

STANDBYME

IN THIS TOGETHER
parkinson's
NSW

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**InfoLine is your gateway
to living with Parkinson's**

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Making peace with 'Parky'

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From the CEO

After many months of COVID-19 lockdowns, social distancing and closed cafes and meeting venues, the end is hopefully in sight.

Our community in particular felt the impact of these restrictions. People living with Parkinson's and caregivers were prevented from seeing one another to share experiences and seek mutual support.

However, the Parkinson's InfoLine continued its support uninterrupted, and other key Parkinson's NSW services made the transition to telephone and videoconferencing communications.

Meanwhile, our Senior Leadership Team kept a close eye on expenses because the pandemic had an effect on charitable giving as well. However, I am pleased to say our organisation is tracking well financially and working towards break-even or a moderate profit as of 30 June.

As you will read in this magazine, there have been some changes at the Board level of Parkinson's NSW. President David Veness has stepped down to the Vice President role, and Margaret Scott has been elected President of the Board.

David has made significant contributions to our organisation and the Parkinson's community as a whole during his time as President. He has been an outstanding representative for regional, rural, and remote communities, and generous in sharing his lived experience of Parkinson's.

His greatest passion and contributions have been around advocacy for Parkinson's Specialist Nurses. Thanks to David, we have been successful in placing a second nurse in the Mid North Coast Local Health District and one in the Tweed region of the Northern NSW Local Health District.

A Parkinson's Specialist Nurse has also recently been appointed at Hornsby Hospital, to support people living with Parkinson's around the under-served northwestern fringes of Sydney.

Our thanks also go to Margaret Scott for stepping into David's big shoes. In particular, Margaret has the skills to help us make headway on one of our most important strategic imperatives: diversifying our sources of funding.

I hope you find the variety of articles in this edition of Stand by Me useful and interesting. As always, we would be delighted to receive your feedback.

Jo-Anne Reeves
Chief Executive Officer



Changes in Board leadership



David Veness has been President of the Parkinson's NSW Board of Directors for three years and during this time has made significant contributions by sharing his lived experience with Parkinson's during Board discussions and decision-making.

David has now stepped into the Vice President position of the Board to enable him to focus more on the Chair position he holds on The Parkinson's NSW Trust Board and his advocacy work for Parkinson's NSW.

As a result, Board Member Margaret Scott has been voted into the position of President of the Board.

This transition frees David to focus more strongly on his passion and area of expertise – advocating for more Parkinson's Specialist Nurses in NSW. He also remains a staunch advocate for Support Groups and Members in country areas of the state (he and his wife are long-time residents of Bathurst).

"I am very proud of our achievements over the past three years during my time as President – especially with the placement of Parkinson's Specialist Nurses. And I will continue to represent the needs of people living with Parkinson's in country areas of NSW," said David.

During his time as President of the Board, David was instrumental in placing a second nurse in the Mid North Coast Local Health District and one in the Tweed region of the Northern NSW Local Health District. He also worked closely with key partners on Parkinson's-focused projects and pilot programs.

If you would like to ask any questions about this change in Board leadership, email pnswn@parkinsonsnsw.org.au or phone (02) 8051 1900 for referral to the most appropriate person to answer your query.

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InfoLine is your gateway to living well with Parkinson's

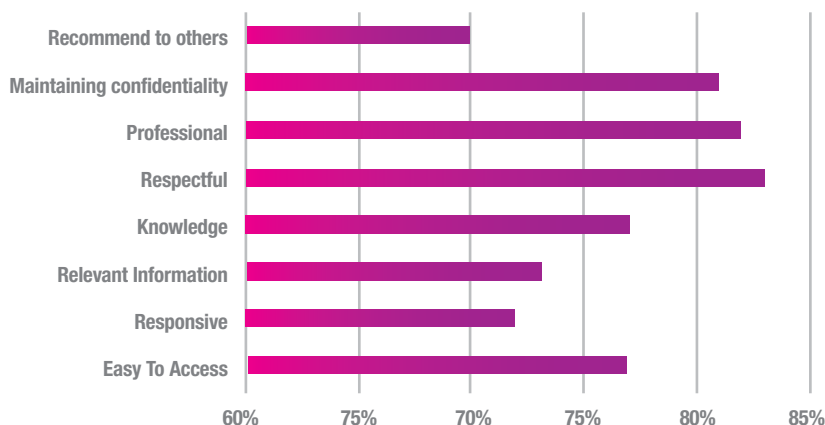
1800 644 189 is more than the number of the Parkinson's NSW InfoLine; it's your gateway to a range of services facilitated by a team of Parkinson's Registered Nurses.

Collectively they have more than 60 years of experience in supporting people living with Parkinson's, caregivers, and families – as well as related fields like aged care, critical care, and gerontology.

The InfoLine team also maintains a database of vetted Primary and Allied Health providers across NSW, so they can connect you with services in which you can be confident.

Feedback on the InfoLine in the latest Parkinson's NSW Consumer Satisfaction Survey was very positive.

Consumer Confidence in InfoLine



InfoLine Nurse team
Julie and Cathy (right)

A diverse range of people call the InfoLine including:

- U The general community
- U General Practitioners
- U Directors of nursing (DON)
- U Nurses
- U Psychiatrists
- U Psychologists
- U Social workers
- U Podiatrists
- U Educators
- U Other Allied Health professionals

Examples of questions InfoLine assist with:

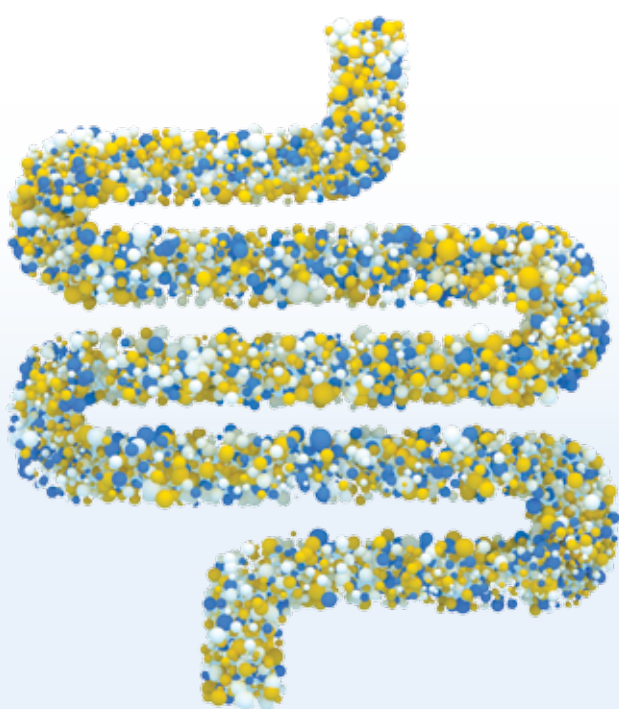
- U Do you think I have Parkinson's?
- U I've just been diagnosed...
- U My doctor says I have PSP... what's that?
- U I'm having a panic attack and need to talk to someone!
- U I want to talk about Parkinson's and my job...
- U My partner/parent is going into a nursing home...
- U I'm not happy with my partner's/parent's nursing home...

InfoLine
Parkinson's
Registered Nurses
are available on
1800 644 189
Monday to Friday
from 9am
to 5pm

In addition to being able to connect you with vetted Primary and Allied Health providers, they can also refer you to Parkinson's NSW Counsellors and the Connect Team which offers NDIS Advocacy and Support Coordination.

"It was a great relief to speak with you on the InfoLine today. Your kindness and professionalism were exactly what I needed. Now I have the confidence to deal with our fractured new reality."
Jo

Partner of a newly diagnosed person living with Parkinson's



Gut Health and the Influence of gut microbes in Parkinson's

Approximately 65 percent of Parkinson's patients experience impaired gut function, also referred to as gastrointestinal dysfunction.

Common non-motor symptoms of Parkinson's-related gastrointestinal dysfunction include drooling, difficulty swallowing, nausea, vomiting, bloating and constipation.

These manifestations of impaired gut function can affect the length of the gastrointestinal tract and can begin at any time during a patient's illness – often preceding motor symptoms of tremor, rigidity and bradykinesia by many years.

However, gastrointestinal dysfunction is frequently overlooked in Parkinson's, despite having a considerable impact on a patient's quality of life.

Recent research suggests that direct communication systems exist between the gut and the brain that may be involved in both the development of Parkinson's and Parkinson's-associated gastrointestinal dysfunction.

Interestingly, this communication involves microbes (bacteria, fungi, viruses) that are resident within the gastrointestinal tract, collectively known as the human gut microbiome.

Of most interest is the bacterial component of the microbiome, which number around one hundred trillion (100,000,000,000,000 or 1×10^{14}) and contribute to functions such as the digestion of food, the production and processing of neurotransmitters (e.g. dopamine and serotonin) and the absorption of nutrients, vitamins and medications into the blood stream.

Importantly, the composition of the gut microbiome is now recognised as being essential for maintaining good health and is often a contributing factor in disease.

With particular regard to Parkinson's, a raft of research studies over the last five years have explored whether there are relationships between the gut microbiome and Parkinson's, stimulated by a greater awareness of Parkinson's potentially starting in the gut and the predominance of gastrointestinal dysfunction throughout the course of the disease.

Collectively these studies have demonstrated differences in gut bacterial populations between Parkinson's patients and healthy control subjects that support a role for abnormal microbiome composition in Parkinson's.

In particular, a decrease in the amount of certain bacteria capable of converting undigestible food into energy for the large intestine has been linked to changes in the structure and function of the gut lining as well as inflammation of the gut.

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New Parkinson's Specialist Nurse for Tweed region

Managing orthostatic hypotension for your safety

Orthostatic hypotension – also known as postural hypotension – is a form of low blood pressure.

It happens when the blood vessels do not constrict (tighten) as you stand up from a sitting or lying position.

It can also be experienced as a side-effect of medication taken for Parkinson's, or when a person is taking anti-hypertensive medications when they are no longer required. **Orthostatic hypotension can also be a pointer to a Parkinson's diagnosis.**

Its symptoms include:

- Feeling dizzy or light-headed
- Blurred vision
- Feeling of weakness
- Feeling confused
- Headache
- Feeling faint
- Fainting
- Trembling
- Nausea
- Cold hands and feet
- Chest pain

How to manage orthostatic hypotension:

- Do not sit or stand or be inactive for long periods
- Avoid activity in the heat and stay cool
- Prior to getting up, move your toes around and adjust your heels and calf muscles
- Allow your feet to dangle on the floor for a short time if getting out of bed
- Gentle marching leg movements may also help
- If feeling dizzy or faint, sit with your legs elevated until the feeling passes
- Ensure that you are well hydrated – drink a glass of water prior to getting up
- Eat smaller meals more frequently
- Avoid straining whilst having bowels open
- Avoid vigorous exercise
- Avoid hot foods and drinks
- Drink extra water if you are going to be standing for long periods
- Drink less alcohol due to its dehydrating effect
- Request a medication review of the blood pressure medications which you may be taking for hypertension as these may be able to be reduced or ceased.

For more information call the Parkinson's NSW InfoLine registered nurses **1800 644 189**

People living with Parkinson's in Northern NSW now have the support of Rebecca Manners, a newly-appointed Parkinson's Specialist Nurse based in Ballina.

Rebecca will support people living with Parkinson's, their caregivers and families who reside in the Tweed, Byron, and Ballina communities.

The appointment was announced in February by Member for Tweed Geoff Provest and Vice President of the Parkinson's NSW Board David Veness.

The position is being co-funded by Northern NSW Local Health District and Parkinson's NSW.

Member for Tweed Geoff Provest said the value of the Parkinson's Specialist Nurse model had already been proven to deliver benefits for people living with Parkinson's and their caregivers.

"This specialist position provides evidence-based advice and advanced nursing services and connects people with the support they require in their own community," Mr Provest said.

"Where communities have access to a specialist nurse, people living with Parkinson's, as well as their caregivers and family members, show significant improvements in their own well-being, with reduced levels of depression. Hospital stays can also be reduced through the intervention of a specialist nurse."

The new role is based at Ballina District Hospital, working across a variety of settings including outpatient clinics, visiting people in their home and hospitals, and supporting the two Parkinson's Support Groups in the region.

Rebecca (pictured below) has 16 years of nursing experience in New Zealand and Australia, spanning general, surgical, and orthopedic nursing – in addition to neurology.

Her neurological experience includes working in an Apomorphine Nursing Service for a leading pharmaceutical company, in addition to hospital neurology wards. Before joining Parkinson's NSW, Rebecca was a Movement Disorder Nurse Specialist at Auckland Hospital.

Prior to her most recent move to Australia, Rebecca had worked here twice before – as a Remote Area Nurse in outback Western Australia and New South Wales.



Neuroprotective benefits of exercise

Exercise for people living with Parkinson's is not only healthy – it is vital for maintaining balance, mobility, and daily living activities.

There is also a potential neuroprotective effect. Exercising enhances the sense of wellbeing, even across different disease stages and severities.

How can I benefit from exercise?

Research has shown that exercise can improve gait, balance, tremor, flexibility, grip strength and motor coordination.

So far, studies have shown:

- U Engaging in any level of physical activity is beneficial, rather than being sedentary – this is associated with improved motor symptoms.
- U For people with mild to moderate Parkinson's, targeted exercises can address specific symptoms. For example:
 - Aerobic exercise improves fitness
 - Walking exercises assist in gait
 - Resistance training strengthens muscles
 - One study showed that twice-a-week tango dancing classes helped people with Parkinson's improve motor symptoms, balance, and walking speed.
- U Exercise may also improve cognition, depression, and fatigue
- U One study showed that people living with Parkinson's who exercised regularly for 2.5 hours a week had a smaller decline in mobility and quality of life over two years
- U There is a strong consensus among physicians and physical therapists that improved mobility by exercising may improve thinking, memory and reduce risk of falls. By avoiding complications from falls you can prevent further injury.

How does exercise change the brain?

What happens in the brain to produce these visible benefits? Researchers at the University of Southern California looked at the brains of mice that had exercised under conditions parallel to a human treadmill and discovered that:

- U Exercising did not affect the amount of dopamine in the brain, but the mice that exercised the brain cells were using dopamine more efficiently.
- U Exercise improves efficiency by modifying the areas of the brain where dopamine signals are received – the substantia nigra and basal ganglia



Scientists at University of Pittsburgh found that in animal models, exercise induces and increases the beneficial neurotrophic factors – particularly GDNF (glial-derived neurotrophic factor) which reduces the vulnerability of dopamine neurons to damage.

What kinds of exercises are helpful for people living with Parkinson's?

Any form of physical exercise you do without injuring yourself will provide benefit.

Before beginning any new exercise, consult your doctor.

Formal exercise programs cover several different aspects of fitness including strength, balance, coordination, flexibility, and endurance.

Each of these areas provide a benefit to people living with Parkinson's. Achieving a balance that works and engages you in a program you can start, maintain, and expand upon is the goal.

Examples of exercise programs for people living with Parkinson's include:

- U Intensive sports training
- U Treadmill training with body weight support
- U Resistance training
- U Aerobic exercise
- U Alternative forms of exercise (yoga and Tai Chi)
- U Home-based exercise (YouTube videos)
- U Stretching
- U Practice of movement strategies

When Should I Start Exercising?

Right now! Everyone should exercise more, whether they have Parkinson's or not.

The best way to see benefits is to exercise on a consistent basis. People living with Parkinson's enrolled in exercise programs with durations longer than six months, regardless of exercise intensity, have shown significant gains in functional balance and mobility as compared to programs of only two-week or 10-week durations.

Regardless of your condition, always stretch, warm up and cool down properly.

Exercise in a way that is safe for you. Know your limits.

First published by the US [Parkinson's Foundation](#)

Making peace with 'Parky'

Parkinson's in the Country: Geoff Bourne

For Geoff Bourne, his farm is not just his home. Those who know him say it's his reason for being.

Geoff grew up on an 1800-acre property at Ben Lomond, between Armidale and Glen Innes and has been farming the land ever since. It's a family concern for Geoff, who works the property with his wife Myreen, his son Nigel and Nigel's family.

"My father was an accountant in Sydney. My mother came from a farm near Guyra and she hated the city. They bought the farm in 1952 when I was four, so while I'm not quite a local I've been here a long time, and my granddaughters are the fourth generation to work on the farm."

"I enjoy the peace and quiet here. You can open the blind in the morning and look out and see green fields and nothing else... if there's not a drought."

At age 65, Geoff was just starting to think about his farm succession planning.

"Nigel moved back 16 years ago but I was still managing the farm on my own, basically. I was very healthy and fit, and I was pleased with myself. At 65 I had nothing wrong. I thought if I can just find out why my hand keeps shaking, I'll be fine."

"My diagnosis with Parkinson's came as a bit of a kick in the guts to put it bluntly. It took a while to get used to it, for both myself and my wife, but after a while you learn that that's what life dealt to you, so you make the most of it."

Geoff has a slow progressing form of Parkinson's that has affected his movement. He also experiences anxiety and depression at times. Fortunately, he is still able to drive, which makes getting to medical appointments that much easier.

"I regularly see my GP in Armidale, which is about 50 minutes away and my neurologist is in Tamworth, which is a four-hour roundtrip."

"When I first was concerned about my condition, I went to Brisbane and consulted a neurologist up there and he diagnosed me with Parkinson's. However, I decided there was no point in going to Brisbane all the time, so we found a neurologist in Tamworth and I generally see him every six months."

"It's okay at the minute. I'm still driving. My wife's not very keen on driving distances, so I don't know what'll happen when I'm not driving. My son would probably take me, but I don't wish to impose on him all the time."

Being able to keep in contact with his GP and neurologist is just one of the challenges Geoff faces as someone living with Parkinson's in a regional area.



Geoff (left) with some Glenn Innes Support Group participants

"I need to be able to talk to people about problems. I imagine talking to a Parkinson's Specialist Nurse occasionally would help me, but I have no experience of them, as there's not one here."

"It would be an advantage to the patients of Glen Innes to have a Parkinson's nurse to help us in our travels through the disease – particularly on a practical level for day-to-day living and for any problems that you might run into."

Geoff said he and Myreen have both benefitted from taking part in the Glen Innes Parkinson's Support Group. Geoff has also been Secretary of the Group for the past five years.

"It's a place to go and talk about things. To share problems and hopefully share solutions. My wife always comes with me and talks with other patients and carers."

"At the Support Group, medication is a big topic. People have tried different ones and encountered problems and discuss how they solved them. We also support people financially if they need to see a physiotherapist or travel away. It's mainly just being able to talk to people with the same problem and trying to help each other."

"You have to talk to other people with the disease, otherwise you feel on your own and isolated with the problems of the whole thing. If you can just talk to people and compare notes and treatments, I think it helps."

While his Parkinson's – or 'Parky' as he and Myreen have come to call it – may mean one day he has to leave the farm he loves, Geoff plans to stay put for as long as he can.

"I still own part of the farm and work on it. My son is the manager now, which means I don't have the stress of that job. I basically do what I want and not what I don't. I think my son forgets that I've got Parkinson's every now and again, but that's not a bad thing."

"I find working on the farm gives me motivation. It keeps me moving and is a reason to get up in the morning and do things. When I get depressed, I go and do something and it cheers me up, so I'll certainly stay here while ever I can."

To find out about a Support Group near you, contact the Parkinson's NSW InfoLine 1800 644 189



Help us fund more Specialist Nurses like Rebecca

Rebecca Manners is our new Parkinson's Specialist Nurse, providing support to people in Northern NSW thanks to funding contributed by thoughtful supporters like you.

With COVID-19 recently locking down the nearby border into Queensland, where most in the area go to see neurologists, Rebecca's help has been particularly crucial.

"My main focus as the Parkinson's Specialist Nurse is to support patients and their families through what can be a challenging and isolating condition," Rebecca says.

"To provide integrated care we liaise with specialists, GPs and allied health such as physiotherapists and social workers to manage their Parkinson's symptoms."

There are still many places around NSW where people don't have a Parkinson's Specialist Nurse. They desperately need this reliable and professional support on-hand in their own community.

parkinson's IN THIS TOGETHER
NSW

Your support will help people like Tony & Jenny

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

PO Box 71, NORTH RYDE BC NSW 1670 | InfoLine 1800 644 189 | parkinsonsnsw.org.au | ABN 93 023 603 545 | ACN 622 455 985

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FOR YOUR SUPPORT**
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