

In Touch Newsletter **April 2024**

People with Parkinson's may benefit from 7 walking strategies

Various strategies can help people with Parkinson's who have difficulty walking, but a new study finds that many people have never heard of or tried these strategies.

The study also found that how well different compensation strategies worked depended on the context in which they were used, such as indoors versus outdoors, under time pressure or not.

"We know people with Parkinson's often spontaneously invent creative 'detours' to overcome their walking difficulties, in order to remain mobile and independent," said study author Anouk Tosserams, MD, of the Radboud University Medical Centre in Nijmegen, the Netherlands.

"For example, people walk to the rhythm of a metronome, by mimicking the gait of another person, or by counting in their head. We found that people are rarely educated about all the different compensation strategies. When they are, people often find strategies that work better for them and their unique circumstances."

For the study, researchers surveyed 4,324 people with Parkinson's and disabling gait impairments. These include problems like imbalance, shuffling, falling, staggering, and freezing.

Of the participants, 35 percent found that their walking difficulties affected their ability to perform their usual daily activities and 52 percent had one or more falls in the past year.

The survey explained the seven main categories of compensation strategies. They are:

- Internal cueing, like walking to a count in your head
- External cueing, like walking in rhythm to a metronome
- Changing the balance requirement, like making wider turns
- Altering mental state, which includes relaxation techniques
- Action observation and motor imagery, which includes watching another person walk
- Adapting a new walking pattern, like jumping or walking backwards
- Other forms of using the legs, like bicycling and crawling.

Each category was explained and participants were asked if they were aware of it, if they'd ever used it, and if so, how it worked for them in a variety of contexts.

Researchers found that people with Parkinson's commonly use walking compensation strategies but are not aware of all seven strategies.

For example, 17 percent of the people had never heard of any of these strategies, and 23 percent had never tried any of them. Only 4 percent were aware of all seven categories of compensation strategies. The average person knew about three strategies.

Other than the use of walking aids and alternatives to walking, the best-known strategy was external cueing, like listening to a metronome, known by 47 percent of the respondents. That was followed by internal cueing, known by 45 percent. Action observation and motor imagery was the least known category, known by 14 percent.

For each strategy, the majority of people who tried it said it had a positive effect. For example, 76 percent said changing the balance requirement made a positive impact, while 74 percent said altering their mental state did.

However, researchers also discovered that strategies worked differently according to the context in which the person used it.

Internal cueing, for example, seemed highly effective during gait initiation, with a 73 percent success rate. Only 47 percent found that tactic useful when trying to stop walking. Similarly, visualising the movements had an 83 percent success rate when people used it walking outdoors. It only had a 55 percent success rate when people used it to navigate a narrow space.

"Our findings suggest that a 'one-size-fits-all' approach doesn't work, because different contexts might require different strategies, or because individuals simply respond better to one strategy compared to another," Tosserams said.

"We need to go a step further and teach people about all the available compensation strategies, for example through a dedicated online educational platform. This may help each person with Parkinson's find the strategy that works best for them."

A limitation of the study is that people reported their own gait disability, which was not confirmed by an independent neurological examination.

Source:

[Neurology Journal](#), American Academy of Neurology

Handy domestic tools for people living with Parkinson's

Plate guard

Plate guards can be fitted onto ordinary plates to help those who can only eat with one hand or have an unsteady grip. The inward facing slope helps with food collection and prevents spillages.

Tailor-made cutlery

Electronic stabilising handles are designed specifically to help people with hand tremors. The utensils are tailor-made to counteract the effect of tremors and have inbuilt sensors and motors to help combat tremors.

Kettle pouring stand

Making your morning 'cuppa' has never been easier with kettle tippers that help users pour boiling water without lifting the kettle up – reducing the risk of spills. The frames wrap around your kettle and are held in place with a secure Velcro strap.

Foam tubing

This tubing slides easily over popular household items such as hairbrushes and toothbrushes to provide a firmer grip.

Electric razor

Parkinson's symptoms like dyskinesia and tremors can make shaving difficult or dangerous. An electric razor is one simple swap that can speed up a morning routine and avoid nicks and cuts.

Grabber tools

These tools are ergonomically designed to mimic how a finger and thumb pick things up. They help users reach for things high or low, small or large around the house without stretching or bending.

Touch lamps

Touch table lamps help to avoid a struggle with tricky light switches. Simply touch the base lightly to control the light output and reach the desired brightness.

Reading rest

For those who find it hard to keep a book still, consider a reading rest for a more comfortable reading experience. Simply clip the book in and adjust the angle as required.

Button and zip hook

You can find many easy-to-use, low-cost hooks that help combat fiddly buttons and zips while dressing and undressing.

Roller Mouse

A wireless Roller Mouse sits directly in front of the computer keyboard and the cursor can be moved by touching the roller bars lightly. Users can switch control between hands when fatigue sets in – improving accuracy and increasing the amount of time spent online in comfort.

Keyguards

Keyguards are placed above the keys on a standard computer keyboard and stop people with hand tremors hitting unwanted keys while typing. While they slow typing speed, they also improve accuracy and comfort.

Sources:

Author: Roisin McCormack

Parkinson's Life

Recommended by Newcastle Parkinson's NSW Support Group

Amplitude Movements aka BIG

In recent years, the evidence backing the benefits of exercise for Parkinson's has grown rapidly. There have been many types of exercise that has been proven to improve, function and quality of life for those with Parkinson's.

A frequently asked question is, what's the best exercise for Parkinson's? Well, it's not what exercise or activity you choose, but how you do it.

It's all about the amplitude of the movement. Amplitude training is when you focus on making the movement as big and as powerful as you can.

Many people living with Parkinson's have difficulty performing daily tasks. They can't get out of bed as easily as they used to, and often takes multiple attempts. They need to use their hands to help them get out of a chair or they are shuffling when they walk.

Although strength and balance may be an issue, often these can be improved with amplitude training.

When you have Parkinson's, your brain is telling your body that the size, or amplitude needed to perform a movement (like standing up from a chair or getting out of bed) is less than what is actually required.

To explain this concept, it's like when you are driving and there are speed limits. Your brain believes the speed limit is 40 km when everybody else is moving at 60 km. Subsequently, it often takes multiple attempts to do the intended movement – and as a result is also more fatiguing.

Now, if you were driving on a highway and are consistently being passed you would get the hint and put your foot on the accelerator to keep up with all the other cars.

With amplitude training, the therapist or trainer you work with helps to be that guide and show you how BIG your movements actually need to be in order to complete those tasks that are most difficult.

Studies have shown that exercises or activities that focused on the amplitude of movement can benefit people living with Parkinson's. This then leads to improved quality of life and independence with mobility.

There are many therapists that are trained in amplitude training and many specifically for those with Parkinson's

Amplitude training and reinforcing BIG movements can not only improve the ability to perform daily tasks better, with less fatigue, but other areas including balance and speed of walking improve as well.

So get moving BIG! Your body will thank you.

New Choir for People with Parkinson's in Mosman

Due to popular demand a new choir is now being established in Mosman Sydney.

Carer and friends are welcome to join. Have fun singing out loud together while enjoying the proven benefits singing can offer, in good company. You'll sing all sorts of songs, strengthen your voice, meet new people, and above all, have fun.

"You don't have to have a good voice. If you can make a noise you belong!"

Peter K. Bushlarks Choir, ACT



In this group, everyone is encouraged to give it a go, no-one will judge, so join in, have fun and set your voice free! There's safety in numbers, and you could be surprised how much you'll gain from lifting your spirits and letting your voice grow strong, in good company.

Choir leader Chrissie Shaw is a musician/educator with many years of experience working with individuals and community choirs. Chrissie was Musical Director of the Bushlarks Parkinson's Choir in the ACT for 5 years. Back in Sydney, she directs a Parkinson's choir in the Inner West of Sydney and is looking forward to establishing the new Mosman choir, with the support of the Mosman Uniting Church.

WHEN AND WHERE?

DAY: Thursday mornings every week, starting May 2nd, 2024.

TIME: 10.30am – 12.30pm (coffee/tea and chat!)

VENUE: Mosman Uniting Church, cnr Belmont Street and Cowles Road, Mosman.

COST: \$10 per session, cash preferred. Carers and partners free.

Mobile phone: 0407 079 748 Email: chrissieshaw44@gmail.com

Please leave your name, phone number and email address, and Chrissie will reply!

This choir is an opportunity for people to get together in a warm and friendly environment, and sing in a group!

In Australia and overseas, choirs for people living with Parkinson's are having great success in helping people deal with voice, breathing and swallowing problems, as well as providing a relaxing and enjoyable activity.

Singing out loud is not only fun, it is also beneficial for people with Parkinson's as it exercises the lungs and abdominal muscles. Singing gives us a heightened feeling of wellbeing and can provide a range of health and holistic benefits, including:

- regulating breathing
- strengthening the voice – volume and projection
- building-up the vocal chords
- improving mood
- enhancing confidence
- aiding concentration,
- and helping swallowing

To find out about the [Inner West of Sydney choir click here](#)

Are Parkinson's NSW and Parkinson's Australia related?

There is often confusion between Parkinson's NSW and Parkinson's Australia. However, the two organisations are completely separate and unrelated, with very different roles.

Parkinson's Australia is an advocacy body, reaching out to the Australian Government about issues of national significance. It is based in Canberra for access

to the Government and bureaucracy and is not focused on delivering services which meet the day-to-day needs of the Parkinson's community.

No state-based Parkinson's organisations are affiliated with Parkinson's Australia. Parkinson's NSW and all of the other state organisations are currently in the process of agreeing and signing a Memorandum of Understanding for closer collaboration.

Parkinson's NSW concentrates on service delivery to meet the needs of its home state's Parkinson's community, and advocacy to both the Australian and NSW Governments. It has a 45-year history of service delivery to the community.

Parkinson's NSW services meeting the needs of people living with Parkinson's, care partners and families include:

- A 1800 InfoLine advice and information service staffed by Registered Nurses, a pharmacist and a social worker.
- Comprehensive Parkinson's information kits available through the InfoLine.
- Community-based Parkinson's Specialist Nurses in regional and rural areas. These roles are co-funded by Parkinson's NSW and NSW Health.
- Two specialist counsellors
- A network of 76 Parkinson's Support Groups across the state
- Focused education for people living with Parkinson's, care partners, and health and aged care professionals – delivered both online and face-to-face.
- An information-rich web site, digital and print publications, and social media channels.
- NDIS Advocacy for people living with Parkinson's under the age of 65.
- Fundraising to underwrite the cost of delivering these services – because Parkinson's NSW receives less than 3 percent of its operating costs from Government sources.

Parkinson's NSW joins National Parkinson's Alliance

Parkinson's NSW has joined the National Parkinson's Alliance (NPA).

It is a new national collaboration of key stakeholders and leaders in the Parkinson's community of Australia who have come together to shape policies, strategies, and initiatives to enhance the lives of people living with Parkinson's across the country.

The Alliance is leveraging national collaboration and leadership to work across regions and populations to shape policies, strategies, and initiatives to enhance the lives of individuals affected by Parkinson's.

Parkinson's is now the fastest-growing neurological condition in the world and affects more than 200,000 Australians. It poses a significant threat to our health and aged care systems and is estimated to cost the Australian community \$15 billion annually.

This disease is progressive and highly debilitating, taking a huge personal and financial toll on individuals, care partners, families, and communities. This highlights the importance of increased funding for research and multidisciplinary care and support for those affected by this debilitating condition.

The Alliance includes:

- Parkinson's NSW
 - Fight Parkinson's
 - Parkinson's Tasmania
 - Shake it Up Australia Foundation
 - Menzies Medical Research Institute
 - Neuroscience Research Australia (NueRA)
 - Queensland University of Technology
 - University of Tasmania
 - Walter and Eliza Hall Institute
 - Wings for Parkinson's
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Step Up for Parkinson's in May

Have you or your Support Group signed up to Step Up this May?

We all know that exercise is second to medications in improving Parkinson's symptoms. So join the community, get active your way and raise much needed funds for Parkinson's NSW.



1800 644 189

Parkinson's NSW InfoLine

www.parkinsonsnsw.org.au