

## InTouch Newsletter

November 2021

### Meet Cassie

**Cassie Morgan has been appointed as the new Support Group Coordinator.**

She succeeds Felicity Jones in this role. Felicity has moved to the role of Client Services Coordinator for Parkinson's NSW.

Cassie moved from her hometown in Warrnambool, Victoria, to take up her new job.

She completed a Bachelor of Health Sciences degree at Deakin University before conducting research in the Aged Care space, and then worked in local government delivering Social Connection projects.

"My studies in Health Sciences have enhanced my understanding of Parkinson's and how the disease can impact a person's physical, social, and mental health and wellbeing," said Cassie.

"I'm excited to use my background in community engagement to connect people living with Parkinson's and their carers to Parkinson's NSW Support Groups across the state.

"I'm passionate about increasing the reach and engagement of Support Groups – and look forward to working closely with them to provide a safe space and social connections for people living with Parkinson's and their carers."

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### Australian company achieves promising results with laser therapy

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 about to commence in Sydney and Canada, with results expected in April 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  
Parkinson's South Australia & Northern Territory

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## My Telehealth Experience

Geoff Whale from Taree, was diagnosed with Parkinson's six years ago – but suspects he had Parkinson's for two years prior to that.

Geoff, now 80, only found out about Parkinson's Specialist Nurses 18 months ago when he was dealing with an admin nurse in a medical practice.

"She was the main contact for referrals and things," explained Geoff. "I was speaking to her about another referral so that I could continue to attend the special exercise classes run by exercise physiologists for old veterans.

"The classes have been wonderful. She also told me about the Parkinson's Specialist Nurse Rachael Mackinnon and gave me her contact details. I got in touch with Rachael and she explained how she could assist me.

"Rachel is absolutely wonderful for knowledge about Parkinson's – infinitely superior to any doctor in town. They read her reports and say: 'I couldn't have done that'."

**Geoff used Rachael recently for a Telehealth conference with his new specialist, Dr Sam Bolitho, who is based in Sydney at St Vincent's Hospital.**

(Coincidentally Geoff knew Dr Bolitho's grandfather when they were both in the air force in the late 1950s).

"Rachael set up the Telehealth conference and it was excellent," says Geoff. "I was having some big changes made to my medications because some of the medications I had for other health issues were not Parkinson's-friendly.

"Sam knew things needed adjusting and it was as good as being in his surgery. Even though I had written out a list of questions for the appointment, I was about to forget one thing.

**"Rachael was able to prompt me because she had gone through things with me before. If I'd been alone to see him, I could easily have forgotten things.**

"There is no neurologist in Taree, just one who visits Forster on weekends. The Parkinson's Specialist Nurses are the best thing that's ever happened for people with Parkinson's. Rachael is so experienced and knowledgeable and worth her weight in gold."

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## The Parkinson's Voice Project takes off

Bonnie Nilsson and Sally Ireland make a great team.

Bonnie is a Music Therapist and Sally is a Speech Therapist with a background in singing.

Together with Vince Carroll – a Parkinson's Specialist Nurse based in Coffs Harbour – they developed the Parkinson's Voice Project which is now poised for launch across the state.

The Project had its beginnings in the pre-COVID era when Bonnie was delivering the program in person for the Nambucca Parkinson's Support Group with Vince's support.

As many as 50 to 90 percent of people living with Parkinson's experience speech issues including reduced loudness, limited respiratory support, a monotone voice and reduced voice quality. This can seriously affect their ability to communicate their wants and needs.

The voice intervention addresses these speech challenges through high-effort vocal and respiratory tasks, speech exercises, and group singing – as well as providing social communication opportunities.

Seeing the success that Bonnie was achieving, Vince asked her to work with him to start up a voice development program for the Coffs Harbour Parkinson's Support Group.

They felt that the program could be further developed with the addition of a Speech Therapist to the team, so they approached Sally Ireland – both for her professional skills and passion for music.

The Parkinson's Voice Project was established as a face-to-face program in February 2020 but had to transition online due to COVID-19 restrictions in the following months to help participants maintain social connections.

The Project began a formal eight-week online program in October 2020. It was delivered in 90-minute sessions including voice warm-up, high-effort vocal and respiratory tasks, speech exercises, group singing and social communication.

The online program's objective was to improve participants' voice-related quality of life and voice intensity by 50 percent.

The results it delivered included:

- 100% of participants maintained or improved their voice-related quality of life
- 100% of participants reported being satisfied with the program
- Pulmonary function improvements in individuals ranged from 3% to 37%

The Voice Project also achieved significant peer recognition when it won the 2021 Quality Awards of the Mid North Coast Local Health District.

“While working with Zoom does not allow real-time interaction – so assessment of individual progress can be tricky – it does have other advantages. For example, Zoom has ‘break out rooms’ which allow myself and the person I am assessing to virtually step aside from the main group so we can work one-on-one,” explained Sally Ireland.

“We are learning what works and what doesn’t in the online space as we go along, so the Project is evolving,” said Bonnie Nilsson. “We can certainly assess functional improvements using questionnaires, and we are able to directly observe rhythm, coordination and facial expressions. And there is no doubt this program – whether face-to-face or online – has a positive impact on the mental health of people living with Parkinson’s.”

While Bonnie, Sally and Vince are the public faces of the Parkinson’s Voice Project, it would not have been possible without the financial support of:

- The Rotary Club of Coffs Harbour Daybreak
- Palm Beach Bowls Club
- Charles Sturt University
- Parkinson’s NSW, and
- The Mid North Coast Local Health District

Interested in participating in the Parkinson’s Voice Project in your area?

Please phone Vince Carroll, Specialist Parkinson’s Nurse: **02 6659 2333**

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## New smartcard for easier taxi trips

The Taxi Transport Subsidy Scheme (TTSS) is replacing paper travel docketts with smartcards.

The credit card sized smartcard is easier to carry, includes a photo for added security and works by simply tapping a taxi payment terminal where the subsidy portion of the fare will be deducted.

So far the TTSS Smartcard has been introduced to the following areas:

- New England including Tamworth, Armidale, Glen Innes and Inverell
- Goulburn
- Queanbeyan

Cards are currently being distributed to participants in Western, Northern and Southern NSW (excluding the Hunter, Central Coast, and Illawarra) and will be rolled out to the rest of regional NSW and Metropolitan Sydney later this year.

Participants are required to provide a photo to be printed on their card.

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Transport for NSW will be in contact with participants prior to the rollout in their area. Participants can call 131 500 to check that their contact details are up-to-date.

To find out more, please visit <https://transportnsw.info/taxi-subsidy-scheme>

**Source:** Transport NSW

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## My (Parkinson's) Life - Glenda Reichman

Glenda Reichman was born in Benoni, South Africa and grew up in the town near Johannesburg.

"I finished high school and decided to study pharmacy," says Glenda. "Looking back I was far too young to make a decision about a career then, but I knew I wanted to go to university. My brother was a pharmacist and it looked quite OK as a choice, so off I went."

While at university, Glenda met her husband Barry, and they began planning their future lives.

In 1986 they moved to London for a few years where Glenda requalified as a pharmacist. They married two years later and emigrated to Australia where she requalified again.

"Our boys were born in Australia," says Glenda. "Shaun is now 27 and Craig is 24. All of Barry's family and mine have made the move here. Family is very important to us and it's nothing to have 18 people for dinner."

As Glenda's family life developed, she left pharmacy and ran a successful daycare centre from home for 13 years. It was in 2004, while she was running that business, that Glenda noticed the first signs of something not quite right with her right hand.

"When I was brushing my teeth, or even waving, I realised I was using my left arm," says Glenda. "On closer attention I realised the fingers on my right hand weren't moving properly. So off I went to my GP, who sent me to a neurologist. I went on my own, thinking it was nothing serious. He sent me for a battery of blood tests and booked me in for an MRI scan. He told me to bring the scan and Barry to the next appointment."

This last suggestion tipped off Glenda, just 39, to the seriousness of her specialist's suspicions.

"I began to get really frightened as this was proceeding a lot faster than I had anticipated," she recalls. "When I arrived for the appointment with Barry, the neurologist proceeded to tell me that by a process of elimination, and the presentation of classic symptoms, I had early-onset Parkinson's disease."

“Barry jumped for joy, and I crumbled. I said to him ‘Are you mad? I’ve got Parkinson’s disease!’ I hadn’t realised he was thinking I could have a brain tumour and Parkinson’s was a much better diagnosis. I would probably die with Parkinson’s, but not from it.”

While Glenda struggled to understand how she came to have Parkinson’s so young and with no family history of the disease, her husband’s positive, supportive attitude meant she could start to adjust.

“We had two wonderful boys who were just ten and seven; how could I curl up into a ball and feel sorry for myself?” she recalls. “I had to fight this with everything I had.”

Glenda’s neurologist suggested she keep the diagnosis to herself.

“Nobody needs to know, your symptoms are mild, you are young,” she says he advised. “So I listened. I was running a daycare centre and did not want to be labelled with a condition that could impact on my ability to look after young children. I shared the diagnosis with the adults in the family who showered me with loving support, but I did not tell anyone else.

“I learned to hide my mild symptoms and hoped nobody noticed the slight shake in my right hand or question why my handwriting was so small.

“As part of my pharmacy degree I had studied a topic on Parkinson’s which was all about how it affected old people, but nobody had told me it could also affect young people. How I wish someone young had shared their story. Maybe it would have made my diagnosis easier to accept.”

During what Glenda refers to as her ‘silent years’ as she kept her diagnosis secret, she found the support groups from Parkinson’s NSW were helpful, whether a teleconference group or face-to-face with the Tulip Belles’ monthly meeting.

“All this gave me the strength to reach a turning point, ten years on, where I was ready to share my story,” says Glenda. “I invited my close friends to my 49<sup>th</sup> birthday lunch and told them about my diagnosis. I wanted it to be a happy occasion and a celebration of life.”

By early 2016, Glenda had decided to have Deep Brain Stimulation surgery, after much research and consideration.

“I was well-prepared, and I came through with no complications,” she says. “I wanted to have it at the optimum time for improved control and it’s given me a second chance at life. I am not currently in the workforce but am busy as a wife and mum.”

Today Glenda continues to share her experience of living with Parkinson’s and has even written an e-book, *Love Yourself and Laugh, Laugh, Laugh*. This book details Glenda’s experience of Parkinson’s and how she made decisions about surgery as well as managing various symptoms.

“I want to help as many people as possible,” says Glenda. “It took me a long time to share my diagnosis but now I am completely open. If people want to ask me anything about Parkinson’s I am happy to talk about it.”

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## Regional Seniors Travel Card

If you live in regional NSW and receive a Disability Support Pension or Carer Payment you will be able to apply for a Regional Seniors Travel Card from next year.

In addition to the newly eligible applicants, the Regional Seniors Travel Card trial is being extended to allow all eligible seniors to apply in 2022 and 2023.

The \$250 pre-paid Visa card is designed to ease the burden of travel costs and can be used to pay for pre-booked NSW TrainLink train and coach services, taxi trips and fuel.

This means access to affordable travel options to attend medical appointments, buy groceries, or make a few extra trips to visit the grandkids.

**Source:** Transport NSW

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## Carer de-stressing exercises

Whether caring begins gradually or happens suddenly, most carers will need to develop new knowledge and skills. One of the most experienced effects of caring is stress.

Learning to manage your stress is an important and possibly new skill you will need to learn. If you don’t care for yourself, you won’t be able to care for someone else.

These five simple tips can help you manage your stress.

1. **Stay positive.** Laughter lowers stress hormones levels, reduces inflammation in the arteries, and increases ‘good’ HDL cholesterol levels.
2. **Meditate.** Practice focused thought and deep breathing. They have been shown to reduce heart disease risk factors such as high blood pressure. Meditation's close relatives – yoga and mindfulness – can also relax the mind and body.
3. **Exercise.** When we exercise our body releases endorphins. Exercising not only helps you to de-stress, it also protects against heart disease.
4. **Disconnect.** It is difficult to de-stress when it follows you everywhere. Unplug yourself. Avoid emails and TV news. Take some quiet time for yourself each day.



5. **Things you enjoy.** Simple things like a warm bath, listening to music, or spending time on a favourite hobby, and being creative can all help to lower the stress in your life.

Make time to exercise. Many of us find it difficult to carve out time to exercise – but 30 minutes of moderate activity daily will assist you to manage the emotional and physical challenges of being a carer.

Regular exercise improves resilience, promotes better sleep, reduces stress and depression, increases strength and flexibility, and increases your energy and alertness. It also helps maintain a healthy weight and build immunity, and protects against common health problems.

Here are some easy de-stressing exercises you can do at home.

### **Belly Breathing or Abdominal Breathing**

When we are stressed, we generally breath shallowly in the chest. Taking deeper breaths and filling the lungs completely triggers many physiological changes. Your heart rate slows, blood pressure decreases, and muscle tension eases.

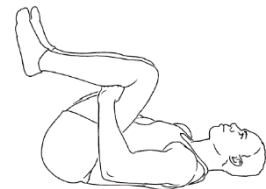


Lie down and put one hand below your belly button. Breathe in through your nose to completely fill your lungs (your stomach should rise). Slowly release, breathing out through your mouth. Continue for a few minutes.

### **Knee Hug**

This exercise will help relieve a tired back and release stress.

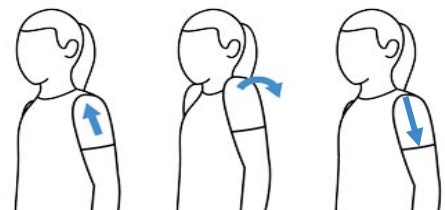
Lie down and hug 1 or both knees to your chest. If you can hug both knees at the same time, rock from side to side to massage your spine.



### **Shoulder Shrug**

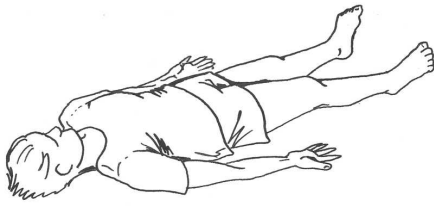
Holding tension in your neck and shoulders is common. Shoulder shrugs can help release the tension.

Sitting comfortably with good posture. Breathe in and bring your shoulders up towards your ears. Tighten your arm and shoulder muscles. Breathe out and relax your neck and shoulders pulling your shoulder blades down. Repeat a few times.



### **Corpse Pose**

In this exercise you're trying not to anything. Sounds a bit contradictory but it's more difficult than you think. It's about noticing and acknowledging your thoughts and feelings but not dwelling on them.



Lie down with your arms, palms up, relaxed at your sides. Close your eyes and focus on the rise and fall of your breath. If you have invasive thoughts, acknowledge them, and visualise them floating away. Return to focusing on your breathing and relaxing any tight muscles.

If one method doesn't work for you, try another. Learning to de-stress takes practice. Be patient with yourself and you will reap the benefits.

Getting help from a professional is always a good idea, especially if you feel that nothing seems to help. Talking to your primary care doctor is a great place to start.

Contact Carers NSW on 02 9280 4744 or Carer Gateway on 1800 422 737 or visit [www.carergateway.gov.au](http://www.carergateway.gov.au)

#### References:

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## Carers Tips – Physical Assistance

Looking after yourself physically as a carer is as important as caring for the person with Parkinson's. A carer who is injured can't effectively care for anyone.

Following are some helpful tips for when you need to physically assist someone and don't have any specialised equipment.

### Helping Someone Stand

- Make sure the person is wearing shoes or non-skid socks, otherwise their feet may slide.
- Ask them to move to the front of the chair and place their feet directly under them.
- Block their knees with your knees to help them keep their legs under them.
- Place your arms around their waist.
- Instruct the person to put their hands on the arms of the chair (never around your neck).
- Ask the person to lean forward so their nose is directly over their toes.
- Tell them to push off with their hands when you are both ready.

- Count to three, and then provide any additional support the individual needs to stand.

### **Helping Someone Walk**

- If the individual needs only minimal assistance to walk, ask them to take you by the arm.
- If they need more assistance, walk behind them; place one hand on their shoulder and the other on their belt or waistband. Stand close and walk in step behind.
- Do not attempt to do all the work yourself. Ask the person to do as much as they possibly can.

With care and practice, you can help someone rise to a standing position and walk safely with minimal risk to yourself.

References:

<https://www.highspeedtraining.co.uk/hub/ergonomic-approach-manual-handling/>

<https://www.alwaysbestcare.com/how-to-help-someone-stand-up-and-walk/>

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