

STANDBYME

IN THIS TOGETHER
parkinson's
NSW

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IN THIS ISSUE

Mediterranean diet could delay Parkinson's disease onset

Read more on page 3

Parkinson's Specialist nurses in action

Read more on page 7

From the CEO

Welcome to the Winter Edition of *Stand by Me*.

Not only have the seasons changed, but so have our way of lives since COVID-19 restrictions eased.

Support Groups are enjoying the social opportunities of meeting in person once again, our Counsellors are able to meet clients face-to-face if they wish, and our Support Coordinators are making home visits.

Change is also in the air within the Aged Care community. The Royal Commission into Aged Care Quality and Safety has just handed down 148 recommendations on how to improve the sector.

Some of these recommendations will be beneficial to the Parkinson's community, and it is our intention to become a provider of Aged Care services.

This will enable Parkinson's NSW to deliver more services in the home, supporting people living with Parkinson's to continue enjoying their own surroundings for as long as possible.

I raised this subject in a recent speech to a gathering at NSW Government House. It was a reception generously co-hosted by Rose Jackson, MLC (Labor) and Leslie Williams, Member for Port Macquarie (Liberal) to wrap up Parkinson's Awareness Month. A report on the event appears in this issue.

We are optimistic that the people we met at Parliament House now have a better understanding of the challenges facing the Parkinson's community. This new awareness – along with the initiatives recommended by the Royal Commission – will create new opportunities for Parkinson's NSW.

Jo-Anne Reeves
Chief Executive Officer



New Parkinson's Specialist Nurse in Hornsby

Suliana Manuofetoa has joined Parkinson's NSW as a Parkinson's Specialist Nurse based at Hornsby Ku-ring-gai Hospital in Sydney.



She began her nursing career eight years ago and became a Clinical Nurse Educator in Neurology four years ago.

Suliana's interest in Parkinson's came about while nursing patients with the disease. She found it a very challenging condition, yet very rewarding to work with people who are bravely living with Parkinson's.

Suliana's passion for assisting Parkinson's patients grew after her grandmother was diagnosed with the disease.

"It built my interest in it even more when I learned a lot from her about how she manages her Parkinson's," recalled Suliana.

Suliana, who grew up in Tonga, had first wanted to become a teacher and then changed her mind to study medicine. However her father disapproved, and she studied commerce instead.

"A year after I moved to Australia I began studying nursing at university," says Suliana. "I am very pleased to be setting up a clinic now at Hornsby Ku-ring-gai Hospital where patients living with Parkinson's can come and see me.

"The northern suburbs of Sydney patients need to travel some distance to access specialists and other Parkinson's services – particularly if they can't drive. I will now be available to guide patients and their caregivers through ways of managing their Parkinson's.

"Caregivers can also be at risk of burnout so providing them with support is important, too," she said.

"It's quite challenging for partners who are caregivers to look after their spouse – especially as the disease progresses. They generally want to keep their partner at home as long as possible, but they will get to a point where they need respite or the partner needs nursing home care.

"I can help to educate caregivers to recognise advanced symptoms of Parkinson's such as cognitive issues or hallucinations, so they can adjust their care. Just as importantly I can also offer caregivers emotional support."

"I'm looking forward to opening the clinic and also speaking at Parkinson's support groups," says Suliana. "I can also facilitate telehealth appointments with neurologists for patients and their caregivers who have difficulties with travel."

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Mediterranean diet could delay Parkinson's disease onset

Eating a Mediterranean diet is linked to later onset of Parkinson's Disease, a study by researchers at the University of British Columbia, Canada, has found.

According to the research, following a Mediterranean-style diet could delay Parkinson's disease by up to 17.4 years for women, and 8.4 years for men.

The researchers studied two diets – the Mediterranean and MIND diets. They are similar, with both focusing on vegetables, pulses, seafood, olive oil, and wine in moderation.

Both diets also encourage minimal consumption of processed and fried foods, red meat, refined grains, added sugars, and saturated fats.

There are small differences between the two. The MIND diet emphasises green leafy vegetables, berries, beans, whole grains, and poultry. It also discourages fruit, milk, and potatoes.

The researchers found that women reaped the most benefits from the MIND diet while the Mediterranean diet had a greater positive effect on men.

The study assessed 286 Canadian participants in total, 167 of whom had Parkinson's onset (i.e., the first symptoms appearing) in the previous 12 years, and 119 were a control group.

Of those with Parkinson's, 68 percent were men – compared to 39 percent in the control group. However, men are 1.5 times more likely to have the disease than women, according to Parkinsons.org.

Adherence to the MIND or Mediterranean diet was assessed for each participant – also considering other health markers, such as exercise, smoking, and diabetes.

The researchers found a correlation between MIND diet

adherence and later onset of Parkinson's, particularly for women.

Females who followed the MIND diet the closest were found to have Parkinson's onset 17.4 years later than those whose adherence was lowest.

"The study shows individuals with Parkinson's disease have a significantly later age of onset if their eating pattern closely aligns with the Mediterranean-type diet. The difference shown in the study was up to 17 years later in women and eight years later in men," said Dr. Silke Appel-Cresswell of the Pacific Parkinson's Research Centre, the Djavad Mowafaghian Centre for Brain Health, and the Division of Neurology in the University of British Columbia Faculty of Medicine.

"There is a lack of medications to prevent or delay Parkinson's disease, yet we are optimistic that this new evidence suggests nutrition could potentially delay onset of the disease," she said.

The MIND diet was originally designed to minimise cognitive decline, and it has been linked to the prevention of Alzheimer's disease and dementia in the past, but the new study is the first research into the effect of the MIND diet on those with Parkinson's disease.

However, the research supports a previous study that found that the MIND diet could reduce incidence and delay progression of Parkinson's disease.

Sources:

Business Insider Australia

*Faculty of Medicine, University of British Columbia, Canada
Parkinsons.org*



Parkinson's Awareness Month boosted community engagement



Nepean Blue Mountains Support Group

April was Parkinson's Awareness Month, including World Parkinson's Day on the 11th of the month.

It was a very busy period for Parkinson's NSW and Support Groups across the state but the results were gratifying in terms of publicity and community engagement achieved.

Parkinson's NSW this year launched 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.



Chinatown Bilingual Support Group

The 18 Support Groups which took advantage of this opportunity to generate publicity and acknowledge their local heroes in their communities were:

- U Chinatown Bilingual
- U Dubbo
- U Illawarra North
- U Kiama
- U Maitland
- U Narrabri
- U Newcastle
- U Port Macquarie
- U South Coast Young
- U Onset and Nowra
- U Coffs Harbour
- U Eurobodalla
- U Inner West
- U Lismore
- U Nambucca Valley
- U Nepean/Blue Mountains
- U Orange
- U Snowy Monaro
- U Tweed



Eurobodalla Support Group



"Nominations varied widely – including Members of Parliament, Allied Health practitioners, supportive community organisations, and active fundraisers," said Support Group Coordinator, Felicity Jones.

"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."



Support Groups also rose to the occasion by holding a variety of community outreach events, including information stands, barbecues and picnics.

Parkinson's NSW also promoted activities throughout the month on its digital and social media platforms, and through publications and media outreach – particularly through radio interviews with the involvement of local Support Group spokespeople.

The special month culminated in a reception held at NSW Parliament House early in May. The event was co-hosted by Rose Jackson, MLC (Labor) and Leslie Williams, Member for Port Macquarie (Liberal).

Attendees included Members of Parliament and Ministers, ministerial advisors, Parkinson's NSW Board Members and senior executives, and representatives of the Parkinson's Support Group community – including:

- U Barry and Vivienne Ross – Nepean/Blue Mountains Support Group
- U Bill and Robyn Lindsay – Manly-Mosman Support Group
- U Lawrie and Christine Gray – Newcastle Support Group and former Director
- U Sandra Elms – Newcastle Support Group and former Director

Guest speakers included Former Deputy Premier John Watkins who spoke compellingly about living with Parkinson's, and Parkinson's NSW CEO, Jo-Anne Reeves.

Jo-Anne's speech emphasised the importance of obtaining Government funding to enable the long-term viability of critical services such as Parkinson's Specialist Nurses in regional and rural communities, the Parkinson's 1800 InfoLine staffed by Registered Parkinson's Nurses and Counsellors, and education for consumers, Primary and Allied Health practitioners, and Aged Care nurses and support staff.



Rose, John and Jo-Anne

"The population growth rate of Australia is just over one percent. However, the average growth rate in Parkinson's will be 40 percent over the next 20 years," said Jo-Anne.

"Today we have more than 69,000 people living with Parkinson's in NSW. A growth rate of 40 percent from that base just cannot be supported with services funded by goodwill and donations.

"Demand for Parkinson's NSW services and support – and pressure on NSW Health – will clearly continue to grow. We can't just kick the can down the road on this issue," she said.

Jo-Anne also emphasised the importance of the outcomes of the Royal Commission into Aged Care Quality and Safety. She said that Parkinson's NSW will be entering this sector in order to better support people living with Parkinson's to live at home for as long as possible with appropriate services for quality of life and wellbeing.

Exercise helps to prevent falls

Exercise is a proven way to prevent falls by strengthening the muscles that keep us upright and improving our balance.

For the greatest benefit try a combination of exercise types – aerobic, flexibility, coordination, and strength. This combination can be found in activities like riding a bike, climbing stairs, yoga, or tai chi.

Following are some simple exercises that can be done at home to help reduce the risk of falls. Do them any time and at multiple times throughout the day. This will enable you to build up your capacity and strength slowly and safely.

Before starting any new fitness program, see your doctor to make sure it's safe for you.

To ensure you are exercising safely, ask your doctor to refer you to a physical therapist or ask a personal trainer to walk you through your routine.

Helpful hints for exercise:

- U Move slowly
- U Stop if you feel faint or experience sharp pains
- U Hold on to a strong support as you exercise – such as a sturdy chair or bench.
- U Stand tall and breathe deeply to improve your posture.

Balance Exercises -Single Leg Balance

1. Stand near a chair or stable object. Hold it with both hands.
2. When steady take one hand off, lift one leg, and hold that position for 10 seconds.
3. If still steady take your other hand off and hold that position. Build up to holding the position hands-free for 45 seconds.
4. Repeat with your other leg.



Tandem Balance

1. Stand near a stable object and hold on to it.
2. Put one foot directly in front of the other. Lift one hand and try to hold that position for 10 seconds.
3. If stable, lift the other hand and hold that position for 10 seconds. Gradually build up to holding 30 seconds.
4. Repeat with other foot in front.



For more information on falls prevention phone the Parkinson's NSW InfoLine: 1800 644 189

If having one foot directly in front of the other is too difficult, try taking a big step forward. Try to not hold onto anything and hold that position for one minute.



When you improve with this exercise, try with one foot directly in front of the other.

Marching on the spot

This exercise will help with foot clearance oversteps. It will assist you with getting in and out of a car or bus and help you feel stronger and less fatigued in climbing up stairs.



Feel free to hold on to one or two sturdy supports – one in each hand if required.

Stand tall. Keep the body straight (avoid leaning to one side). Don't worry if your knee doesn't lift to knee height, just lift as high as you feel comfortable. It will improve over time!

Practice: Two sets of 5-10 steps, alternating between lifting the left and right legs.

Sideways Walking

This will help to improve your hip stability and help you keep your balance if you need to take a sideways step to avoid something.

Face a clear wall and steady yourself against it by placing your palms flat at shoulder level. Then take sideways steps parallel with the wall, sliding your hands along to maintain your stability.

Your steps don't need to be large; small is fine too. Just remember to hold on and maintain a tall stance as you move.

As you improve, try to hold on to the wall with just your fingertips.

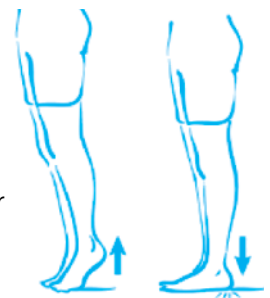
Practice: Two sets of 10 steps – either on the spot or up and back the length of the wall.



Heel raises

Stand up straight behind a chair, holding the back with both hands.

Position your feet hip-width apart. Lift up on your toes. Hold. Lower your heels to the floor. Repeat 10 times.



Sources:

- Harvard Health Publishing, Harvard Medical School
- Stay on your Feet
- Active and Healthy, NSW Government
- Exercise Right

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 jointly funded 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.

Brian and Barbara Grant –

Supported by Nina Digiglio

Brian Grant was 82 when he was diagnosed with Parkinson's in August 2020, but the previous 12 months had been difficult for him with his health.

"He'd had a lot of problems with falls and things, but nobody ever suggested it might be Parkinson's until well after that," said his wife, Barbara. "It was a shock when it was finally diagnosed. It's not hereditary and we didn't know anyone who'd had it. We knew nothing about it."

"It wasn't until Brian had a bad fall and injured his ribs and ended up in hospital that the nurse caring for Brian got in touch with the Parkinson's Specialist Nurse. We met her when she came to see us at home."

"I'd seen the specialist and my doctor but neither of them really went into what it was in any detail," recalls Brian. "Until Nina came to see us I didn't really understand my Parkinson's."

Parkinson's Specialist Nurse Nina Digiglio visited the Grants in their home in Bangalee, a suburb in Nowra in the Shoalhaven area of New South Wales.

"She was here for two hours with Brian and she sat and started from the beginning," said Barbara.

"She explained exactly what Parkinson's is about and talked through all the symptoms. She got Brian to walk and did lots of tests (for Parkinson's) on him and as she did it she explained what it meant and how it comes about. She was really, really wonderful."

"She was really lovely," Brian agrees. "She sat and talked and answered my questions and was so very helpful."

Barbara, who is a member of the local CWA branch, also invited Nina to speak at one of their meetings.

"She was very informative, and it helps people to understand about Parkinson's," said Barbara. "She rang me recently and just asked how things were going. She's absolutely marvellous. It should be essential that anyone diagnosed with Parkinson's can have a Specialist Nurse come to their home to explain it."





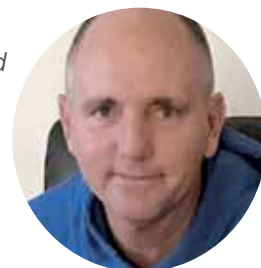
Helping life go on after Parkinson's

Every 40 minutes of every day, someone in Australia is diagnosed with Parkinson's.

1 in 5 people living with Parkinson's are of working age like Dean.

"I was only 52 when I was diagnosed and it hit me hard. I was devastated.

Parkinson's NSW got me the help I needed. I don't think I would be here doing what I'm doing without the help they've given me. They've helped me every step of the way, from that very first call to their InfoLine"



Our team at Parkinson's NSW can support others to build their knowledge and understanding of Parkinson's. They provide the practical support people need to live each day and offer strategies to minimise some of the challenges Parkinson's presents.

But of course, our team is only here and strong because we have a team of wonderful supporters like you. Thank you.

Your generosity means we continue to keep making lives better. Thank you for your donation.



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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

