

## In Touch Newsletter

January 2023

### Meet the staff – Stacey Foster, Support Group Coordinator

Stacey Foster has joined Parkinson's NSW in the role of Support Group Coordinator.

After graduating with a Bachelor of Sports Management degree, Stacey decided to pursue a career in the not-for-profit healthcare sector.

She began with a four-year stint at Cerebral Palsy Alliance, working as Sport Development Coordinator – a role which involved providing sport and recreation options for children and adults of all abilities.

Stacey then moved to One Disease Limited, an organisation committed to eliminating crusted scabies as a public health concern in Australia. She worked there for five years in a series of increasingly senior roles, culminating in the position of Project and Communication Communicator.

At Parkinson's NSW Stacey is responsible for coordinating the operations of our network of more than 40 in-person and 15 online Support Groups.

“My priorities are helping Groups keep up the good work on managing their plans and finances, growing and improving connections across the network, and encouraging succession planning in Group leadership teams,” said Stacey.

When she's not working with Support Groups, Stacey has another important role – mother to two boys aged 3 and 7. In her rare moments of down-time, she enjoys reading and working out to online High Intensity Interval Training (HIIT) programs.

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### What exercise can I do if I have difficulty standing or walking?

You can still reap the benefit of exercise, even with advanced Parkinson's. If walking or balancing is difficult, use a bar, heavy table, or chair to hold onto when exercising or stretching. If standing or getting up is hard, exercise and stretch in a chair or bed.

There are loads of different seated exercise classes such as general exercise, dance, yoga, and balance. You could also use a recumbent bike (a bike with a low seat and back support) which can help you exert yourself safely.

If none of the suggestions above can help you to do some exercise, here are some more to consider.

You can do facial exercises that can help fight facial masking and speech and/or swallowing difficulties:

- Chew your food longer and more vigorously.
- Exaggerate your face and lip movements when you speak.
- Make faces in the mirror.
- Sing or read out loud. Or join a choir or online singing group.

You can also do mental exercises give your brain a workout and can improve memory as there is also cognitive decline with Parkinson's, For example:

- Name as many animals, vegetables (or colours, or cars) as you can in one minute.
- Play brain games and do puzzles.
- Solve math problems in your head, or try Sudoku or a crossword

Another way to get some exercise is to add an activity in small bits throughout your day:

- Stretch or do leg exercises while watching TV.
- Swing your arms in a multitude of directions each mealtime.

Talk to your neurologist and your primary care provider before starting a new exercise regimen. They can assist you on how intense your exercises can be and recommend exercises appropriate for your individual abilities.

#### References:

- <https://my.clevelandclinic.org/health/articles/9200-exercise-for-people-with-parkinsons-disease#:~:text=You%20should%20begin%20an%20exercise,outcomes%20and%20ove,all%20well%2Dbeing.>
- <https://www.hopkinsmedicine.org/health/conditions-and-diseases/parkinsons-disease/fighting-parkinson-disease-with-exercise-and-diet>
- <https://www.stlukeshhealth.org/resources/managing-early-onset-parkinson-s-disease-with-exercise>

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## Meet & Greet: Tumut Support Group

Work on establishing the Tumut Support Group began in June 2022 when Barry Whiting reached out to his local Rural Health Coordinator and the Parkinson's NSW Support Group Coordinator.

“I had been diagnosed with Parkinson's in May 2021 and naturally started doing lots of research into the disease, what supports might be needed, and what was available locally.

“It quickly became apparent that a local Support Group would be a good idea because I reasoned that there must be other local people in the same boat as myself,” said Barry.

The Tumut Support Group first met in July 2022 and Barry was appointed Leader.

The fledgling Group wasted no time in setting up a roster of interesting and relevant guest speakers – including a local exercise physiologist and speech pathologist. It also tapped into regional resources including a Parkinson's Nurse from the Murrumbidgee Primary Health Network based in Wagga Wagga.

The Group attracts an average of 10 people per meeting from the township of Tumut and surrounding areas.

“Actually we'd like to attract more people from Tumut itself,” said Barry.

To that end, the Group has been very active in building its profile in the local community. Fliers have been displayed in local businesses, there have been interviews with the local newspaper, listings on the local radio station's community notice board and even interviews with ABC Radio Riverina.

“I'm very impressed with what the Tumut Support Group has achieved within the relatively short time it has been operating,” said Parkinson's NSW Support Group Coordinator Stacey Foster.

“It is a good example of simple but effective outreach to the local community, and the warmth and support that community has offered in return.”

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## **Newly Diagnosed Pack now available faster online**

Recently diagnosed with Parkinson's? Need information asap?

Parkinson's NSW can help. We have developed an online version of our InfoLine Newly Diagnosed Pack.

If you, a friend, or family member has an email address, we can now send a Pack to you within minutes and you won't have to wait to access vital information.

If you need a Newly Diagnosed Pack of information to help you through this stressful time, call the Parkinson's NSW HealthLine: **1800 644 189** and speak to one of our Parkinson's Registered Nurses.

## ***Nurses in Action***

### **Rebecca Manners**

Experienced nurse Rebecca Manners moved from New Zealand to Australia two years ago when she began a new role as Northern NSW Parkinson's Specialist Nurse.

Rebecca began nursing at Waikato Hospital in Hamilton, New Zealand in 2005, and worked more recently at Auckland Hospital in the Movement Disorder Department. She has worked in a number of nursing fields, including surgical wards as well as remote nursing in Western Australia.

"Five years ago I worked for a pharmaceutical company in Auckland," says Rebecca. "It was during this time that I started working with people with Parkinson's. I've always enjoyed working in Australia and the sunshine is a bonus.

"When I heard about the role, it sounded like an exciting opportunity; creating a new nursing service and providing support to people where access to neurology services is limited. In the end it was a fairly easy decision."

Actually getting to start work was a little more complicated, as the process took place during COVID restrictions in Australia and New Zealand. Once Rebecca had gained approval to leave New Zealand to take up the position, she then had to quarantine in Sydney for two weeks before she could finally travel to northern New South Wales, find accommodation, and settle into the new role.

"During COVID, face-to-face contact was restricted for extended periods in 2021," says Rebecca. "And the close proximity to Queensland and the result of border closures meant many people were unable to attend specialist's appointments – this was challenging to navigate.

"I was limited to phone support, but it was also an opportunity to develop Telehealth services. Being a regional nursing service, I did miss connecting with colleagues in other locations as we were unable to travel."

And then came the record-breaking February 2022 floods.

"Where I live in Lennox Head, I was fortunate not to be directly affected by the floods," says Rebecca. "The event happened really fast. Watching it on the news, it was quite chaotic. With assistance from the Support Group leaders and team at the hospital, our priority was to provide welfare checks to patients and their families. Evacuation centers were set up around the region and locals donated belongings and offered help.

"The following day saw flooding in Ballina and as a result Ballina Hospital was evacuated to the local high school. Anyone with medical experience living in the area turned up to assist and for two days a makeshift hospital was created.

“It was organised chaos; air mattresses and bedding were donated, and food was delivered by local restaurants. For the 50-odd patients transferred it was quite an experience.

“We are trained to handle earthquakes in New Zealand, but not floods. It was humbling seeing the community really pulled together – an extremely strong and resilient community.”

Even months after the floods, Rebecca says she is still seeing people struggling, many in temporary accommodation with disruption to social services and routines.

“Displaced housing and sickness meant staff were either unavailable or carers were different; this can be very unsettling for people with Parkinson’s as routine is so important and change leads to heightened anxiety which is a common symptom of Parkinson’s,” says Rebecca.

“In Australia, due to its size, access to specialist care can be challenging. Lockdowns and border closures have added to these challenges”

Rebecca is finding that facilitating Telehealth consultations with movement disorder specialists helps reduce travel for patients.

“We hope to see more Telehealth in the future,” she says. “Although, people still value meeting in person and connecting with their peers. It’s so important for their well-being. Our Support Groups have continued for this reason.

“Since I started, we’ve overcome several major events which has been difficult and overwhelming at times. But one step in front of the other is the answer.

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## **Tips on growing your Support Group**

*The following tips have been submitted by Sandra Elms of Newcastle Support Group. This is an ongoing series of tips from various Groups across the state.*

- It’s hard to decide what works and what doesn’t. For me, I feel one has to have time, energy, and a passion to do something to help others.
- A quote I heard once: “I have this disease and I am going to use it to do something good with it”. That sums up for me, but I wouldn’t expect others to feel the same.
- I think on a general note try and have a Group of like-minded people who all work together well. If everyone does a little bit then the whole lot gets done rather than leaving it all to one person.
- Have a few formal meetings throughout the year:
  1. Decide what to do in the year.
  2. How is it going?

### 3. How well it went.

- Think big. I have found people in the community are happy to donate, etc.
- The Carers group was a very important addition to the Support Group. Carers need caring.
- Be assertive.
- If there is a Young Onset group try to link the 'oldies' with the 'young' ones. We are all in this together.
- Network as much as possible.
- Try to apply for grants – you need money to do things to make the Group more interesting and dynamic. (This is, however, hard to do)

These are just a few ideas, but I think group dynamics and how successful they are depend entirely on the participants who come – and that is not something one has any influence over.

One needs a lot of energy to make them successful.

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## Inflammatory Bacteria in Nose Linked to Parkinson's Risk

by Marisa Wexler

People with [Parkinson's](#) tend to have high numbers of pro-inflammatory bacteria in their noses, according to a new study.

Researchers think these bacteria may be a trigger for inflammation in the brain, which could help to set the stage for the development of Parkinson's.

The study – [Deep nasal sinus cavity microbiota dysbiosis in Parkinson's disease](#) – was published in [npj Parkinson's Disease](#).

Our bodies are home to billions of bacteria and other microorganisms, collectively referred to as the microbiome. These tiny creatures play important roles in health and disease that are only beginning to be understood.

An emerging body of research has suggested the microbiome is dysregulated in Parkinson's. Prior studies have found abnormalities in patients' [gut](#) and [mouth bacteria](#), for example.

Prior studies looking at bacteria toward the outside of the nose have failed to find noteworthy Parkinson's-specific differences. However, a team at Rush University in Chicago analysed bacteria in the deep nasal sinus cavity of 30 people with Parkinson's. The team noted that the deep nasal sinus cavity – far up in the nose – is close to the olfactory bulb, a brain structure involved in the sense of smell.

“We posit that the unexplored deep nasal sinus cavity is a more relevant site for neuroinflammation (brain inflammation) in Parkinson's and hypothesised that the

deep nasal microbiota community has a pro-inflammatory profile in PD,” the scientists wrote.

Bacteria diversity was analysed in 30 individuals with Parkinson’s using a technique called 16S rRNA gene amplicon sequencing. This involves sequencing a specific part of the genome in a sample of bacteria, which researchers can use to deduce which species are in the sample and their relative abundances.

For comparison, the researchers also analysed bacteria in the deep nasal sinus cavities of 11 of the patients’ spouses who did not have Parkinson’s. Spouses were chosen in order to account for environmental factors (e.g., bacteria that happen to live in a person’s house). Bacteria from 17 non-spousal healthy controls also were analysed.

Results showed that, compared to the controls, people with Parkinson’s tended to have higher amounts of certain bacteria that are likely to have pro-inflammatory effects.

For example, many patients had high abundancies of *Moraxella catarrhalis*, which is known to be an opportunistic pathogen – a bacteria that usually does not cause disease but can under certain circumstances.

The team noted that *M. catarrhalis* was not always linked with Parkinson’s – indeed, some patients had no detectable amounts of this type of bacteria. But microbiomes with the highest abundances of this bacteria consistently came from people with Parkinson’s.

Statistical analyses indicated that patients with higher amounts of *M. catarrhalis* and other pro-inflammatory bacteria tended to display more severe Parkinson’s symptoms.

“Although the presence of *Moraxella* was not always associated with the nasal microbiome of Parkinson’s subjects, an increased relative abundance of *M. catarrhalis* in Parkinson’s subjects ... as well as other pathogens (disease-causing microorganisms), suggests a role promoting nasal inflammation and possibly neuroinflammation in Parkinson’s,” the team wrote.

In addition to high levels of pro-inflammatory bacteria, Parkinson’s patients also tended to have lower amounts of bacteria with anti-inflammatory properties, including *Blautia wexlerae*, *Lachnospira pectinoschiza*, and *Propionibacterium humerusii*.

“These organisms and other similar taxa (biological groups) may play an important role in maintaining a balanced (anti-inflammatory) microbial composition in the nasal microbiome,” the researchers wrote.

Collectively, the team said this study “...supports the hypothesis that gut and deep nasal dysbiotic microbiota communities are triggers/enablers of neuroinflammation,” which may help to drive the onset of Parkinson’s.

The researchers noted this study was limited by its small sample size and highlighted a need for more research to understand how the microbiome affects the development of Parkinson's.

**Source:**

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## **Marty Cobcroft releases new album to fundraise for Parkinson's**

Professional musician and singer/songwriter Marty Cobcroft will release a new album on **31 January** and its sales will benefit Parkinson's NSW.

The album is titled *Free Bird* and Marty has pledged to donate 50 percent of his earnings from sales of any single track, album stream or CD of the album. The donated funds will be used to support service delivery by Parkinson's NSW.

Anyone who buys the CD will also be able to scan a QR code which will enable them to download the digital version of the album for free.

Marty has been living with Parkinson's for the past four years.

He has been a musician since he was 15 years old and is now in his early 60's. Marty worked steadily in the pub rock scene with various local bands then throughout the '90's built a career as an in-demand session singer and voice-over artist for a number of production houses.

Marty is also a talented photographer. Examples of his work can be seen on [Instagram](#). And to sample his musical style before buying the new album, listen to Marty's previous work on his YouTube channel [here](#).

Marty's new album will be on sale via his [web site](#) as well as Apple Music, Spotify, and all leading streaming services.

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## **Seniors Festival 2023**

With NSW Seniors Festival running from 1-12 February 2023 we have put together some top pick events, courses, workshops and classes for this year. From high teas, expos, shows, workshops and so much more.

There are many more activities and events across the state so be sure to search on your local council website and the [NSW Seniors Festival website](#) for what's happening near you.

Link:

<https://www.parkinsonsnsw.org.au/seniors-festival-2023/>



