

STANDBYME

IN THIS TOGETHER
parkinson's
NSW

Parkinson's NSW Limited | Issue 150 Autumn 2023
ISSN 1839-0269



IN THIS ISSUE

**How hallucinations affect
people living with Parkinson's**

Read more on page 3

My [Parkinson's] Life

Emma Tinkler

Read more on page 7

Message from the CEO

Welcome to the Autumn edition of *Stand by Me* – the first for 2023.

I'm writing at a particularly busy time for Parkinson's NSW. We are just weeks away from the NSW State Elections. That means we have also been busy building relationships with both existing Ministers and MPs – and potential new people in those roles, depending on the outcome of the election.

Speaking of fundraising, our annual Step Up for Parkinson's campaign launches on 1 May. You can enrol now if you like, by going to this page www.stepupforparkinsons.org.au

Step Up for Parkinson's is a choose-your-own fitness challenge open to everyone. You can do any form of exercise you like – just set yourself a daily target and ask others to sponsor you.

We have two targets: raise more than last year (which was \$126,000) and encourage everyone to exercise for their own health and wellbeing.

In closing, allow me to recommend some interesting articles in this edition of *Stand by Me*.

Read about the challenges and positivity of a young woman living with not one, but two degenerative diseases including Parkinson's.

Then there is an article on an ingredient in cough medicine that is being evaluated as a treatment for Parkinson's, as well as an interesting opinion piece which asks, 'Are older women with Parkinson's overlooked?'

Enjoy your reading, and the milder weather of our Australian autumn.

Jo-Anne Reeves
Chief Executive
Officer



Voluntary Assisted Dying Act passed by NSW Parliament

Community interest in Voluntary Assisted Dying finally came to fruition with the passing of the Voluntary Assisted Dying Act 2022 by NSW Parliament on 19 May 2022.

NSW Health is now going through an implementation process aiming to bring the legislation into effect from 28 November 2023. This process will oversee and guide the establishment of the specific governance arrangements and processes as required by the law.

See a full overview of the Act and its requirements here.

Certain criteria need to be met by people wanting to access voluntary assisted dying (VAD):

1. They must be an adult who is an Australian citizen, a permanent resident of Australia or have been resident in Australia for at least three continuous years.
2. They must have been living in NSW for at least 12 months.
3. They must have at least one disease, illness or medical condition that is advanced, progressive and will on the balance of probabilities, cause their death within six months (or within 12 months for neurodegenerative diseases like motor neurone disease), and is causing the person suffering that cannot be relieved in a way the person considers tolerable.
4. They must have decision-making capacity in relation to voluntary assisted dying and be acting voluntarily.
5. They must have the ability to make and communicate requests and decisions about voluntary assisted dying throughout the formal request process.

Medical Specialists providing Voluntary Assisted Dying have to hold specialist registration, general registration of 10 years of practice, approved mandatory training and cannot provide VAD to a family member.

There will be a NSW VAD Care navigator established to act as a primary point for contact of patients, families and clinicians.

In addition there will be VAD Board independent oversight and decision-making body.

Macquarie Hospital Building 17
51 Wicks Road
North Ryde NSW 2113
1800 644 189

pnswn@parkinsonsnsw.org.au
www.parkinsonsnsw.org.au
www.facebook.com/parkinsonsnsw
www.instagram.com/parkinsonsnsw

How hallucinations affect people living with Parkinson's

Around 50% of people with Parkinson's disease will experience hallucinations. But what are they and what causes them? Professor Per Odin – a neurologist and head of the Neurology Department at Lund University, Sweden – shares what you need to know about the symptom

What are hallucinations?

Hallucinations are sensory experiences that appear real but are created by our brains. They can affect all five of our senses.

You might hear voices that no one else hears or see things that no one else sees. They are normally separate from illusions, which are distorted or misinterpreted real perceptions – for example, you could see a person where there is actually a tree.

What causes hallucinations in people living with Parkinson's disease?

Hallucinations are very common in Parkinson's disease. More than half of patients experience them at some stage.

They are normally thought to be an effect both of the condition itself and of Parkinson's medication. The risk of hallucinations increases with cognitive impairment, longer disease duration, age, and other diseases.

Visual (seeing) and auditory (hearing) hallucinations may occur as a side effect of drugs which are used to treat Parkinson's. They are often dose-dependent – and in principle reversible.

What types of hallucinations can people living with Parkinson's experience?

Visual hallucinations are the most common in Parkinson's disease. Auditory hallucinations occur mainly in depression. Tactile (touch) or olfactory (smell) sensations are unusual.

Often the symptom starts with lively dreams, then illusions, then hallucinations at night-time. After that hallucinations can also appear in the day.

Initially the patient understands that the experience is a hallucination, but if things progress it becomes difficult to say what is real and not.

Further progression could mean that the hallucinations become scary, and patients can develop confusion or delusions (for example, believing that a partner is unfaithful). Auditive hallucinations are seldom linked to Parkinson's.

Mild hallucinations do not need to impact life very much and can even be experienced as entertaining in

some cases. But when the hallucinations become more pronounced and it is difficult to differentiate them from reality, they can have a big effect.

Can hallucinations be treated?

The treatment for hallucinations consists primarily of removing any existing medical cause, especially reducing, or stopping any triggering pharmacological cause – for example by reducing a dose or discontinuing treatment with a certain drug.

If the increase in motor symptoms then becomes troublesome, a return to the earlier anti-Parkinson's drug may be considered – but with the addition of an atypical neuroleptic drug (a type of drug acting against hallucinations and psychosis).

Most neuroleptics can worsen Parkinson's (sometimes dramatically) and are forbidden when treating people with the condition.

Medications for dementia can also reduce the incidence of illusions and hallucinations when there is underlying cognitive impairment.

Parkinson's treatments are developing fast and it is likely that we will see even more effective ways of avoiding and treating hallucinations in the coming years.

The most important thing is to report hallucinations to your doctor or nurse, and to discuss if they should be treated in some way.

Do you have any advice for the family, friends, and caregivers of people with Parkinson's experiencing hallucinations?

Tell the patient that what they are experiencing is not real and do not pretend that you also experience the same thing. Be calm and friendly with the patient – experiencing hallucinations can be quite stressful.

Per Odin is a neurologist, professor, and head of the neurology department at Lund University, Sweden. He also works at an outpatient clinic in Bremen, Germany. He has focused on Parkinson's disease, both clinically and in research, since 1987.

Author: Saskia Mair

First published in Parkinson's Life

Postural instability and balance

Balance problems are one of the main symptoms of Parkinson's. Poor balance which makes people unsteady when standing or walking as is known as postural instability.

When you have postural instability the possibility of falling from being bumped or walking on an uneven surface is significantly increased. Falling or the risk of falling can be disabling for many people and therefore leads to a decrease in their quality of life.

Postural instability may occur while doing regular activities such as:

- U Just standing still
- U Getting up from a chair or a seated position
- U Getting out of bed
- U Making sudden, quick movements or when making a turn while walking.

Signs that may indicate postural instability include stooped posture, small shuffling steps, and a tendency to lean forward when walking.

Postural instability often occurs when a person is first diagnosed with Parkinson's, but it becomes more common and worsens as the disease progresses. People with Parkinson's are more prone to falls if they cannot re-stabilise from changes in motion, leading to hospital stays or serious injury.

Your doctor will conduct a variety of physical tests to assess your balance. One exam your doctor will perform is called the 'pull test'.

Standing behind you, your doctor will pull on your shoulders to try to make you fall backward. If you can stay upright with just one or two steps, the test is negative. If you need more than two steps or fall backward, the test is considered positive which means your balance needs improving.

Many doctors and allied health practitioners will tell you that exercise is the best approach to treating postural instability and balance issues. Exercise has been proven to improve balance and your walking (gait). Which can help reduce your risk of falling.

Balance exercise done three times per week can help reduce the risk of falls and improve your balance. Practicing daily is best.

When practicing your balance exercise you want to be safe. Here are some tips to help you exercise safely.

- U Choose a time when you are at your best.
- U Be rested and ensure symptoms are at their best with your medications
- U Exercise at your own pace

There are many symptoms that contribute to poor balance in Parkinson's. Postural instability is when poor posture causes the inability to correct your balance after being thrown off balance.

Freezing of gait is the abnormal walking pattern where you can't take the next step forward.

Festinating gait which is when you pick up speed walking and can't stop.

Visuospatial changes which make manoeuvring around obstacles difficult and tripping easy. These are all common symptoms with Parkinson's

Prevention is a vital step to help someone keep their balance and prevent falls. Here are some suggestions:

- U Remove rugs and potential obstacles.
- U Install grab bars in key areas in which falls are more likely, such as the bathroom.
- U Choose the right supporting shoes for you.
- U Wear a medical alert bracelet in case of a fall.
- U Always have a firm support close by to hold onto if needed, such as a chair or table that won't move.
- U If you experience pain or great difficulty with any exercise, STOP and consult your physiotherapist or doctor.

Balance Exercises

Single Leg Stand

Standing tall, pull your stomach in and lift one leg up off the ground and hold for 10 seconds. Breathe.

If unsteady you can keep your toe of the raised foot in contact with the floor.

Swap and do the other leg.

If you are steady hold each position for a longer time.



Contract the muscles in the buttock & thigh of your standing leg

Weight shifts

Stand with your feet hip-width apart.

Shift your weight onto your right foot.

Raise your left foot.

Hold this position for up to 30 seconds.

Then do the opposite side.

Do each side three times.



Sources:

parkinsonsdisease.net/symptoms/balancing-issues-postural-instability

www.apdaparkinson.org/article/impaired-balance-falls-and-parkinsons-disease


eldergym.com/balance-exercise

parkinsonsdisease.net/symptoms/balancing-issues-postural-instability

www.healthline.com/health/exercise-fitness/balance-exercises-for-seniors#exercises-to-try

[www.ohse.in/2021/01/single-leg-stand-exercise \(image\)](https://www.ohse.in/2021/01/single-leg-stand-exercise-image)

[www.mayo.edu/Mayo foundation for medical education and research \(image\)](https://www.mayo.edu/Mayo-foundation-for-medical-education-and-research-image)



Cough medicine could be used in new treatment for Parkinson's

Ambroxol is a drug which is currently used to treat respiratory conditions. It promotes the clearance of mucus, eases coughing and has anti-inflammatory properties.

Pre-clinical studies, led By Professor Anthony Schapira at the University College London (UCL) Queen Square Institute of Neurology identified ambroxol as a candidate drug to slow the progression of Parkinson's.

Results of the Phase 2 clinical trial by Professor Schapira and performed at UCL was published in January 2020 and tested ambroxol in people with Parkinson's.

It found that ambroxol was able effectively reach the brain and increase levels of a protein known as GCase (glucocerebrosidase). GCase allows cells to remove waste proteins, including alpha-synuclein (a protein that builds up in Parkinson's and is thought to be important in its cause), more effectively.

Additionally, the Phase 2 trial showed that ambroxol was safe for people with Parkinson's and was well tolerated.

The world-first Phase 3 trial, named ASPro-PD, will also be led by Professor Schapira in partnership with U.K. charity Cure Parkinson's and the Van Andel Institute following eight years of work with the Parkinson's community.

The trial will involve 330 people with Parkinson's across 10 to 12 clinical centres in the U.K. It will be placebo controlled and participants will take ambroxol for two years.

The effectiveness of ambroxol will be measured by its ability to slow the progression of Parkinson's using a scale including quality of life and movement. Preparations for recruitment of trial participants have already started.

Professor Schapira, said, "I am delighted to be leading this exciting project. This will be the first time a drug specifically applied to a genetic cause of Parkinson's disease has reached this level of trial and represents ten years of extensive and detailed work in the laboratory and in a proof of principle clinical trial.

"The study design is the result of valuable input from people with Parkinson's, leaders in the field of Parkinson's, trial design and statistics from the UCL Comprehensive Clinical Trials Unit (CCTU), the Medicines and Healthcare products Regulatory Agency (MHRA) and a consortium of funders led by Cure Parkinson's – all operating as an effective team to ensure we have reached this stage.

"We look forward to working with all these groups to ensure successful completion of the study."

After the Phase 2 data from Professor Schapira's group at UCL found that ambroxol could increase the removal of alpha-synuclein, the international Linked Clinical Trials (iLCT) program prioritised research into the drug.

Created and operated by Cure Parkinson's and the Van Andel Institute, the iLCT program's mission is to slow, stop and reverse the progression of Parkinson's.

It aims to significantly reduce the time to bring disease-modifying treatments to clinic for the Parkinson's community by testing promising drugs that already have extensive safety data and, in some cases, have been approved by regulators for other medical conditions.

Will Cook, CEO of Cure Parkinson's, said,

"This trial is a big step forward in the search to find new treatments for Parkinson's. Once the ambroxol trial is underway, it will be one of only six Phase 3 trials on public record of potentially disease-modifying drugs in Parkinson's, worldwide."



Sources:
Neuroscience News
University College London (UCL)

Are older women with Parkinson's overlooked?



UK resident Pam Archer was diagnosed with Parkinson's at the age of 74. As a former nurse whose sister lives with the condition, she said she already had some understanding of its progression – but when she looked for information about women with Parkinson's, she found that almost all of it focused on the experiences of younger women.

I was 74 years old when I was diagnosed with Parkinson's in 2021, which ironically happened during Parkinson's Awareness Week.

A year or two earlier, I had become aware that the fingers on my left hand would sometimes shake. I knew a bit about the condition because my sister was diagnosed twenty years ago, so I was aware that this could be a sign – but it wasn't enough to make me seek advice.

Then I noticed that my forearm had developed an occasional shake, and my shoulder hurt if I tried to reach for things. Typing also became harder, especially with my left hand.

This was during COVID-19; because of the restrictions, we were advised that we shouldn't go to the doctor unless necessary, and my symptoms were only gradually developing – so I avoided it. I didn't panic, but I was beginning to think I might have Parkinson's.

When the neurologist eventually told me I did, I felt lucky, in a way, because I was 15 years older than my sister had been when she was diagnosed, and I was probably better informed than a lot of people.

I've not kept my diagnosis a secret. I think some people expected me to be different and appeared a bit surprised. Maybe they expected me to shake more. I found that people were asking me how I was in a more concerned tone, and I'd reply, "Oh, I'm fine!" because I was, and I still am.

"It makes me feel invisible"

Now, I read anything I can find about women and Parkinson's, but usually the articles are about younger women.

Of course, I am deeply worried about how many people in their 50s, 40s, 30s and even their 20s are being diagnosed with Parkinson's. But a lot of articles focus on issues like working life, motherhood, menstruation – and none of that impacts me as a woman in my 70s. It makes me feel invisible.

I am still a woman. We can expect to live for many years as older women; I've already been one for 20 years and could have another 20 ahead of me! I want to know if Parkinson's affects me differently compared to men of any age.

Even though I'm definitely not the only older woman going through it, it sometimes feels that way because I can't find anyone describing it.

I have my sister as a role model. Twelve years after her diagnosis, things seemed to take a turn for the worse. She seemed tired more often, and her mobility was deteriorating. It later became apparent to her family that she could no longer live alone, and she moved into a care home.

During COVID-19, my sister wasn't allowed visitors – not even a hairdresser – and her world began to shrink. She developed dementia, which often goes alongside Parkinson's.

As her condition progressed, we all adapted in our interactions with her, but our relationships weren't that different at all. Her attitude has really helped us as a family – she never expected to be treated any differently.

"Even older women aren't just variants of men"

Because of my sister's experiences, I have taken a keen interest in Parkinson's – and since my own diagnosis, I've been exploring it from a different perspective.

Though everything I've read about the condition has been highly interesting and informative, it doesn't impact me as an older post-menopausal woman.

I've begun to feel that perhaps people think it doesn't matter if older women are treated differently to men. What I really want to know is if we experience Parkinson's differently.

Things like finance and pensions still do affect women differently, and it has been pointed out that women have been more adversely affected by Covid-19 in some ways. Then there are questions around medication – do we need different doses at different stages? If we are all getting the same doses regardless of gender or size, could this be affecting older women more?

As one of the original Baby Boomers, the generation born post-war, I have been a feminist since the 1970s. Perhaps it's just a coincidence, but many of my generation became feminists. Younger women who may benefit from this are probably unaware of how things used to be.

I'd like women with Parkinson's to be able to communicate more openly and honestly. We all have two important things in common: our gender and our condition.

When it comes to older people being diagnosed with Parkinson's, it seems to be only about older people – which we are. But even older women aren't just variants of men.

Source: Parkinson's Life

My [Parkinson's] Life

Emma Tinkler

Emma grew up on the Central Coast of New South Wales, enjoying school life near the beach and thinking that being a flight attendant would be a perfect career.

"Travel and seeing the world was my passion back then," Emma recalls. "When I left school, I joined Contiki (an international travel company) in Sydney and eventually worked in Europe for them for three summers as a site rep in Antibes (on the French Riviera) and then as a mobile cook on their camping tours. I came back to Australia and worked at Flight Centre for a couple of years afterwards."

A marriage and two children followed, the girls now aged 11 and nine. But it was a couple of months after Emma's honeymoon, 12 years ago, that the first hint of problems with her health surfaced.

"I had issues with my vision so I went to my GP," says Emma, who now lives in Sydney.

"He asked me whether I'd experienced numbness or tingling anywhere. It made me recall I'd had pins and needles in my hands a few years before. My eye problems were ultimately diagnosed as optic neuritis, and this led to a diagnosis of multiple sclerosis (MS)."

Emma's life continued with bringing up her two children, then a couple of years ago, she again faced some odd symptoms.

"I was in class at a yoga retreat and my leg started shaking," she says. "A couple of months later I was out walking when I realised I was having to think about moving my leg to walk. It wasn't happening automatically."

"Since having MS I'd become more sensitive to my body and I also realised my left hand was a little bit numb and my left arm didn't seem to swing while walking."

Emma took herself back to her MS neurologist who told her to just ignore her symptoms and they would go away.

"Of course they didn't," says Emma. "So I decided to seek the help of a physiotherapist through MS Australia and I was given some exercises to do."

"Months later, with no improvement, I went back to my neurologist and he told me I had functional neurological disorder (FND), where serious stress or trauma can skew messages between the brain and the central nervous system, resulting in a variety of symptoms happening even though there's no structural damage to the brain."

"While I was a very positive person, I'd had a few stressful life events, so the idea of FND seemed very possible. The only things recommended to treat it were psychology and physiotherapy."

"Over the next 18 months things continued to go downhill. I went from a limp to a walking stick, to a mobility scooter. I had a tremor in my right hand and a fixed position in my left. I couldn't write, type or text, and eating was a challenge. Drinking was through a straw."

By October 2021 Emma decided to seek a second opinion.

"I found a different neurologist and went in on my scooter with my disability support worker," recalls Emma. "She assessed me and told me she didn't think it was FND. I did an internal eye roll! She said she thought it was early-onset

Parkinson's. After the initial shock of hearing those words my first thought was, 'Oh, what am I going to tell Mum?'"

Fortunately, the medications which came with the diagnosis made an almost immediate difference to Emma.

"This second opinion was literally life-changing," Emma says. "After a few days on the medication I took a photo of my laced-up shoe and messaged it to my Mum. I didn't have to put any words to it, she knew what it meant. Four weeks later, instead of my mobility scooter I was able to walk around with a limp."

"Organisations like Parkinsons NSW, Michael J Fox Foundation and MS Plus have so many resources on how to live well, and a really positive outlook, it's fantastic!"

"Learning to live with PD is like trying to tame a beast. It has its ups and downs and is constantly changing. Cooking for a bus load of people all over Europe is a piece of cake compared to living with PD and MS!"

"Mentally you have to be extremely resilient and strong. You have to also make friends with the beast - because ultimately it is part of you. I'm not there yet, but I'm working on it!"



Our NSW Parkinson's community needs more nurses



When Lauren Hogan saw the position of Parkinson's Specialist Nurse advertised in her region just over a year ago, she immediately felt she could be the right person for the job. A former surgical nurse and clinical educator, she'd also completed specialist and post graduate studies in Parkinson's.

"I thought that the role really needed a local nurse. Not just because I know a lot of the community members, but also because I know a lot of the health professionals here."

But far too many people living with Parkinson's in regional areas have no Lauren to help them. Most of their neurologists work in major cities. And if you have any experience of Parkinson's, you know that new and puzzling symptoms don't wait for a long journey to care and a six-monthly check-up.

We now have seven Parkinson's Specialist Nurses in our team – but we need to both maintain these roles and fund more in the future.



Want to help us fund more nurses? See the coupon below.

YES, I would like to help improve the lives of people living with Parkinson's and their families...

Title: _____ First Name: _____ Last Name: _____

Address: _____

Email: _____ Phone: _____

Please accept my donation of the following amount:

\$15 \$30 \$50 Other \$ _____

I would like to make a monthly donation of \$ _____ (\$15 minimum)
Please debit my credit card monthly, until further notice.

I would like to pay by:

Cheque/Money order (payable to Parkinson's NSW)

Credit Card (details below) Visa Mastercard American Express

Card number _____

Name on card _____

Signature _____

Exp date _____

Please send me at no obligation, information on how I can leave a bequest to Parkinson's NSW

I have already included Parkinson's NSW in my will

