



Richelle Flanagan has been a registered dietitian for the past 19 years, is a wife and mum to two children and has lived with YOPD for six years. Her lived experience has led her to develop My Moves Matter, a digital self-care companion tailored to support and empower women to live well with Parkinson's. Here she gives advice on what kinds of diet plans people with Parkinson's should follow.

How important is diet for people with Parkinson's?

I think it's totally underutilised as a way of helping people with Parkinson's (PwPs). That is from the perspective of both being a dietitian and living with the disease and doing the research myself. I think in some cases people may be being escalated up with Parkinson's medications before looking at how their symptoms may be improved by certain lifestyle aspects as they do for other chronic diseases.

I have never worked with a chronic disease where diet and nutrition play such a fundamental role regardless of age, gender, ethnicity and Parkinson's stage. However, we need more research to investigate the effect of diet and nutrition on Parkinson's in areas such as malnutrition, post-DBS weight gain, bone health, medication influences, executive function, cognition, bowel function and so much more. Diet in Parkinson's is totally under-researched in comparison to other chronic disease areas such as cardiology, cancer and diabetes.

What Sort of Diet Should a PwP Follow? Can It Slow Progression?

The evidence is beginning to build for the benefit of diet and nutrition not only in helping to manage

and reduce Parkinson's symptoms, but also in potentially slowing progression. Research papers have assessed diet quality in terms of the Mediterranean diet, of which there are several regional variations, including the Greek Mediterranean diet and the MIND – Mediterranean in neurodegenerative delay – diet.

These variations share fundamental characteristics, which are beneficial in the health of people living with Parkinson's. One key characteristic is the reduction of intake of less healthy foods such as highly processed, high-fat and sugar snacks and baked goods, sugary drinks, processed meals and processed meats high in saturated fat and salt.

Healthy patterns of the diet include eating a largely plant-based diet with plenty of unprocessed cereals, especially whole grains, fruits and vegetables, pulses, nuts, seeds, herbs and spices; olive oil as the main source of fat; moderate consumption of fish and seafood, poultry, eggs and dairy products such as yogurt and a low consumption of red meat. There is some evidence that the MIND diet may have more specific advantages for Parkinson's due to the additional focus on berries and green leafy vegetables.

A study in 2018 of older PwPs showed that the MIND diet may be associated with slower progression of the condition. The same authors also found that specific nutrients within the PwPs' diets were associated with slower progression. These include carotenoids, vitamin E and vitamin C, which are found in leafy greens and berries. A 2022 study suggests MIND and Mediterranean diets are associated with fewer patient-reported symptoms over time, with the MIND diet being twice as effective in reducing symptom severity.

There is limited but hopefully growing evidence that the Mediterranean diet may help to slow progression of Parkinson's. The question remains as to whether this is a direct or indirect result of the diet. For example, the high fibre content may improve Parkinson's symptoms by reducing constipation, which for many PwPs improves levodopa uptake into the brain and therefore

improves symptoms. Or does the diet indirectly improve symptoms by improving the balance of good and bad bacteria in the gut which we know plays a role in Parkinson's? Or is it the anti-inflammatory phytonutrients in fruit and vegetables that have an effect? There are so many constituents in foods that it is hard to identify which specific element is potentially beneficial. Research shows that it is the synergistic effect of the different elements of food that confers the benefit, i.e., the fibre and the phytonutrients acting together.

There is limited but hopefully growing evidence that the Mediterranean diet may help to slow progression of Parkinson's.

Are there any differences between diets that male and female PwPs should follow, or diets to follow at different ages?

One study showed that higher adherence to the MIND diet was significantly associated with developing Parkinson's at a later age, especially in women, with an almost 17.5-year difference between those women with the highest adherence to the diet versus the lowest. They found that the Greek Mediterranean diet was more effective than the MIND diet in men, with an almost 8.5-year difference between those men with the highest adherence versus the lowest. The effect size of the MIND diet in women was more than three times that of the men. The tendency for women to adhere more strongly to the MIND diet may have contributed to their lower rates of Parkinson's.

There are a couple of studies that suggest women with Parkinson's suffer from more food addiction issues. There is also some evidence indicating that women suffer from more weight loss particularly in the earlier stages of the disease and have higher levels of osteoporosis and higher fracture risk. What we lack is more sex- and gender-specific research on PwPs. Determining the subtle differences in the metabolic profiles of the different diets and their interplay with sex/gender may help to elucidate elements of what causes Parkinson's and how we might slow its progression.



To ensure we get a good night's sleep, the human body has an internal clock that regulates our sleep-wake cycle. Parkinson's symptoms can affect your sleep cycle in a variety of ways – but there are lots of things that can help.

Common Sleep Issues With Parkinson's – And Solutions

Pain, Stiffness And Involuntary Movements

Talk to your doctor about medication to ease stiffness, muscle cramping, night time rigidity, and restless leg syndrome if they are keeping you awake or disrupting your sleep. Massaging your legs, doing relaxation exercises, taking a bath before bedtime or applying hot and cold compresses might improve the symptoms of cramping and restless legs too.

Parkinson's Medication Not Working Properly

Drugs that alleviate Parkinson's symptoms can sometimes end up interfering with sleep – because they either wear off at the wrong time, or they have side effects that keep you awake. Discuss with your doctor what best suits you and your body, and whether any changes need to be made to your medication.

Nightmares, Sleepwalking And Other Sleep Disorders

Parasomnias are a group of sleep disorders that make it difficult to stay asleep, including the process of acting out your dreams, or thrashing around in bed. This can result in injury, so it's important to tell your doctor if you're experiencing

this. You should also make your sleep environment safer, for instance installing rails or padding to stop you falling out of bed, removing clutter in your room, or sleeping in a separate bed to your partner.

Anxiety

Sometimes changes in your brain chemistry can cause anxiety, which in turn can affect your sleep. Worries about your health can also affect your quality of sleep. Your doctor might prescribe antidepressants or refer you to a counsellor for Cognitive Behaviour Therapy (CBT) – talking about how you're feeling with friends and family may also help.

Frequent Urination

Regular night-time trips to the toilet can interrupt your sleep cycle. Some medications can cause this, as can eating salty foods or bladder infections. Your doctor might prescribe medicine to help or refer you to a continence specialist.

Insomnia

There are various causes for insomnia and not all are related to Parkinson's. So you may benefit from keeping a basic sleep diary for a short period of time to try and identify what is keeping you awake at what times of night. Your doctor may adjust your medication, or in some cases prescribe sleeping tablets as a short-term help, but these need to be managed carefully.

Daytime Sleepiness

Excessive daytime sleepiness and sleep attacks may cause you to fall asleep frequently during normal waking hours. This can sometimes be caused by Parkinson's medication, or because you're not getting enough sleep at night. You should try to stay awake during the day if possible as this improves the quality of night-time sleep. If you experience daytime sleepiness, take extra caution when driving, operating machinery or doing any other dangerous activities.

Turning Over In Bed

Lack of movement in bed caused by stiffness, muscle and/or joint pain can interrupt your

sleep. Speak with your doctor, as adjusting your medication might help you manage this. You could also try satin sheets or nightclothes to make movement in bed easier.

Sleep Apnea

Sleep apnea – when you stop breathing for a few seconds during sleep – occurs frequently in people with Parkinson’s and causes loud snoring or choking noises, which disturb sleep. If you wake with a headache, or if your bed partner notices any symptoms, you should speak to your doctor for a formal diagnosis and effective treatment. A machine called a PAP machine can be used to improve your breathing during the night.

How to Improve Your Sleep Environment

Just a few easy changes can help make your bedroom a more welcoming space for a good night’s sleep:

- Keep it calm, uncluttered and cooler at night. A lower temperature (16-18°C) promotes better sleep
- Do your best to sleep in total darkness (black-out blinds or curtains are good for this) but take care to have some kind of lighting should you need to get up in the night.
- Mattresses, pillows and sheets are a very personal choice – but try to buy the best-quality possible and experiment to find the style of mattress and pillow that you find most comfortable. One-way glide sheets help you move up the bed, but prevent you from also sliding down it.
- Ditch the screens! Computers, phones, tablets and televisions produce blue spectrum light, which affects your sleep quality. Avoid screens for at least an hour before bed.

Keep a notebook and pen by your bed – if worries are keeping you awake, write them down. This can help you “switch off” and get to sleep.

Lifestyle tips to improve sleep

There are various tip and tricks – from diet to daily routine – which can improve your sleep:

- **Routine**
Try to stick to a regular pattern of mealtimes, exercise and the time you go to bed and wake up. This will help your body clock get into the habit of sleeping.
- **Diet:** As well as regular mealtimes, following a well-balanced Mediterranean type diet has been shown to have therapeutic effects on sleep, and its lean meats and high-fibre foods will give you all the proteins, essential vitamins and minerals you need. Eat your last meal of the day at least a couple of hours before bed to give enough time to digest it.
- **Fluids:** Keep hydrated during the day, and try to limit caffeine drinks to the morning. And be cautious with alcohol: it might help you fall asleep, but studies show the quality of sleep is poorer. If you have bladder problems, try restricting your water intake an hour or so before bed to prevent you waking in the night.
- **Exercise**
Moderate to intensive exercise, on a regular basis, is thought to promote sleep and reduce daytime sleepiness – and stretching exercise can also reduce rigidity. Discuss what exercise level is right for you with your doctor.
- **Relaxation**
Allow time to unwind before bed and adopt a bedtime routine that encourages relaxation, such as having a warm bath or a massage, or listening to relaxing music.

Research - Tasmania Parkinson’s Project

The Tasmania Parkinson’s project aims to improve the lives of people with Parkinson’s through research and education.

To register: <https://parkinsons.utas.edu.au/>

What are 'off' periods – and how can they impact with Parkinson's disease?

Author: Sophie Parrott Published: 13 July 2023



What are 'off' periods, what causes them – and why is raising awareness of them so important? Dr Lazzaro di Biase and advanced nurse practitioner Brian Magennis share their insights

"Management of Parkinson's is really about symptom control," says Brian Magennis, an advanced nurse practitioner based at Mater Misericordiae Hospital in Dublin, Ireland. His deep knowledge of Parkinson's comes not only from his patients, but also his father, who lives with the condition.

As Brian explains, one way to control Parkinson's symptoms is through levodopa, a dopamine replacement agent considered by many to be a "gold standard" treatment for the condition. However, as the condition progresses, moments can occur when, despite medication, it becomes more difficult to manage both motor and non-motor symptoms. These moments are known as 'off' periods.

Dr Lazzaro di Biase, a neurologist and head of the movement disorders service at the Campus Bio-Medico University of Rome, Italy, refers to this 'off' state as a "hallmark of Parkinson's symptoms". It can come in several forms.

Describing one such form, known as wearing 'off', Lazzaro says: "The 'off' state can kick in when

levodopa is eliminated from our body – and people begin to express motor symptoms that are related to the low amount of dopamine going to the brain."

Other types include partial 'on' or dose failure: "Sometimes, a dose of medication may provide incomplete relief of symptoms people or fail to provide any symptom relief at all," Lazzaro explains.

Meanwhile, unpredictable 'off' episodes are the moments when people transition suddenly from 'on' to 'off' with no obvious link to medicine dosage timings. "These are often the most difficult to manage," says Lazzaro, "as they are not easily corrected by adjusting the medication schedule."

Another type is "delayed 'on' – which is when it takes longer for someone's medications to kick in", says Brian.

Lazzaro adds that 'off' periods are complex and can impact a wide range of symptoms, including "tremor and stiffness, as well as non-motor symptoms such as panic attacks and depression".

"Most people don't just suddenly turn 'off' but wind down"

Brian explains that the 'off' period phenomenon has often been compared to an on/off light switch, but he sees it as more of a dimmer switch. "Most people don't just suddenly 'turn off', but wind down, slowly switching 'off'," he says. This means that these states can sometimes be anticipated – and even avoided altogether.

But this might be easier said than done, according to Lazzaro – who says informing people about how to recognise an 'off' state is a key challenge. "This is especially the case for people in the beginning phases of Parkinson's. 'Off' periods can be present, but as the symptoms are very mild, people are unlikely to recognise them." He also notes that these periods are more noticeable in the later stages of the condition, regardless of the person's age.

In addition to emphasising the value of being able to identify when these periods occur, the two experts stress the importance of monitoring them over

time. As with many Parkinson's symptoms and characteristics, 'off' periods are likely to develop in severity as the condition progresses. "That's when you might have to adapt the current baseline treatment or look to other options," says Brian. These other treatment options might include on-demand medication, which is designed to tackle 'off' periods when they occur.

He advises people with the condition to keep a diary of symptoms and medications to help identify possible 'off' periods. Constipation, infection and dehydration are among the factors frequently identified for triggering 'off' periods in such journals, he says, because they can "inhibit oral medicine absorption and limit the optimal response".

Lazzaro adds that because levodopa is absorbed in the small intestine, delays to gastric emptying can slow the absorption of the drug. "There can also be variations in how individual people metabolise levodopa," he adds, "which can lead to different durations of effect and levels of symptom control."

Consistent medication intake is key. "Timing is very important to avoid 'off' periods," says Lazzaro, "because it's related to the level of fluctuation of dopamine. It may take some trial and error to find the regimen that provides the most effective symptom control."

Brian agrees: "I always say to my patients that the more reliable they are with taking their medication, the more predictable the control of their symptoms will be."

The importance of raising awareness

Lazzaro argues that awareness is "the most important part" of effectively managing challenges associated with 'off' periods. "By recognising and being aware of these symptoms, people with Parkinson's may be able to manage parts of their own therapy," he says.

"People often learn to recognise their own individual 'off' symptoms over time. It's important for people with Parkinson's to communicate closely with their healthcare providers about any changes in symptoms or medication response, so that the

treatment plan can be adjusted as needed," he continues.

"It's not only for the person with the condition to understand, but also for their family or the people around them," adds Brian. "'Off' periods can be very distressing for both groups when they happen." He explains how anxiety around these states can prompt people to, for example, take risks with walking that may lead to falls. "But if people understand what 'offs' are, they can do something about it."

For Brian, learning about 'off' periods and raising awareness of how to manage them comes back to supporting people with symptom control. "If we can get that right, then people with the condition may function better, live better, be less prone to having medical problems – and have a better quality of life."

Fundraising

A big thank you to Danielle who along with her daughter raised \$700 by cooking pancakes at her workplace (as seen below) to support those living with Parkinson's.



Save The Date

The 7th World Parkinson Congress will be held in Phoenix, Arizona, US from May 24-27, 2026.

Information on the Congress can be found at www.WPC2026.org.



IN THIS TOGETHER
parkinson's
TASMANIA

Dates to Remember



SUPPORT GROUP MEETINGS

SOUTH

2.00pm Senior Citizens Club Rooms
Lambert Ave., Sandy Bay
28th August, 25th September, 30th October 2024
27th November 2024 Christmas Luncheon

NORTH

2.00pm Launceston Conference Centre, Door of Hope Church, 50 Glen Dhu St., Launceston
10th September, 8th October, 12th November 2024
3rd December 2024 Christmas Luncheon

NORTH WEST

2.00pm Gnomon Pavilion, 3 Wharf Road, Ulverstone
11th September, 9th October, 13th November 2024
4th December 2024 Christmas Luncheon

CARERS GET-TOGETHER

SOUTH

10.00am 12 Adelle Place, Kingston
19th September, 21st November 2024

NORTH

2.00pm Launceston Conference Centre, Door of Hope Church, 50 Glen Dhu St., Launceston
13th September, 6th December 2024

NORTH WEST

2.00pm Willaway Apartments, 2 Tucker Street Ulverstone
12th September, 5th December 2024

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