

InTouch Newsletter

June 2022

Parkinson's Community Heroes

This was the second year that Parkinson's NSW promoted the Parkinson's Community Heroes program to both commemorate Parkinson's Awareness Month and provide opportunities for Support Groups to recognise their local supporters – while also raising their Groups' profiles within their communities.

The Heroes program was not designed to recognise Support Group participants, but local community heroes who had assisted them.

The 12 Support Groups which took advantage of this opportunity to generate publicity in their communities were:

- Ashfield
- Blacktown
- Chinatown Bilingual
- Coffs Harbour
- Kiama
- Lismore
- Macarthur
- Narrabri
- Nepean/Blue Mountains
- Port Macquarie
- Southern Highlands
- Tweed Heads

“Nominations varied widely – including a boxing and exercise trainers, politicians, Allied Health practitioners, supportive community organisations, and active fundraisers,” said Support Group Coordinator Cassie Morgan.

“It was heartening to see Groups taking advantage of this new opportunity to acknowledge their local supporters while driving publicity and hopefully also attracting new participants.

“These Groups also conducted community outreach campaigns with information stands, raffles, picnics and contacts with local media,” she said.

How not to lose sleep over Parkinson's

Did you know that 90 percent of people with Parkinson's suffer sleep disturbance? Here is advice from an advanced nurse practitioner, a physiotherapist and a person living with Parkinson's about why good sleep hygiene matters.

"Have you ever been fishing and caught a fish – and it's landed, flipping around, on the bank?" asks Matt Eagles.

He is describing his typical night in bed with Parkinson's.

"I can be very, very still, then start flapping. My wife leans over and puts her hand on my leg or my tummy and, usually, it stops. During that time I'm semi-conscious, but it's not a good quality of sleep."

Throughout his 46 years of having Parkinson's, Matt has tried many ways of getting to sleep. Like 90 percent of people living with the condition, he suffers from sleep disturbance brought on mainly by troubles with movement when lying in bed – although he admits things are not as bad as they once were. His limbs can go from being highly active, to completely rigid.

"Trying to move your legs in the middle of the night can be like you've got somebody else's legs, or you're stuck in treacle, frozen in your bed," he says.

Years of trial and error have taught him what makes a difference. He is now a firm advocate of good sleep hygiene which, these days, involves going to bed between 22:30 to 23:00 every night, and waking up at 7:30. He aims to get at least seven hours of sleep a night.

What is sleep hygiene?

To ensure we get a good night's sleep, the human body has an internal alarm clock that regulates our sleep-wake cycle. Keeping to a regular night-time routine, creating an ideal sleeping environment, and getting into healthy habits during the day can all help you develop good sleep hygiene.

Brian Magennis, an advanced nurse practitioner in Parkinson's disease and movement disorders, thinks sleep hygiene is vital to improving your sleep.

“It’s one of the most important things I consider when assessing the sleep problems of a person who has Parkinson’s. There are other things like insomnia, urinary issues, movement problems and mind disturbances – but sleep hygiene is an obvious first step,” he says.

“If you get this right, you’ll be on your way to improving the quality and quantity of your sleep. If you still have problems, you need to talk to your doctor or neurologist, who can help adjust your medication as getting the timing and dosage of this right is essential too.”

How to get a good night’s sleep

General habits like having regular mealtimes and going to bed at the same time every night, keeping alcohol and caffeine to a minimum and ensuring your bedroom is cooler during the night have all been shown to improve the quality and quantity of your sleep.

Sleeping in total darkness and making sure you have the right bedding can also be important as Matt testifies. “We have black-out curtains in the bedroom which really help,” he says. “And a good mattress is essential. I have a memory foam mattress which is very comfy. The only issue for me is that it mimics my body shape and sometimes it means when I want to turn over, I have to climb out of the dip I’ve just created for myself!”

One thing that’s not a healthy habit is exposure to blue spectrum light before bedtime. Computer monitors, smartphones, tablet screens and televisions all produce light in the blue spectrum, which tricks the brain into believing it’s daytime, thereby reducing the production of melatonin – a hormone that helps you sleep.

Getting your nutrition right is also key to a good night’s sleep. It’s important not to eat too late and to ensure you don’t have too many high-protein foods, or carbohydrates, which can sometimes interfere with the absorption of Parkinson’s medications or be associated with poor sleep quality.

A good dose of exercise can also aid sleep quality. Physiotherapist Josefa Domingos helps people with Parkinson’s to improve their functional wellbeing.

She says: “During the day, it’s important to get proper aerobic exercise when you have Parkinson’s – not only because it potentially helps delay progression of the disease, but also because it’s been shown to improve sleep and relieve a variety of motor and non-motor symptoms.”

Stretching and slow mobility exercises before bed can also help in reducing rigidity and some discomfort during the night too, according to people with Parkinson’s.

For Matt, improving his sleep hygiene has helped to boost his energy and cope better with the condition. “Parkinson’s is exhausting,” he says. “If you wake up and you’re tired, apathy can kick in and you really don’t feel like doing anything. I think sleep is so important to Parkinson’s.”

7 ways to improve your sleep

1. *Keep to a regular routine*, including a regular pattern of meals, exercise and going to bed and getting up – it will help your body clock get into the habit of sleeping.
2. *Get your nutrition right* – regular mealtimes and a well-balanced Mediterranean-type diet has been shown to have therapeutic effects on sleep.
3. *Stay hydrated during the day*, depending on your body type and needs, and avoid caffeine and alcohol which are stimulants.
4. *Exercise on a regular basis* – how much you should do depends on your personal fitness and circumstance.
5. *Sleep in a cool, dark room* – but take care to have some kind of lighting should you need to get up in the night.
6. *Upgrade your sleeping accessories* – pillows, mattresses and sheets can all make the difference between a comfortable and uncomfortable night.
7. *Avoid electronics* at least one hour before bed. Computer monitors, smartphones, tablet screens and televisions all produce blue spectrum light, which mimics daylight.

Source:

[European Parkinson's Disease Association](#)

New Parkinson's Specialist Nurses - Goulburn

A new Parkinson's Specialist Nurse has been appointed in Goulburn to support people living with Parkinson's in the Goulburn, Yass and Crookwell areas.

Nurse Lauren Hogan is a Goulburn local who has spent 13 years working at Goulburn Base Hospital – nine of which have been as a Registered Nurse. Her most recent role was Clinical Nurse Educator on the surgical ward. She has also had experience in nursing, assessment and planning for Parkinson's patients, reduction in falls causing serious injury, working in multidisciplinary teams, and infection control.

Lauren's appointment was made possible by years of fundraising by the Goulburn Support Group, and the support of loyal local donors including the Goulburn Workers Club and Goulburn Invitational. Both organisations also made additional surprise donations during the announcement event for the nurse position. Ganter Constructions has also been extremely generous but its representatives were unable to be present on the day.

"We are extremely excited to see our hard work come to fruition, this has been our dream for over 10 years. The support of the local community, our family and friends who all had faith in our dreams has made this all possible," said Gill O'Connor of the Goulburn Support Group.

"Lauren will make an immense difference in the lives of all those living with Parkinson's in our community – not just for our Support Group participants but for all people living with this disease, their caregivers, and families in our region.

"It's a great outcome for us all. It has been so wonderful to have people stop us in the street to congratulate us – news has spread!" said Gill.

Announcing the new role, Parkinson's NSW CEO Jo-Anne Reeves said the Local Health District-based Parkinson's Specialist Nurse model had already been proven to deliver benefits for people living with Parkinson's and their caregivers.

"This model permits the Specialist Nurses to work across a number of settings including hospitals, clinics, patient's homes and Aged Care facilities," she said.

"There is also evidence that this model of care helps to reduce the sense of isolation many people with Parkinson's experience, along with the high rates of depression and anxiety associated with the disease."

"Where communities have access to a Specialist Nurse, carers and family members also show significant improvements in their own well-being, with reduced levels of depression," she said.

Parkinson's NSW, in partnership with Local Health Districts in NSW, now co-manages neurological nurse positions in five regional areas – Port Macquarie, Coffs

Harbour, Shoalhaven, Tweed and Goulburn. A sixth position is based at Hornsby Kuring-gai Hospital in Sydney.

New Parkinson's Specialist Nurses – Port Macquarie

People living with Parkinson's disease in Port Macquarie, Kempsey and surrounding communities recently welcomed Parkinson's Specialist Nurse Jody Lloyd.

She replaces Specialist Nurse Rachael Mackinnon who has relocated to Sydney and now works in the role of Clinical Lead for Parkinson's NSW.

Jody is a nurse with advanced education and more than a decade of experience spanning roles in both Australia and the UK. She has experience in Parkinson's, Aged Care, Cardiology, health education and evaluation of standards of care.

Member for Port Macquarie, Leslie Williams said, "Specialised neurological nurses are proven to have many benefits for people living with Parkinson's and their families.

Parkinson's NSW CEO Jo-Anne Reeves said the jointly funded, LHD-based Parkinson's Specialist Nurse model had already been proven to deliver benefits for people living with Parkinson's and their caregivers.

"This model permits the Specialist Nurses to work across a number of settings including hospitals, clinics, patient's homes and Aged Care facilities," she said. "There is also evidence that this model of care helps to reduce the sense of isolation many people with Parkinson's experience, along with the high rates of depression and anxiety associated with the disease."

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Red light therapy for Parkinson's

There is a keen interest in the Parkinson's community about the potential effectiveness of 'red light therapy' or 'laser light therapy' for the treatment of Parkinson's symptoms. It is one of the most frequently asked questions by our InfoLine callers.

This type of potential treatment is more accurately known as photobiomodulation or PBM.

Parkinson's NSW endorses evidence-based research and therapies which have been rigorously evaluated using scientific methodologies. To date, no large-scale studies or peer reviewed scientific research have established the safety and effectiveness of PBM for treating the symptoms of Parkinson's.

There are, however, some promising smaller scale studies going on – which will eventually ramp up to full scale studies if initial results justify it.

Australian medical technology company SYMBYX has completed its first human trial of the use of laser light therapy (photobiomodulation or PBM) to reduce the symptoms of Parkinson's by targeting the gut-brain axis.

The proof-of-concept trial showed that measures of mobility, cognition, dynamic balance, sleep, motivation, and fine motor skills of participants were all significantly improved.

Since then, these results have been confirmed in a follow-up trial in Sydney – soon to be published in the *Journal of Photomodulation, Photomedicine and Laser Surgery*.

Combined, these results reinforced that larger, randomized placebo-controlled trials are warranted to further consolidate the data.

Two such trials using SYMBYX lasers are underway in Sydney and Canada, with results expected in the first half of 2022.

SYMBYX uses proprietary, super-pulsing laser technology that delivers optimal doses of light therapy without generating heat. The lasers are non-invasive, painless to use and portable. They are medical grade lasers, containing diodes manufactured in Sweden under exclusive license to SYMBYX, and are CE marked and ARTG listed.

“Photobiomodulation therapy can energise cell mitochondria and help with the loss of cellular energy that is common in Parkinson's,” said SYMBYX CEO Dr. Wayne Markman.

“Most people don't realise that their colon has the capacity to produce both dopamine and serotonin, the critical neurotransmitters required for healthy brain function.

“Photobiomodulation to the gut reduces inflammation and promotes the metabolism of short-chain fatty acids – in turn influencing the production of more dopamine and serotonin. This process delivers therapeutic benefits to people with Parkinson's, who are impacted by the loss of dopamine,” he said.

The proof-of-concept trial in Adelaide involved 12 participants who had been diagnosed with Parkinson's by a neurologist. Six were randomly chosen to begin 12 weeks of transcranial, neck and abdominal photobiomodulation in a clinical setting before continuing with the treatment for a further 40 weeks at home.

The remaining six were waitlisted for 14 weeks before commencing the same treatment.

The cranial, neck and abdominal regions were targeted for treatment based on the importance of the gut-brain axis in Parkinson's, the richness of the enteric nervous

system that governs the function of the gastrointestinal tract, the proximity of the vagus nerve in the neck – and previous success via these target areas in animals.

Participants were assessed for mobility, fine motor skills, balance and cognition before treatment began, at the four-week mark, after 12 weeks and then at the end of the home treatment period.

All showed improvement in the clinical signs of Parkinson's – including functional mobility, fine motor skills and cognition. These improvements were maintained for as long as treatment continued, for up to one year in a neurodegenerative disease where decline is typically expected.

None of the participants experienced significant decline in any outcome measure over the year.

It is believed this was the first clinical trial of using photobiomodulation to target the gut-brain axis. However, several small trials and case studies are underway exploring transcranial photo biomodulation for Parkinson's.

Sources

[SYMBYX](#)

[Improvements in clinical signs of Parkinson's disease using photobiomodulation: a prospective proof-of-concept study](#)

[Gut health to affect changes in Parkinson's disease](#)

Other scientific articles on photobiomodulation (PBM) for Parkinson's

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6128061/>

<https://www.frontiersin.org/articles/10.3389/fnagi.2020.00089/full>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6041198/>

Martin Pryor and the tales of his dog, Bungee

Writing a children's book about a dog named Bungee – in fact, a series of books about this dog – was never on Martin Pryor's to-do list.

"It was an accident," laughs Martin, 68, who is living with Parkinson's and has so far released *Bungee, A Doggy Tale*, and *Bungee's Buddies*.

"I was just sitting down taking a rest from writing music and in walked our dog. Instead of going on with the song, I wrote a few lines of poetry about him. It became a book and then a second, and a third, and now there are eight in the series I've written, with the first two released.

"Bungee is our dog, and he was a rescue dog. The books follow his life and adventures and are written to make reading enjoyable for primary school children. Once the publishing costs are covered a percentage of the profits will go to

Parkinson's NSW. It's the least I can do to thank them for all they do for people living with Parkinson's."

Martin, who lives with his wife in North Balgowlah, released a CD in 2017 called *Hot Sand*, which raised \$1500 for Parkinson's NSW. He had played guitar in bands as a young man but had a variety of careers until his retirement in 2016.

"Originally I was an art teacher," Martin explains. "And then for many years I was a professional sailor, sailing around the world. Then I was a history teacher for 20 years and from 2011 I transferred from history to directing a sailing program at the school where I had taught."

By 2013, Martin was also a keen cyclist, very fit and slim, when he fell down some stairs.

"It took me ten weeks to recuperate," he recalls. "I had problems with my left knee and other things. I could ride again, but it just didn't feel right. I couldn't get the power I used to have. In 2016 when I had issues with my back, I went to see a physiotherapist I'd known a long time.

"She asked me to put my arms across my chest and I noticed my wrist shake and wondered what that was about. I had no idea, but I could see the look on her face. She asked me to see a neurologist. When I was diagnosed with Parkinson's, I said thank heavens for that. It was a relief because I thought it was something much worse."

Following his diagnosis, Martin retired, and it was when he was tidying his study at home that he found his old guitar.

"The words to Parkinson's Blues just came into my head," he says. "I'd been in bands from rock to jazz, in choirs, but I hadn't touched a guitar for 37 years. Now I've done three albums, with the fourth to come."

Since writing his first children's book two years ago, Martin and his family have been working on promoting the books.

"It was fun to write the books and as a teacher I have a good understanding of what helps children to read," says Martin. "I also have lifelong friends who are primary school teachers. I knew what I wanted for the illustrations and supplied the artist with lots of photos of the dogs I was writing about as well as a description of how I wanted them used. I'm very happy with the illustrations.

"We plan to sell books at book fairs and the Manly markets; my son's girlfriend promotes them on an Instagram account, and I do school visits and email broadcasts.

Just recently I've signed with a book outlet in Britain called Featherbed Tales (<https://featherbedtales.com/>). My book is their first outside author on their website.

This site allows people to record themselves reading the books there so that their child or grandchild can log in and hear the book being read to them as they follow the pages, which is great for families who can't see each other easily."

If you'd like to buy copies of Martin's books, you can purchase them on Amazon, Barnes & Noble, Xlibris and Booktopia. Martin also has a number of personally signed books available through Thebungeebooks@gmail.com

New Support Group Leader

People living with Parkinson's disease in the Mid North Coast Local Health District now have the support of Parkinson's Specialist Nurse Jody Lloyd. She replaces Specialist Nurse Rachael Mackinnon who has relocated to Sydney and now works in the role of Clinical Lead for Parkinson's NSW.

Jody is based in Port Macquarie and will support the Port Macquarie, Kempsey, and surrounding communities. The position is being co-funded by Mid North Coast Local Health District and Parkinson's NSW.

Jody is a nurse with advanced education and more than a decade of experience spanning roles in both Australia and the UK. She has experience in Parkinson's, Aged Care, Cardiology, health education and evaluation of standards of care.

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Meet our Staff - Peter Evans, Digital Campaigns Manager

Peter Evans – who prefers to be called Pete – has a role at Parkinson’s NSW which bridges the work of the Fundraising and Digital Marketing teams.

He is responsible for helping to conceive, then building, driving, and measuring all of the Parkinson’s NSW online sponsorships and events. It’s a job which requires knowledge and experience of both the event management and fundraising worlds – with a large dose of technology skills thrown into the mix.

Pete began his career almost 20 years ago in event management in his hometown of Brisbane – from where he still works remotely. He then made his first foray into the not-for-profit world by joining Drug ARM, an organisation that provides a range of services to support individuals and families affected or at risk of being affected by drugs and alcohol.

From there, he moved into fundraising for Guide Dogs Australia, Seeing Eye Dogs and Vision Australia.

“During my time at Vision Australia I was fortunate to be mentored by Jo-Anne Reeves and Margaret Scott, who are today the CEO and Chair of Parkinson’s NSW, respectively.

“Jo-Anne and Margaret were among the pioneers of modern, more targeted, and efficient fundraising. As new trends emerged, they would urge me to explore and develop new skills – particularly in the online space,” he said.

Pete has been growing that skillset for the past 16 years now, and he didn’t think twice before accepting an offer to join Parkinson’s NSW which was itself evolving from a traditional approach to fundraising, to a more modern and measurable model.

“I really enjoy working for an organisation where everyone gets along and shares the same goals,” said Pete. “I’m also in a role where I can experience and appreciate the services actually delivered by the organisation. I can be exposed to Support Groups and see exactly what our nurses, counsellors and support coordinators are delivering for people living with Parkinson’s and their families.”

When he is not on his computer for work, Pete prefers to take a distinctly non-digital approach to life. He enjoys watching movies, walking his dog, and building Lego models.

Resuming travel is high on his future agenda. Pete and his partner were on the first leg of an overseas adventure when COVID-19 struck and Queensland closed its borders. They quickly returned and were able to quarantine at home instead of in a hotel.

Fast forward two and a half years, and now Europe and America have re-opened. “I can’t wait to get on a plane again!” said Pete.

Support Group Celebrates

Eurobodalla Parkinson's NSW Support Group celebrates 30 years of friendship and community.

The Eurobodalla Parkinson's Support Group celebrated 30 years of providing support, community, and friendship to people living with Parkinson's disease in the Eurobodalla Shire.

Secretary for the Group and longest-serving member, Joy Overs said the group has grown since she joined eight years ago. "30 years is a long time for a group like this. To be able to support each other for that long and for people to continue to get something out of the group is amazing."

The vibrant group gets together socially but also share information and builds connections friendship and camaraderie.

When asked what the Eurobodalla Parkinson's Support Group has meant to her, Ms Overs had one word: "Survival".

"Being able to relate to people who can understand what's happening and the friendships I've built, have been wonderful. My family has also been marvellous – there are some people who have nobody to rely on outside of this group, which is something we don't take lightly".