

In Touch Newsletter November 2024

Want to learn more about healthy, active living?

The NSW Government Active Ageing Team has developed a web site featuring information and inspiration on safe and healthy living for ageing adults.

It is called [Active & Healthy](#) and features useful tips on:

- Choosing an enjoyable physical activity
- Goal setting
- How to get started and keep going
- Dealing with barriers and setbacks
- Healthy eating
- Home safety and falls prevention

The site also features video learning modules on healthy food choices, food shopping and recipes – as well as vision and oral health, and exercise sessions for home.

Don't feel comfortable using a web site?

There is also a printed brochure entitled *Staying Active and On Your Feet* available on request. Just ask a friend or relative to help by ordering it online for you by [clicking here](#).

Support Group Roundup

By Stacey Foster, Support Group Coordinator

Spring is in the air, and we have been out and about visiting Support Groups.

In August, we visited 10 Support Groups:

Mary Kay Walker, Parkinson's NSW CEO, visited the Inner West Support Group. The group has undergone a transformation over the past 12 months with a new leader (Dr Paulo Pelicioni, lecturer at University of NSW, School of Health Sciences), and a new venue. Paulo's commitment and passion is appreciated by the group and by us.

Mary Kay also visited Hawkesbury Support Group, which has been very ably led by Meryl Heynsdyk for over 10 years. Wonderful dedication, commitment, and knowledge sharing – thank you Meryl.

Gary Cowlshaw, Donor Development Manager, visited Wagga Wagga Support Group which put on a fabulous fundraiser with all proceeds going to Parkinson's NSW. The group raised \$1811 through raffle ticket sales and two gentlemen who grew their beards and were sponsored to shave them off! A heartfelt thank you to Support Group Leader Ann Mitchell who spearheaded the day, and to those that helped in many different ways.

Mirelle Brockett, Marketing and Digital Manager, and I travelled to Batlow and met with Tumut and Tumbarumba Support Groups. It was lovely to see everyone again after meeting them for the first time last year. We brought with us Parkinson's NSW resources, and Parkinson's Specialist Nurses Kate Warren and Sarah Wood also spoke. Both Support Groups have strong and committed leaders in Karen Doyle and Barry Whiting. Thank you both for always making sure your groups' needs are met.

Other Support Groups visited in August: Kiama (with a strong leadership team), Yass (long-time leader Jan Scanes with support by Liz Gailer) , Blacktown (under new leadership this year by Kathy & Gordon Gilchrist and Wendy Symington) and St George Sutherland (another strong leadership team).

September was quieter in terms of visiting Support Groups, but me and John Back, Communications Manager, visited Orange Support Group. The group has been led since 2009 by Bernie Duffy, a dedicated carer to his wife, Petah. After speaking with Bernie many times over the last couple of years, it was lovely to finally meet in person.

Over the last 12 months, Associate Professor Rachel Rossiter, a researcher with the School of Rural Medicine at Charles Sturt University, has come onboard and is supporting Bernie and the group. John and I enjoyed speaking with the group, hearing about their past lives, and sharing information about Parkinson's NSW – what we do and how we can support you.

Parkinson's NSW Counsellor, Viviem Luo, also facilitated the Eastern Suburbs Support Group as fellow counsellor and Support Group Leader Shushann Movsessian was away.

Upcoming Support Group visits:

- Eastern Suburbs Young Onset
- Bega Valley
- Kempsey
- Coffs Harbour North

- Grafton
- Nambucca Valley

If you'd like us to visit your Support Group in 2025, please let me know!

How to choose the right gym for you

There are many different gyms out there today and all of them are a little bit different. Finding one you feel comfortable with is key.

If you join a gym where you are uncomfortable or intimidated, you will more than likely quit and give up. Therefore it is important to really feel at home with whatever gym you choose.

First, consider what you really want. Are you strictly at the gym to lift weights? Do you want to take aerobics classes? Do you want it for the cardio equipment? Or perhaps you want all of these things?

Once you have a clear idea about your needs, here are some other things for you to consider when choosing the right gym for you.

Location

You want to find a gym where you don't have to travel very far. If getting to the gym takes too much time out of your day, you are most likely not going to stick with it or go as often as you would like.

Hours of operation

Do the hours of the gym fit in with your schedule? Can you comfortably get in a workout and not be pushed for time?

Cost

This should really be at the top of your list. How much money will it cost you and will you get your money's worth?

It's much easier to spend a little extra money on a membership with a gym that has top of the line equipment and that is more inspirational to be in, rather than a worn-down gym that looks like a cave.

Cost may also vary according to the time of the year you are purchasing a membership. Gyms tend to have better deals during the high times of the year such as around New Year. If you can hold off getting a membership until there are special offers, you will surely end up saving some money in the long run.

Also make sure you are paying for exactly what you want for that price. Don't get coaxed into adding on services that you aren't going to use or paying for things that don't interest you. Watch out for salesmen who run down a list of extra options/services that you could add to your membership.

Another thing you want to watch out for are gyms that want to lock you in with a long-term agreement. These places will try to sign you up for 1 to 3 years, and then there is no way to get out of the membership contract. You need to have flexibility.

Cleanliness

How clean is the facility? Are there staff members who wipe down the equipment daily? Do they make sure members wipe down their equipment after using it? Is there rubbish on the floor? Are the locker rooms a mess?

These are all things to consider when purchasing a membership. If the place looks like a mess, you need to evaluate whether that is something you can put up with every day visiting the gym.

If the management of a gym can't take care of their facility, how do you expect them to take care of you?

Membership privileges and features

Do you get discounts on anything they sell once you are a member? How much will you be paying for these things?

You need to find out what extra features come with the membership and what you have to pay extra for. See if there are any perks to joining that gym over another one.

Make sure you understand exactly what comes with your membership (and what doesn't) before you sign any papers.

Equipment

The equipment that you use needs to be in good working condition. Look at the different styles and brands of equipment that they have, and make sure that it is something you are interested in using.

How is the free-weight room? Make sure the dumbbells aren't broken or missing. Make sure the grips on the barbells are not worn down so badly that they are completely smooth and your grip will be compromised.

Look around to see how the members are handling the equipment. Are they dropping the dumbbells on the floor? Are they slamming the machine weights down when they are done with a set?

If you see any of these things, be wary about the gym and the equipment. Especially look to see how the staff handles a situation like that. If they have good equipment, they will surely make sure things like that don't happen.

Clientele

What types of people are working out at the gym? Do you see many men? Do you see mainly women? Is there a good split between both? Make sure you feel comfortable working around the people you see at the gym.

If you feel intimidated or unsafe being around these types of people when working out, keep searching for a place that you can call home. Remember, searching for the right gym is all about you, no one else.

Try before you buy a membership

No matter what you see, always try out the gym before you purchase a membership. You will make a big mistake if you just walk in and buy a membership without looking around at other options, as well as seeing how the gym you are considering is operating.

It's a good idea to ask for a trial membership, a guest pass, or any arrangement they have that will allow you to try out the gym for at least one day. Most places will give you a free pass to try it out. However, for those that don't have a free offer, the average price for a day pass is roughly around \$10 per day.

Even if they make you pay, it will be well worth it to see if you like it. A \$10 investment is much better than spending \$500 and hating every minute.

Also, make sure to go to the gym at the same time that you would normally work out. This will allow you to see how busy it gets during the times you are going to be there.

Always read the fine print before you sign

By reading the agreement and the fine print, it makes you aware of the contract you are signing. This can include how you will be paying for the membership, the term of the contract, cancellation policy, and other pertinent information that you need to know.

References

<https://www.bodybuilding.com/fun/weik29.htm>

<https://www.choice.com.au/health-and-body/diet-and-fitness/gyms/buying-guides/gym-memberships>

<https://www.houseofwellness.com.au/health/fitness/choosing-gym-personal-trainer>

Parkinson's patients often battle a hidden foe: Stigma

Patients with Parkinson's disease already face poorer mental and physical health, but now a new study shows they also suffer from decreased levels of hope and self-esteem due to the stigma associated with their disease.

"There are patients who don't even disclose the disease to family members because they're afraid that the children may change their opinion of them or start making plans to put them in a nursing home or take over their finances or freedom to some degree," said Dr. Alessandro Di Rocco, a professor of neurology at the Zucker School of Medicine at Hofstra/Northwell in Hempstead, N.Y.

The study found that when most people think of Parkinson's, they imagine older white men who are drooling, shaking and hunched over. This singular image can be damaging to people with Parkinson's who differ in race, gender or age, and can lead to misdiagnosis or a delay in diagnosis.

Furthermore, those who have several visible, physical symptoms of the disease can face greater stigma and even discrimination.

And those fears are illustrated in the research, which found that more than half of people with Parkinson's conceal their diagnosis for fear of stigma. For example, actor Michael J. Fox, who has Parkinson's and spearheads The Michael J. Fox Foundation for Parkinson's Research, kept his illness hidden for years before coming out to the public.

Having symptoms of the disease can lead to anxiety stemming from being identified as a person with a disability, being isolated, and being diminished in character by others, the report said.

Dealing with society's perceptions of Parkinson's can also lead to self-stigma, the report said, which it defined as a negative attitude stemming from internalisation of limiting stereotypes about people with the disease.

Becoming aware of the inability to perform simple motor tasks can also damage people with Parkinson's self-esteem, the study noted. Self-stigma can lead to depression, anxiety and neglecting to seek health care.

The study was recently published online in the journal *Parkinsonism and Related Disorders*.

"I think there's a lot of commonalities with people when they first get the diagnosis," said study co-author Dr. Indu Subramanian, a neurologist at UCLA Health, in Los Angeles.

"They're embarrassed, they're ashamed, they feel like they did something to deserve it – 'Why me?' They isolate, they think they're the only person who's living with this, and they tend to sort of spiral into sometimes very negative thought processes."

Therefore, she said, it's important that family members offer a helping hand.

"Give them time, give them support," Subramanian said. "If you do see that they're having what looks like anxiety or depression, bring it to the attention of their physician. Getting psychological support, working with a psychologist through certain types of therapies like cognitive behavioural therapy, group exercise or group meditation, yoga... things like that, can connect people to others in this time where they feel kind of alone."

Media and public awareness is also critical to lessening the stigma of Parkinson's, Di Rocco added.

"One of the ways in which the stigma is removed is when the world changes the perception of the disease," he said. "The way the media represents people with Parkinson's is immensely important. The way that public figures like Michael J. Fox portray, in a very honest way, the challenges and difficulties, but also the abilities, are key."

The Parkinson Foundation defines Parkinson's as a "...slowly progressive disease, which causes a gradual loss of the nerve cells in the brain that produce the neurotransmitter dopamine." Dopamine carries signals to the part of the brain controlling movement and coordination, and a loss of it can lead to tremors, slowness and stiffness of the limbs.

Other physical symptoms of Parkinson's include speech changes, loss of automatic movements and handwriting changes. Around 500,000 Americans are diagnosed with the disease, but the U.S. National Institute of Neurological Disorders and Stroke notes that, due to undiagnosed or misdiagnosed cases, the actual number is likely much higher. Parkinson's is currently incurable, but treatment can greatly help ease symptoms.

Even with a Parkinson's diagnosis, continuing to live life to the fullest extent possible is also important, said Subramanian.

"It's important for Parkinson's patients to continue to try to live their life and communicate with others. You know, socialise, not be isolated, try to do exercise, get out in the sunlight... things like that," she said.

Sources:

Original article by Sarah D. Collins

[Medical Xpress News](#)

[Parkinsonism & Related Disorders](#)

smart±step exercises shown to effectively prevent falls

A large, randomised control trial conducted by Neuroscience Research Australia (NeuRA) researchers found that at-home game-based step exercises were effective at preventing falls in people over the age of 65 – reducing falls by 26 percent when compared to a control group.

One in three people over the age of 65 living in the community will experience a fall every year. Falls are a significant public health issue. They contribute to mobility-related disability and loss of independence and are the second leading cause of unintentional injury deaths worldwide.

With a steadily ageing population, scalable and effective fall prevention strategies are needed to address the growing impact of falls in the community.

“Regular balance challenging exercise is effective at preventing falls, so we tried to make exercise fun and easy to do,” said Dr Daina Sturnieks, lead author of the study and Senior Research Scientist at NeuRA and the University of NSW Sydney.

“It was really encouraging to see that smart±step – an exercise gaming console that anyone can enjoy at home without assistance from a therapist – brought a benefit to older people by preventing falls.”

About the study

People who participated in Dr Sturnieks’ study were living in the community, over the age of 65. They were asked to do smart±step exercise games for 120 minutes per week over the course of 12 months.

They reported their falls over this period and this data was compared to a control group, who only received a public health pamphlet about preventing falls.

Over a 12-month period, participants who used smart±step showed 26 percent fewer falls. The results of the trial were published in *Nature Medicine*.

Why gamified exercise for preventing falls?

The best evidence for fall prevention in the community is balance challenging exercise, according to Dr Sturnieks.

“We’ve known for a long time that, if done correctly and consistently, balance challenging exercises can prevent falls. But the problem is that often people don’t keep up with their exercises because they can get boring very quickly,” she said.

This led Dr Sturnieks and the team at the Falls, Balance, and Injury Research Centre at NeuRA to explore the idea of ‘gamifying’ the balance exercises.

“People get addicted to games because they are fun and they become motivated to beat their high score and just get lost in the game,” said Dr Sturnieks.

smart±step is connected to a television screen and once a game of choice is selected it requires the person to step on target panels on a step mat, just like one would with a game controller.

Brain training added benefit

With smart±step exergames, there’s not only the physical exercise benefits. People are also undertaking cognitive or rather brain training, which is easily incorporated into these games.

“These exercise games require people to think quickly, unlike traditional exercise programs where you just go through the movements,” said Dr Sturnieks.

The smart±step exercise games involve stepping on a mat, which acts as a controller. The games vary in content: from collecting treasures to stomping on moving cockroaches or avoiding obstacles. Overall, the games require quick movement and thinking to keep up.

“Exercise games are like a two-in-one: you get physical benefits but also you are keeping yourself cognitively challenged – a which is good for the brain and healthy ageing. Plus, it’s fun!” Dr Sturnieks concluded.

Want to purchase smart±step?

Email smartstep@neura.edu.au to be added to a waitlist to purchase smart±step,

Sources:

[Neuroscience Research Australia](#)

[Nature Medicine](#)

🌈🍵 Spring into action for ***The Great PARKINSONS's Tea Party*** 🌸🎉

The Parkinson's Tea Party season extends right throughout Spring, so there's still time to gather your besties for a Tea Party 🤗

The Parkinson's NSW team had an office Tea Party enjoying treats and a fun game of bingo!

Join in the fun and make a difference while sharing a cuppa and conversations with your family, friends or colleagues

It's free to register and you'll receive a host kit with everything you need to make your ***Parkinson's Tea Party*** a brewing success 🍵

Sign up and information www.greatteaparty.org.au

My [Parkinson's] Life
Donald Conolly

I have long had a personal connection with Santa Cruz, California. It came about entirely through a happy accident – a chance encounter with a lady who hailed from there. We met each other on Sydney Harbor in 1987, immediately fell deeply in love and in five years would marry.

During the 30 years we were together we would visit Santa Cruz multiple times, with it becoming like a second home to me. My latest visit in June this year was coincidentally the sixth anniversary of my Parkinson's diagnosis.

Funnily enough, I also believe that my Parkinson's story starts in 2003 at a Santa Cruz watering hole by the name of *The Poet & the Patriot*.

After settling in to imbibe some restorative beverages, I made my order. The server came back with my drink and when reaching out my left hand to secure the glass, my hand promptly went berserk!

Strangely – or should I say fortunately – the progress of my condition remained glacially slow for the next few years. It wasn't until late in the first decade of this century when other symptoms made their presence known.

Around 2008 my sense of smell all but left me. A computerised tomography (CT) scan of my sinuses and an eye-watering nasal endoscopy revealed nothing out of the ordinary.

Then came the random drooling, usually at an awkward moment. (But then, drooling at any moment automatically renders it awkward).

After this came the mumbling. I work in the medical records department of a hospital. One of my duties was then working in the enquiries section.

I was one of those people who managed to always sound chirpy and upbeat on the phone. Now, at times, it seemed like I had a mouthful of marbles when I spoke, usually in a dull monotone. When asked to repeat myself, I could only respond with a slightly louder mumble, frustrating communication all the more.

By this stage I had a fair idea of what was wrong, as my mother had Parkinson's and I was displaying all the same symptoms. However, I didn't want to know about it. I was very much in denial.

I was also distracted as I had become a caregiver for my wife who had Pick's Disease – a type of frontotemporal dementia – and was rapidly deteriorating. She would pass in 2017.

My Parkinson's confirmation came in the form of a chance meeting on the hospital grounds with a neurology professor the following year. I recognized him as the one that had diagnosed my wife.

After striking up a conversation I noticed he was studying me. At a pause he said: "Do this" (foot stamping), "Now do this" (finger tapping).

After several seconds of compliance, and feeling like a total twit, he stopped me with: "Not good. Go to the front desk and make an appointment to see me. Tell them it's urgent."

In a way, I was relieved at my diagnosis as, in its early stages this disease is very similar to much worse conditions such as Multiple System Atrophy or Motor Neuron Disease. Parkinson's? Now, THAT I can deal with!

I've heard Parkinson's cynically described as 'the gift that keeps on giving'. For me, it's been one that's kept on taking – taking my fine motor control, my sense of balance and sense of smell.

But one sense it couldn't take was my sense of humour, and that's what's kept me going these past six years. Also, while I initially found my diagnosis daunting, I realise now that without it I would not be promoting Parkinson's awareness.

It seems that Fate has steered me in this direction, whether I liked it or not, and I'm OK with that. In addition to my daily work at the hospital, building awareness around Parkinson's helps me feel that I can continue to make a meaningful contribution to others.

It is widely thought that in the Chinese alphabet, the character for *crisis* is the same one for *opportunity*. I'm not sure if that is so, but it is really something that I now believe.

For evidence-based information and advice call the Parkinson's NSW InfoLine

(02) 8051 1900

Parkinson's NSW InfoLine

Email: pnsw@parkinsonsnsw.org.au

Web: www.parkinsonsnsw.org.au