

STANDBYME

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Pickleball for Parkinson's

parkinson's
NSW

IN THIS TOGETHER

In this issue...

There is something for everyone in this edition of *Stand by Me* – regardless of whether your interest lies in exercise, the latest developments in diagnosing Parkinson's... or even funny hats!

Learn about the many benefits Marina Haralambous is enjoying from her involvement in the popular and accessible sport of pickleball. Or for advice on other forms of exercise, read tips on how to get the most out of your physiotherapy, exercise physiology or personal training sessions.

And then there is Mark Peterson, whose chosen exercise to raise funds for Parkinson's services was an epic 1,500-kilometer walk along the Shikoku Temple O-Henro pilgrimage route in Japan.

Fundraising is also where the funny hats come in. We have a story about the success of The Great Parkinson's Tea Party fundraiser which included social get-togethers with themes as diverse as Mad Hatters, Alice in Wonderland, Seafood Luncheon, and more.

Good news on the research and medical care fronts as well. Read about the On Time Every Time medication awareness campaign – including a pointer to useful resources for you on the Parkinson's NSW website.

There is also an exciting first look at a method of detecting signs of Parkinson's disease 20 to 30 years before symptoms appear – based on research undertaken in Melbourne.

Enjoy your summer reading!



Help to light a beacon of hope

"How long have you had the tremor in your hand?" asked Stephen's doctor.

Stephen's symptoms had been happening for a while, with no obvious cause. A frozen shoulder. Aches and pains. A sudden loss of his sense of smell. Urinary problems. A ringing in the ears. Occasional difficulty remembering words.

But until then, the 65-year-old chef and teacher had considered his ailments completely unrelated. It was the first time anyone had put them together.

That day, Stephen left his doctor with a referral to see a neurologist and when he looked at the letter, he was shocked to read the words, "possible Parkinson's."

Stephen went home and told his wife, Laurine. Together, they googled the symptoms – and sure enough, Stephen ticked almost every box.

"You suddenly have all these questions. How are we going to deal with this? How are we going to tell the kids and the family, how are we going to live our lives moving forward?" said Laurine.

A Parkinson's diagnosis can bring shock, grief and a lot of confusion.

But getting in touch with Parkinson's NSW was "a turning point for us." The couple attended a newly-diagnosed seminar and discovered a world of support and information they never knew existed. It was a big relief. They knew they weren't alone.

"Suddenly, we were in a room with people who were in the same boat as us. Even though you've got support from friends and family, you discover there's this group behind you that knows what you're going through and they'll do what they can to help. For us, that was really uplifting." Laurine said.

For Stephen and Laurine, the world is definitely a lot brighter with Parkinson's NSW in it.

"They want to make your day better. And they really do that in lots of practical, supportive ways."

Parkinson's NSW is a beacon of support and information for thousands of families living with Parkinson's, like Stephen and Laurine.

Can you contribute to help keep this vital beacon alight?



How to get the most out of your exercise specialist



Here are five tips to help you get the most out of sessions.

Take an active role Choose a practitioner who specialises in your specific requirements. Come to your first appointment with any records or notes from your healthcare professionals, along with a list of questions or goals you want to achieve.

Ask questions Your practitioner is there to help. Part of the process is patient education and being open to answering your questions. Some suggested questions you may include treatment duration, the number of visits per week or month required, and what to expect during sessions and after treatment is over.

Do your homework Practitioners commonly give exercises for you to do between sessions designed to enhance the work you do during appointments. Performing the home workouts also helps with consistency and repetition to form good habits. It also shows the practitioner you work on your own and how invested you are in your own health.

Speak up during sessions The physical therapy team is there to help you get better. To be successful, they need you to be open and honest during and between sessions. So speak up if you feel pain or discomfort, and let them know if something is not working. They can adjust your exercise routine or change the techniques being used.

Physiotherapy, Exercise Physiology and/or Personal Training are effective for many acute and chronic conditions. However, the practitioner and patient need to work together for maximum benefits.

Follow their guidance It's critical that you listen to the advice and guidance a physical therapist provides. If they tell you to refrain from certain activities, then it's in your best interest to do so.

If you're active and eager to return to exercise or a sport, wait until you're given the green light. Your therapist knows how to best treat your injury and when to clear you for activity.

The bottom line is that your physiotherapist, exercise physiologist or personal trainer all deliver numerous benefits – such as improving mobility and physical function, overall fitness, rehabilitation and prevention of future injuries, and reducing pain, along with accountability, consistency and efficacy.

So once you're established with a practitioner, make sure to ask questions and provide feedback. It's also vital to follow the treatment plan, especially your homework between sessions. With open communication and active participation, you will improve your quality of life with an exercise specialist supporting you along your exercise journey.

The Great Parkinson's Tea Party raises more than \$19,000

The inaugural Great Parkinson's Tea Party fundraising campaign ran throughout October and really captured the imaginations of generous party hosts and their guests.

The purpose-built Tea Party webpage reveals that 38 hosts registered from across New South Wales – including areas as far afield as Dubbo, Lismore, the Southern Highlands, Albury, Newcastle, the Nepean and Blue Mountain regions and Port Macquarie.

Much fun was had in creating party themes, which included Mad Hatters, Alice in Wonderland, High Tea, Garden Tea, Picnic in the Park, and a Seafood Luncheon – as well as generous people who converted their own birthday parties into Tea Party fundraisers.

There were also some seriously yummy sweet and savoury treats on offer, showcasing the talents of home cooks.

"It was great to see the enthusiasm and community engagement that this campaign encouraged," said Mirelle Brockett, Digital Marketing Manager of Parkinson's NSW.

"It really shows that if you have a strong, core idea and then share the right resources, people will pick up the theme and run with it – adding their own creative twists along the way. So it was a successful campaign that was both fun and generated vital funds to support Parkinson's NSW service delivery to our community."



On Time Every Time medication awareness campaign

The Parkinson's and Movement Disorders Clinical Nurse teams in the Coffs Clinical Network and Hastings Macleay Clinical Network have embarked on an education program for nursing staff across the Mid North Coast Local Health District (MNCLHD).

The education campaign, On Time Every Time, aims to raise awareness about time-critical Parkinson's medication.

Medication delays in patients with Parkinson's can significantly impact quality of life and increase length of stay in hospital.

The education opportunities for nurses throughout the Local Health District (LHD) will be available until mid-December 2023. Education sessions will be 'toolbox talk' style of 10 to 15 minutes in duration.

There are competitions and prizes for the departments with the most attendance and improvements in medication timing. Further programs will be carried out every six months.

Want to know more about the importance of On Time Every Time?

The On Time Every Time education program aims to raise awareness about time-critical Parkinson's medication among healthcare professionals.

However, Parkinson's NSW has also developed a useful tool for people living with Parkinson's and their caregivers. The tool is a card which is part of the Parkinson's Passport - a suite of information which is available on the Parkinson's NSW website parkinsonsnsw.org.au/parkinsons-passport.

The Parkinson's Passport is a compact booklet of facts and tips about managing Parkinson's medicines to give to health professionals and carers. The booklet includes tools for reminding health professionals that your symptoms get worse if you don't have your medicines on time and includes other tips for your care.

The tool within the Passport which supports the On Time Every Time message is a Wearing Off Card.

This question card has been developed to help you find out whether you are experiencing wearing off. It is designed for people with Parkinson's disease who are currently taking medicines such as dopamine antagonists, levodopa or combinations of these.

You can use the list on the Wearing Off Card to identify any symptoms that occur during a normal day and report whether these symptoms improve after taking your next dose of medication.

Since each person's experience with Parkinson's disease is different, so too will the wearing-off symptoms. Many people find that problems with movement (motor symptoms) return during wearing-off, but other symptoms (non-motor) can also occur.

The Parkinson's Passport product suite was produced by Parkinson's NSW.



Clinical Nurse Specialist Andrea Thatcher and Parkinson's Clinical Nurse Consultant Vince Carroll

PET scans and biomarker can detect Parkinson's up to 30 years before symptoms appear

Signs of Parkinson's disease can be detected 20 to 30 years before symptoms appear using a known biomarker, called F-AV-133, and positron emission tomography (PET) scans, according to a new study from researchers at Austin Health and the Florey Institute at the University of Melbourne.

“Parkinson's disease is very hard to diagnose until symptoms are obvious, by which time up to 85 percent of the brain's neurons that control motor coordination have been destroyed. At that point, many treatments are likely to be ineffective.”

said Kevin Barnham, PhD, a professor at Florey and one of the paper's authors.

Barnham added that Parkinson's disease is often thought of as an illness of old age, when in fact it starts in midlife and can go undetected for decades.

“Our long-term goal is to find a way to detect the disease much earlier and treat people before the damage is done.”

According to The Parkinson's Foundation, an estimated 10 million people worldwide have the disease. The diagnosis is made based on an individual's history, symptoms, and physical exam is used to make the diagnosis. There is not a specific lab or imaging test that can diagnose Parkinson's.

In this study, Florey professor Chris Rowe, MD, and his team at Austin Health scanned 26 patients with Parkinson's disease, a control group of 12 people, and 11 people with Rapid Eye Movement sleep behaviour disorder (RBD) – which is a strong indicator of the disease.

Each person undertook two PET scans two years apart. Regions of interest included caudate, anterior and posterior putamen. At the time of scanning participants underwent clinical evaluation including a UPDRS MOTOR test, Sniffin' Sticks, and Hospital Anxiety and Depression Score.

The team found no significant changes in clinical symptoms in any of the participants according to currently available assessments for Parkinson's disease. By contrast, the PET scans showed “...significant neuronal loss” in three key regions of the brain in individuals with the disease, suggesting F-AV-133 is a more sensitive means of monitoring neurodegeneration than what is now available.

Using mathematical modelling they calculated:

- An approximate total of 33 years' slow neuronal loss in Parkinson's disease.
- This loss, they estimated, occurs for about 10.5 years before the disease is detectable on a PET scan.
- Once a PET scan is able to detect the disease, it will be a further six and a half years before the onset of motor symptoms.
- After onset of physical symptoms, there are about a further three years until clinical diagnosis is confirmed.
- This equates, they estimated, to neuronal loss occurring for about 22.5 years before clinical symptoms are sufficient for diagnosis.

Barnham said the findings open pathways to developing screening protocols for diagnosing and treating Parkinson's disease up to 10 years earlier than is currently possible. It could also assist in identifying patients for clinical trials.

Sources: Neurology journal and Inside Precision Medicine

Artist Michael Costello

presented with Certificate of Appreciation for fundraising exhibition

Michael Costello is much more than the sum of his Parkinson's. He has led a very creative life and career – first as a published author and playwright, then as a visual artist.

In August, Michael generously held an exhibition of his works at Cardinal Freeman Village in Ashfield, where he now lives, to raise money for, and awareness of, Parkinson's NSW.

Gary Cowlshaw (left), Donor Development Manager of Parkinson's NSW, recently visited Michael to present him with a Certificate of Appreciation for his outstanding effort of raising \$4,345 for the Parkinson's cause.

“I accept this certificate on behalf of the wonderful Cardinal Freeman Village community. Without their help, I could not have raised the funds which go straight to raising awareness and providing much-needed specialist supports for people living with Parkinson's disease,” said Michael.





Gold standard of care for people living with Parkinson's on the Mid North Coast

Dr Victor Fung, Vince Carroll, Dr Hugo Morales-Bricenco (left to right)



People living with Parkinson's and other movement disorders, their families and carers are benefitting from a new Movement Disorder Specialist Service based at Coffs Harbour, which was officially launched in September.

Mid North Coast Local Health District's acting Chief Executive Lydia Dennett said the service is bringing gold-standard care to people living with Parkinson's disease and other movement disorders on the Mid North Coast.

"Mid North Coast Local Health District has partnered with Western Sydney Local Health District and Parkinson's NSW to establish the new model of care, which will make a big difference for people living with movement disorders like Parkinson's disease," Ms Dennett said.

"This means patients in and around Coffs Harbour now have access to the best movement disorder specialists in the world right on their doorstep. It's a great example of how our networked health system is working to improve patient care right across the State."

The service will operate as a hybrid hub and spoke model with Movement Disorder Specialist Dr. Hugo Morales Briceno seeing patients in face-to-face clinics and via telehealth consults, supported by a Parkinson's Clinical Nurse Consultant in Coffs Harbour.

Director of the Movement Disorders Unit at Westmead Hospital, Dr Victor Fung, said the innovative program is

leading the way in clinical service delivery and will also provide research opportunities along the way.

"Our goal at Westmead is to support rural and regional areas of NSW. The reality is that 93 per cent of specialists reside in metropolitan areas, leaving only seven per cent in rural and regional Australia. With this service, we're aiming to bridge that gap," Dr Fung said.

"As part of this program, specialists will also work to connect patients with clinical studies and emerging therapies."

Acting Chief Executive Officer of Parkinson's NSW, Mary Kay Walker said the prevalence of Parkinson's increases significantly after age 65 and could take years to diagnose.

"Parkinson's is a progressive, degenerative condition of the central nervous system which affects the brain's ability to control movement and may also be associated with other symptoms including mood, depression, and anxiety. Its causes are unknown, and a cure has not yet been found," Ms Walker said.

The first face-to-face clinic of the Coffs Harbour-based Movement Disorder Specialist Service was held in April 2023.

Patients can be referred to the Movement Disorder Specialist Service by their GP.

Mark Peterson's fundraising pilgrimage in Japan

Mark Peterson took Pitch in for Parkinson's fundraising to a new level earlier this year. On 24 May he set out on a 1200-kilometre temple trek – the Shikoku Temple O-Henro pilgrimage – on Japan's smallest major island. Not only did he complete the pilgrimage on 14 June, but he actually walked over 1500 kilometres and visited an extra 20 temples!

"I figured I might not be back again so I wanted to see others," he says. "Also some of the mountain pathways were not passable or safe due to a typhoon and I had to take a longer way by road to get there."

"The trek was a really positive thing. The beauty of Shikoku overall struck me. I knew the mountains were going to be incredible but the rivers and creeks going down into the ocean areas were unbelievably beautiful."

"It was also quite isolated. Even during Golden Week, which is a peak travel period in Japan, it was quiet. More people were walking then; they would do a section each year and catch up where they left off the next year. There were some foreigners walking but not as many as I thought might be."

While Mark had some issues finding accommodation along the way, after the COVID lockdown had slowed

demand and some accommodations had closed, he had no major issues.

"The people of Shikoku were incredibly supportive," he says. "There is a belief that if you give to pilgrims in some way, you gain some of the benefits of the pilgrimage. This practice is called O-settai. I had people giving me drinks, face-washers, money, and I was offered lifts, which I refused. I was offered to stay in homes free or at a discount rate. In one house I was given the keys and asked to lock up when I left."



My [Parkinson's] Life

Marina Haralambous is passionate about pickleball



One day, about seven years ago, Marina Haralambous was on her way to watch her grandson at soccer and she had a fall.

"I fell badly, and my foot gave me a lot of trouble after that," she explained. "I could not walk properly. Because my father and my two brothers all had Parkinson's, I was pretty sure that I had developed it too. Only my younger sister, Arti, has not been diagnosed with Parkinson's."

Arti was on a long trip overseas while Marina was first struggling with her foot and walking issues after diagnosis.

"I needed a walking stick and at times used a walking frame," Marina recalls. "When my sister returned from her trip, she took one look at me and said, 'you've got to learn to walk again.' I said that if she would walk every day with me, I'd do my best."

"At first, I could only walk 500 metres but within a month or two we were doing five kilometres. One day when my sister and I were out walking, we went past a site where a new basketball court was being put in."

"My sister went to the local council and requested that they also mark in two pickleball courts. I learned that pickleball is played with a paddle across a net, similar to tennis, but with a hollow plastic ball. It was developed in America and can be played indoors or outdoors."

"At first it was mainly popular with retired people, but now the average age of players is around 40."

Marina credits pickleball for getting her moving again. She recalls when she started playing, she could barely lift her feet (she felt as if her feet were embedded in concrete). She persisted and now flits around the court like a bird. Marina plays four to six times a week when she can.

"Pickleball has done absolute wonders for me," says Marina, who lives in Sydney.

"After a session of pickleball, my muscles loosen up and I feel like a different person. My balance has improved tremendously. I used to do PD Warrior classes until pickleball took over my life. Three of us started a pickleball group, and now there are 275 members."

"It's such fun; you can have a long rally and then all burst out laughing. It's companionable, and there are very nice people playing. Now I know so many people and have many friends."

Marina has observed that playing pickleball helps you keep mobile and active and improves hand-eye coordination. Together, medication and pickleball slow the progression of Parkinson's.

Marina's pickleball skills don't just finish in having helped to establish a big group of players. To her neurologist's surprise, Marina continues to improve physically. On one of her routine visits to her neurologist he remarked: "Do you know that you have a degenerative disease? Every time I see you, you look better than the time before."



The proof is that in the past two years she has participated in three tournaments. Marina won a bronze medal in the 2022 NSW State Pickleball Championship in her age group. She won a silver medal in the 2023 NSW Pickleball Championship and in September won a bronze medal in the National Championships!

"The last time I visited my neurologist I wore my medals around my neck to show them to him," says Marina. "He asked me what I was wearing around my neck and I explained that I had won them in State tournaments. He was taken aback and remarked 'do you mean that you competed and won against able-bodied players, not just people with Parkinson's?'"

"I had never won medals in my entire life; now, in my 70s, I've won four of them," she explains.

"When I started playing, I found it hard to buy a pickleball paddle. A year later I started a business manufacturing, importing and selling pickleball equipment. My son and husband work with me in the business. Our mission in life is to make as many people as possible aware of the benefits of playing pickleball."

Be part of a future

where no-one has to
face Parkinson's alone.

By leaving a gift in your Will, you can give people living with Parkinson's a better future.

Without access to specialist information and supports, the Parkinson's journey can be a lonely one. It can be filled with fear, grief – and misinformation.

But through your legacy, people with Parkinson's – and their carers and loved ones – don't have to feel they're going it alone. You can empower them every step of the way.

You'll be making sure people can always access expert, specialist supports and information that helps them be part of life in their community and make the most of every moment.



Your legacy Your kindness will impact the lives of countless people into the future, giving them expert, specialist support so they don't have to face Parkinson's alone.

Our shared vision You'll be part of the greater mission to empower people through knowledge, information, education and advocacy.

Their future Your gift gives people living with Parkinson's a better future – a future where they have more chance to make the most of every precious moment and a future where they will have access to expert and quality services whenever needed, and wherever they live.

A legacy that lives on: John's story

John decided to leave a gift in his Will to Parkinson's NSW to honour his late mother Patricia, who had Parkinson's for 20 years.

"She was only 59 when she was diagnosed, just when she was looking forward to retirement. I saw what she went through.

I also donate to Parkinson's NSW every year, and I know exactly what they do with my money because they tell me about the difference I'm making. They have such a personal approach. They make me feel like my gift is really valuable.

I know I'm helping employ nurses in regional areas to help people with Parkinson's. Their services are really hands-on. This is stuff that really, really helps people."



We welcome the opportunity to discuss how you can be part of a future where no-one has to face Parkinson's alone. We are happy to help with any questions you may have about leaving a gift in your Will. Please call our Donor Development team on **1800 644 189**.

"Thank you for thinking of people living with Parkinson's now and into the future."

