

InTouch Newsletter

June 2021

Coming to terms with Parkinson's progression – Infoline Zoom with Parkinson's Nurse Cathy Melton

Parkinson's is a chronic progressive neurological condition. The cause is not known.

The symptoms are caused by the loss of dopamine producing cells in the brain. Dopamine affects memory, mood, and movement.

Even though there is a diagnosis of Parkinson's, the dopamine producing cells in the brain continue to die off. Everyone's journey with PD is unique.

When you first receive a diagnosis

When you receive a diagnosis of Parkinson's it is important to remember that the disease is not your fault – and you are still the same person. All that's changed is that you are now managing a health condition.

The progression of Parkinson's is slow, and you have time to choose how you will react to your disease. It is an individual choice because everyone is affected differently, and symptoms may vary from day to day.

Be kind to yourself. It takes time to come to terms with your diagnosis and there is no 'right' way to react. Some people want to learn all they can about Parkinson's whereas others prefer to limit their knowledge.

It is completely normal to feel scared, sad, and angry and to feel very emotional. My colleague, Counsellor Viviem Luo, has written a separate article about the feelings of grief and loss associated with Parkinson's.

Remember also that your diagnosis will have an impact on your partner, friends, and family members – and it will take time for them to readjust to the new future with Parkinson's in their orbit.

Steps to managing the diagnosis

- Educate yourself about Parkinson's. Knowledge means that you can make informed choices about how to manage the symptoms and not allow the symptoms to manage you. Good symptom management is key to quality of life.
- Determine your personal goals. Be proactive, practical, and realistic.
- Stay positive, retain your sense of humour, and laugh!
- Find and connect with a neurologist who you feel comfortable with and where there is two-way communication.

- Build a team to support and assist you with managing symptoms. This can include a neurologist, speech pathologist, physiotherapist, dietician, occupational therapist, and counsellor.

Seek someone to talk to about your diagnosis and future plans.

- Create healthy habits – be active, exercise and eat a healthy diet
- Take your medication on time every time. Also keep a diary on medication effectiveness to share at medical appointments.
- Particularly focus on managing stress because it makes the symptoms worse.
- Maintain your social connections. For example, join a Support Group and exercise group, or explore online options
- Review your hobbies and look at how you can do things differently in order to maintain them. In general, it is good to be flexible, adapt to change and consider all options.
- Ask for help; professional support can be very positive.

Managing the progression of Parkinson's

It is inevitable that Parkinson's will progress. However, a healthy approach is to focus on yourself as a whole person, not the disease itself. You have Parkinson's but Parkinson's does not have you!

Since there can be issues with cognition and making informed decisions as Parkinson's progresses, it is better that early discussions occur with your caregiver and family members about long-term care requirements and management.

Ensure that you discuss with your partner, caregiver, and family members how you would like to be cared for when your symptoms begin to escalate. It is best for this discussion to start at the beginning of the Parkinson's journey so that everyone is aware of your wishes and the way that you see the care plan heading.

This plan needs to be flexible and reviewed often. Advanced Care Directives are a good way to start the conversation.

Be aware that medication reviews can help to manage symptoms but will be less effective as your condition progresses. For example, if you experience hallucinations then a reduction in medication may be required – and this may be a trade off with mobility.

Not everyone can fulfil the role of caregiver and this needs to be discussed so that all the people involved have choices.

Nobody wants to reside in an aged care facility but if the care required cannot be provided by the caregiver and family then an informed decision needs to be made about how best that the person living with Parkinson's can have their care needs met.

If this has raised any queries or concerns for you, please call the Infoline on **1800 644 189** to talk with the Parkinson's Specialist Nurses or Counsellors.

Sources:

Parkinson's Disease Foundation

Wolters Kluwer Palliative Approach to Parkinson's

American Parkinson's Disease Association

Parkinson's UK

Young Onset Support Group established in Sydney's Eastern Suburbs

The Eastern Suburbs Young Onset Support Group met for the first time on 20 April at Wolper Jewish Hospital in the suburb of Woollahra. Fifteen founding participants attended.

The Group is facilitated by Speech Pathologists Kristin Arthur and Betsy Rumble, with the support of Wolper's Director of Clinical Services, Tina Boger, and Parkinson's NSW. Wolper Hospital has generously committed to hosting the group on an on-going basis, providing it with both meeting space and refreshments.

Some of the founding participants had established connections and friendships through Parkinson's NSW and groups like PD Warrior. Others were new to the organisation and to one another.

Steve Schiemer, fitness trainer, member of the Parkinson's NSW Board of Directors and person living with Parkinson's himself was the guest speaker for the evening.

He talked to the Group about his life with Parkinson's as well as the benefits he has experienced and seen in others as the result of exercise – especially boxing.

Steve's openness and willingness to share his experiences and knowledge encouraged participation and contributions from all participants.

This Group, endorsed by Parkinson's NSW, is the first of its kind in metropolitan Sydney. It welcomes anyone living with Parkinson's who is 65 or under.

It meets on the evening of the 3rd Tuesday of every month. For more information, call the Parkinson's NSW InfoLine: 1800 644 189

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). Auditory 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](#)

Meet our Staff Member

Suliana Manuofetoa, Parkinson's Specialist Nurse

Suliana Manuofetoa joined Parkinson's NSW as a Parkinson's Specialist Nurse in late March 2021.

She began her nursing career eight years ago and became a Clinical Nurse Educator in Neurology four years ago.

Her interest in Parkinson's came about while nursing patients with the disease. She found it was a progressive and challenging disease, yet very rewarding. Suliana's passion for assisting Parkinson's patients grew after her grandmother was diagnosed with Parkinson's.

"It built my interest in it even more when I learned a lot from her about how she manages her Parkinson's," recalled Suliana.

Suliana, who grew up in Tonga, had first wanted to become a teacher and then changed her mind to study medicine. However, her father disapproved, and she studied commerce instead.

"A year after I moved to Australia, I began studying nursing at university," says Suliana. "I am very pleased to be setting up a clinic now at Hornsby Hospital where patients living with Parkinson's can come and see me.

"The northern suburbs of Sydney patients need to travel some distance to access specialists and other Parkinson's services – particularly if they can't drive. I will now be available to guide patients and their caregiver through ways of managing their Parkinson's.

"Caregivers can also be at risk of burnout so providing them with support is important, too," she said.

"It's quite challenging for partners who are caregivers to look after their spouse – especially as the disease progresses. They generally want to keep their partner at home as long as possible, but they will get to a point where they need respite or the partner needs nursing home care.

"I can help to educate caregivers to recognise advanced symptoms of Parkinson's such as cognitive issues or hallucinations, so they can adjust their care. Just as importantly I can also offer caregivers emotional support."

While Suliana is currently very busy setting up the clinic, in her spare time she loves outdoor activities such as hiking, and also enjoys boxing for exercise.

"I'm looking forward to opening the clinic and also speaking at Parkinson's support groups," says Suliana. "I can also facilitate telehealth appointments with neurologists for patients and their caregivers who have difficulties with travel.

"A benefit of my role is I can translate into layman's terms some information specialists give patients which they may not properly understand. I'm very excited to join the Parkinson's NSW team," said Suliana.

My [Parkinson's] Life

Melanie de Jager – Caregiver for husband Ron

Melanie de Jager met her husband Ron back in Christchurch, New Zealand when they both attended a school disco.

“We married in 1976 when I was 18 and Ron was 21,” recalled Melanie. “I was working as a bank teller and Ron was a survey technician with four years training.

“We decided to emigrate to Australia in 1977 because it was seen as the land of opportunity, with cheaper prices and higher wages. We didn’t plan to stay.”

In Australia Melanie began work in a bank but Ron found that the difference in terrain meant that he would need more training in his career.

“Ron became a train driver and he absolutely loved it,” said Melanie. “I worked in a bank for about ten years. For the first decade we lived around the Parramatta area and began our family. Ron always loved fishing and used to have a boat in New Zealand, so friends said we should look at moving to the Central Coast.

“It was 1988 by this stage and we were having our third boy and Ron was driving freight trains, doing shifts. It was too hard for me to continue working so I stopped.

We lived near the train line, had a boat, and enjoyed the beach life. Each Christmas Ron would drive us up to Yamba, where we would camp for our holiday. Ron loved to drive.”

By 1991 the family had decided to build their own house, with Ron helping with the work when he could.

“He noticed his left hand shaking while he was doing work there,” says Melanie. “We were shocked it was Parkinson’s, but in a way it was fortunate we discovered it early and he could get treatment.

“It was a big secret because he was worried he’d lose his job. He managed to work another 15 years but each year he had to have a medical examination. Sadly, he was asked to leave after 23 years as a train driver. It was devastating,” said Melanie.

“He spent about 18 months in total shock and then decided we should buy a business to operate together. We bought two laundromats, but his condition began to deteriorate quite quickly. We had huge issues with his new medication, and he accidentally took too much.”

What Melanie, and many others, didn’t know was that this particular treatment had serious side effects of disinhibition – causing people to develop gambling or sex addictions or wildly overspend on shopping.

“Ron became a gambler, which none of us saw coming,” said Melanie. “He had a very frugal Dutch family background, and it was so hard to believe what was going on.

“I was busy in the laundromat and he was at the TAB. We lost a lot of money. I was working 60 hours a week and he could no longer work, and we had to sell at a loss in 2009.”

To make matters worse, Ron’s condition had deteriorated to the point where Melanie had to become his caregiver.

“His health was so bad,” recalled Melanie. “We had to get his doctor to actually tell him he couldn’t drive. After the call he just sat on the chair for ages, not moving. It was heartbreaking for him.”

Ron’s last interest was his boat, which didn’t require a license. He liked to fish alone, far out to sea, which led to him becoming lost one day.

“Fortunately, one of the boys told Maritime Services the likely coordinates to search for him,” says Melanie. “We had to sell the boat because he refused to fish close in or with a friend. It was very hard for him.”

While trying to help her husband come to terms with the loss of his independence and hobbies, Melanie also had to take over the family finances, house, and car maintenance – all the things Ron had previously done.

“It was a pretty steep learning curve,” she says. “It was also things like me always having to drive, me ordering our meals when we went out, and me going up to the bar to get the drinks. Ron lost so much, but I lost my husband when I had to become his caregiver.”

That caring role further increased when Ron was diagnosed with dementia six years ago.

“This was incredibly hard for me and I felt very alone,” Melanie recalls. “At the time, our sons did not recognise the additional impact it would have on our relationships.

“Parkinson’s alone has had a huge impact on our sons. Our three oldest knew Ron before he had the disease and so they have struggled in a different way to the youngest one who says, ‘Dad’s had Parkinson’s all my life’.

“The impact of Ron withdrawing emotionally and physically when he was diagnosed, and the gambling brought a lot of hurt and anger. The boys stepped up when they saw the extra work I had to take on.”

Melanie had a stroke of luck when a social worker ensured that Ron was signed up for NDIS support six months before the cut-off age of 65.

“I must say it has been absolutely wonderful and I get three mornings of respite care,” she says. “It’s much better than the aged care services available. He can’t walk very far but he goes in a wheelchair.

“There has been a lot of decline in the last six months, and I want to settle him into a nursing home before it’s a crisis. I’d like to have a say. So much of our life has been decided for us with his condition.

“I think we learned to be strong being in Australia without our family. Our church has also been a great support to us. We used to go to a Parkinson’s Support Group up here, but Ron would just go to sleep, so we aren’t doing that anymore.

“The good thing with Ron is there is no aggression with his decline and as he’s slowed down he’s become very appreciative. But there has been ongoing grief for the boys of the loss of their dad as well as extra responsibilities.

“They also fear getting Parkinson’s themselves. It’s been such a long journey for us all,” Melanie said.

Weight, sleep, and depression linked to risk of cognitive problems in Parkinson’s

Researchers at the University of Pennsylvania, USA, have found that people with early Parkinson’s disease are at higher risk of developing [cognitive impairments](#) if they are overweight, have disruptive sleep behaviours or experience symptoms of depression.

Evaluating data from 405 people, the researchers used statistical analysis to identify relationships between certain characteristics and changes in patient cognition over time.

Their findings suggest that factors such as high [body mass index](#) (BMI) or excessive sleepiness are associated with a faster rate of cognitive decline in Parkinson’s disease.

The researchers wrote: “Despite its common and devastating occurrence, treatment of cognitive impairments in Parkinson’s disease is limited and no medications slow its onset or progression.

“However, identification of treatable or modifiable [comorbidities](#) that affect the rate of progression of cognitive impairments in Parkinson’s disease could provide opportunities for early intervention and improved prognosis.”

*Author: Johanna Stiefeler Johnson
First published in [Parkinson’s Life](#)*

Are you watching our *Wellness Wednesday's* videos?

Wellness Wednesday's videos are hosted by Parkinson's NSW Exercise Physiologist Alyson Blanks.

Topics include short and easy exercises you can do anywhere, nutritional advice, tips on mindfulness and other health matters.

You can join in on Facebook every Wednesday at 1pm by clicking this link:

<https://www.facebook.com/parkinsonsnsw>

Or you can view the growing collection of short videos at your leisure on YouTube here:

https://youtube.com/playlist?list=PLNNFUfiPBotL3pJw0XD3zgLEtkc_juZIG

Topics covered so far include:

- Balance exercises
- Daily stretching exercises
- Neuroplasticity
- Getting started and maintaining an exercise routine
- Movement for Motor Symptoms and posture checking
- Stretches to target stiffness
- The importance of Speech Therapy