

## InTouch Newsletter

August 2021

### Parkinson's Specialist Nurses in action

*Parkinson's Specialist Nurses are highly trained and experienced nurses based in communities of need. They are dedicated to supporting local people living with Parkinson's.*

*These Nurses are funded 50/50 by Parkinson's NSW and the Local Health District in which they are based. This series of articles invites clients to talk about the value of Nurses to their local Parkinson's community.*

### Roslyn and Brian Stone – Supported by Rachael Mackinnon

Roslyn and Brian Stone moved to Port Macquarie 12 years ago after spending many years living in Adelaide.

"We came here to retire and enjoy our life," said Roslyn. "I was originally from Taree, and we had our honeymoon in Port Macquarie. One daughter and her children moved up here as well and the other already lived in the region. Just our son was left in Adelaide.

"I also like to garden, and Adelaide was harder with water restrictions. Moving here worked out really well and we were enjoying life and doing things like going for walks along the beach. Then, eight years ago, Brian was diagnosed with Parkinson's."

Roslyn and Brian, now 82, connected with the local Parkinson's Support Group and worked to fundraise for a Parkinson's Specialist Nurse for their region.

"It's been very successful," says Roslyn of the nurse appointed. "Rachael Mackinnon is just one in a million. I can't believe we got her!"

Roslyn, who had been Brian's caregiver until he recently transitioned into full-time care, has found Rachael particularly helpful.

"I always felt guilty that I wasn't doing enough as a carer," she recalled. "Rachael explained to me that I could only do what I could do, and it was normal to have the feelings and anxiety I was having.

"I was supporting Brian as much as I could and that support from her was there for me, and it was very genuine."

Ultimately, it was Rachael who helped Roslyn to recognise when it was time for Brian to move into a nursing home.

"He had a fall last Easter and was taken to hospital," explains Roslyn. "We didn't want his medication changed in hospital as it would stiffen him up and make it worse.

Rachael encouraged me to move him to a private hospital under his doctor to monitor his condition while I had some respite.

“I was able to see that it was time for full-time care and so that he could get the help he needed. Rachael explained how to make the transition and explained the options for what could be done. The choice always came back to me, and I could understand what was available and decide what would work.

“She was there for him when he was in hospital, watching the monitors. I could call her at different times of the day to ask her things.

“I just can’t explain it enough, how phenomenal she is. Her knowledge is amazing. She’s just amazing.”

### **In-person coaching now available via Carers Gateway**

If you are a carer, you can currently access support and services from the Carer Gateway. From July 2021, carers Australia-wide will also be able to access a new in-person facilitated coaching service through Carer Gateway service providers within their local area.

This new service will mean that carers can talk to a professional coach to reflect on their experiences and needs, identify personal goals and create a plan to reach these goals.

In-person facilitated coaching delivered through Carer Gateway was piloted in South Australia and Victoria from August 2020 to February 2021. Carers who were part of the pilot reported that the in-person facilitated coaching helped with their sense of empowerment and taught them new strategies to put into place to support their own wellbeing in their caring role.

Carers can find out more about the in-person facilitated coaching service and other services such as counselling, targeted financial supports, peer support groups or planned and emergency respite by contacting the Carer Gateway.

Call 1800 422 737, Monday to Friday 8am–5pm and select option 1 to speak with a local service provider. You can access support for emergency respite on the same number at any time.

Source: [disAbility e-news](#)

## **We need to be having more conversations about menopause**

*By Heather Kennedy*

I was first diagnosed with Parkinson's in 2011, at the age of 41.

As I approach the menopause, I've noticed changes in myself.

First of all, I have a lower libido. I just want nothing to do with sex at the moment, which is unusual!

Secondly, I find myself turning inwards. I find myself getting quieter and retreating into my shell, which means I'm further isolating myself inside this condition.

I implore women with Parkinson's to make sure you connect with other women at this time in your life – talk to one another, come together. We need to be having way more conversations about menopause, and particularly about how menopause affects women with Parkinson's.

This getting smaller, this sense of receding as a person – it's the opposite of what people with Parkinson's should be doing.

I never questioned how the condition might affect me as a woman until I started experiencing unexplainable off times in the days leading up to my periods. I was complaining to my girlfriends, when one friend schooled me.

She explained that during periods, the efficacy of women's medication decreases.

No one had ever told me that! I then started to notice the pattern like clockwork. Since being perimenopausal, though, my periods have become far more unpredictable in heaviness and length.

I have started to sweat through my sheets every night. I was unsure if it was a result of my medication or because of the menopause, and that's the problem – none of these changes happen inside a vacuum.

It's not like I can pinpoint that 'this thing is caused by hormonal changes' and 'this part is caused by medication'. All of these things melt into one so it's hard to tell what's happening to my body. Most of the time the doctors can't tell.

I tried to ask my doctor if the night sweats could be because of the menopause. He insisted I was too young – even though at 49 I don't think I am – and just told me to see my gynaecologist. Though he is usually patient, I was a little surprised at how he brushed me off.

There are other ways my progressing Parkinson's affects me as a woman, urinary incontinence being one. Sometimes I'm too stubborn to wear a pad – I'd rather pee in my pants than wear a big honking mattress between my legs! That just doesn't feel sexy!

I suppose getting old in itself makes you feel a little less juicy but combine that with the symptoms associated with this condition – and the onset of menopause – and it's fair to say I feel a little more insecure these days.

Dating men has made that harder too. As soon as I say I have Parkinson's, I never hear from them again.

One thing I've noticed in the Parkinson's community is how women are openly shamed for experiencing impulse control disorders to do with sex (hyper compulsion being a side effect from our Parkinson's medication) but when it's men you hear that phrase: 'Boys will be boys'.

I just think that dynamic is so wrong. I experienced hyper compulsion but, in my case, it was with cleaning and shopping. I got very intense about cleaning out the closet – my daughter said, 'Mum, you've been cleaning the closet for three days'.

These drugs are powerful, and they cause major changes in us. We need more warning about that.

### **Parkinson's and menopause: the facts**

- Common side-effects of menopause can often be confused with Parkinson's symptoms
- Currently there isn't enough research on women with Parkinson's for doctors to know whether to recommend the use of hormone replacement therapy (HRT)
- A study involving a group of women living with Parkinson's aged 35 to 59 revealed that many were anxious about their bodies and sexual image – unfortunately, such concerns are rarely addressed by doctors
- Parkinson's is more common in post-menopausal women.

*Heather Kennedy, a writer, Parkinson's advocate, and mother who lives near San Francisco in the United States. This article was originally published in [Parkinson's Life](#)*

## **Regional Seniors Travel Card extended for two years**

More than 300,000 seniors in the regions will benefit from reduced travel costs with the NSW Government committing \$246 million to extend the Regional Seniors Travel Card for an additional two years.

The [Regional Seniors Travel Card](#) is a \$250 prepaid Visa card designed to ease the burden of travel costs for eligible seniors in rural, regional and remote areas.

Deputy Premier and Minister for Regional NSW John Barilaro said seniors across NSW have benefited from the initial two-year travel card trial, with 337,500 cards issued in 2020 and more than 330,000 cards issued to regional seniors in 2021 so far.

“Living in regional NSW is rewarding in so many ways, but every day we struggle with the tyranny of distance,” Mr Barilaro said.

“This card has made a huge difference to the lives of seniors living in the bush who have fewer transport options than those living in the city, and we’re excited to announce it will be offered again in 2022 and 2023.”

Treasurer Dominic Perrottet said the extension and expansion of the Regional Seniors Travel Card is part of several cost saving measures aimed at seniors in the latest State Budget.

“We know the cost of living is a big issue facing seniors and households, which is why the Regional Seniors Travel Card is being offered to even more people,” Mr Perrottet said.

“Increased funding will allow us to extend the card from 2022 to more seniors in the regions, including those eligible for the Age Pension and receiving either a Disability Support Pension or a Carer Payment from Services Australia.”

The Regional Seniors Travel Card can be used for pre-booked NSW Trainlink Regional trains and coaches, fuel, and taxis.

From 2022, eligible applicants will include seniors who have reached the Age Pension age and are receiving:

- The Age Pension through Services Australia or the Department of Veterans’ Affairs
- A Disability Support Pension or a Carer Payment from Services Australia
- A Service Pension issued by the Department of Veterans’ Affairs
- A Disability Pension through the Department of Veterans’ Affairs under the Veterans’ Entitlements Act 1986
- A War Widow(er)’s Pension issued by the Department of Veterans’ Affairs.

People who hold a Commonwealth Seniors Health Card issued by Services Australia or the Department of Veterans’ Affairs are also eligible.

The regional boundaries for applicants will remain the same in 2022.

More information about which regional areas are included in this initiative can be found at [Service NSW](http://www.service.nsw.gov.au) [www.service.nsw.gov.au](http://www.service.nsw.gov.au).

## **Inner retinal thinning associated with hallucinations in Parkinson’s**

Researchers have found a link between [visual hallucinations in people with Parkinson’s disease](#) and the thinning of the inner retina in the eye.

As part of the study – published in research journal [Scientific Reports](#) – researchers analysed clinical and demographic data from 40 people with Parkinson's, all of whom were over 50 years old and had had the condition for at least three years.

Participants were assessed using the cognitive screening tool Montreal Cognitive Assessment (MoCA) and through interviews with neurologists.

The results showed that patients with visual hallucinations had a thinner inner retinal layer than patients without them.

The researchers wrote: "In patients with Parkinson's disease, visual hallucinations appear to be associated with a thinning of the inner retinal layers and, possibly, with reduced visual acuity.

"Further research using a longitudinal design is necessary to confirm these findings and to establish the causality of these relationships."

**Author:** Simge Eva Dogan

Originally published in [Parkinson's Life](#)

## Seniors boost their digital skills

Older Australians are turning to digital communications like email, zoom and social media like never before, thanks to the COVID pandemic restrictions.

Research from the Australian Communications and Media Authority (ACMA) shows the number of people aged 75-plus who use social media doubled from 18 percent in June 2019, to 41 percent in June 2020.

Emailing increased from 37 percent in 2019 to 81 percent in 2020. Use of messaging/calling applications and mobile texting also increased significantly.

"The digital divide between younger and older Australians has narrowed, with this trend accelerated by the desire to maintain contact with friends and family during lockdowns," ACMA Chair Nerida O'Loughlin said.

77 percent of Australians in June 2020 had used an application to make voice calls, video calls or send messages in the last six months, up from 67 percent in 2019.

More than one in three Australians increased their use of social networking apps following the introduction of COVID-19 restrictions.

"After years of gradual drift towards communications and social media applications, we have now seen a more pronounced shift in the way Australians connect," Ms O'Loughlin said.

"More people are relying on social networking apps and mobile communication services like Facebook Messenger and Zoom to stay connected."

Other findings from the research:

- In regional locations, use of nearly all communication services increased. Messaging/calling apps increased from 48 percent in 2019 to 73 percent in 2020
- Facebook was the most used social networking app for all age groups, used by 93 percent of social network users, followed by YouTube (73 percent), Instagram (57 percent) and WhatsApp (48 percent)
- The report shows a continuation of the long-term trend of declining use of fixed-line home phone services for all age groups except those aged 75-plus – their usage was unchanged since 2019
- Nearly all (99 percent) adult Australians used a mobile phone in the previous six months to June 2020.

National Seniors is an enthusiastic partner in a federal government funded program called Be Connected, which helps older Australians learn more about using the internet, including communicating over digital technologies.

[Be Connected](#) is a free program of key advice, lessons, and practical tips to help you become more involved, whilst being safe and secure, in the online world.

You learn at your own pace with free courses on everything from how to access the internet, make video calls or set up your device.

Source: [National Seniors Australia](#)

## **What Parkinson's symptoms do people most want to see improve?**

*By Simge Eva Dogan*

A study by charity Parkinson's UK has examined what symptoms matter most to people with Parkinson's disease as the condition progresses.

The charity surveyed 790 people with Parkinson's and asked each participant to list three symptoms or side effects that they would most like to see improve.

Of their responses, 59 percent were motor symptoms, 37 percent were non-motor symptoms and 3 percent were medication related problems.

The team identified a link between how often symptoms were reported and disease duration – for example, people who had lived with the condition for two years or less were more likely to report tremor as a key issue than those who had lived with the condition for longer.

Commenting on their findings, the study authors wrote: "We hope these data will stimulate further research to improve treatments, care and support for people with Parkinson's disease that addresses these important aspects of the condition."

Read the research team's full paper [here](#).

Story first published in [Parkinson's Life](#)

## Flexibility / Stretching

✓ Stretch slowly	✓ Feel stretch, but no pain
✓ Hold each stretch 20-60sec	✓ Breathe deeply
✓ No bouncing or jerking the muscles	

### Body Twist

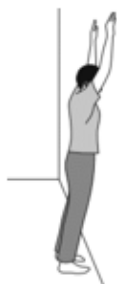
Sit on the edge of a seat. Sit tall. Turn your shoulders to the right. Place your right hand behind you. Twist your body and head to the right as far as you can go without any pain, only a stretched feeling. Hold. Try to relax and breathe.



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### Wall Hang



Face a wall and stand with your feet about 30cm from the wall. Lift your hands straight above your head and place palms on wall, as high as possible. Lean forward without arching your back. The stretch should be felt under the arms and in your chest. If this is too easy, take the feet further back from the wall.

If you can reach, rest your hands on the frame at the top of the door. Keeping your arms straight, slowly lean forward until you feel a gentle stretch. Hold. **Do not over stretch.**



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### Doorway Bend

Stand near a doorway. Lift your arm to the side, to shoulder height. Bend your elbow to 90 degrees and place the entire forearm on the door frame. Gently turn your body away from the arm and feel a stretch in the shoulder and chest. Hold. Repeat on the other arm.



Go to the Parkinson's NSW YouTube Channel to view all of our zoom meeting recordings on the Living Well Playlist at:

<https://www.youtube.com/user/ParkinsonsNSW>

For the upcoming Zoom meetings, see the schedule on the Parkinson's NSW website at: <https://www.parkinsonsnsw.org.au/online-meetings-for-support-groups>