

STANDBYME

IN THIS TOGETHER
parkinson's
NSW

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From the CEO

Welcome to the Summer edition of Stand by Me.

What a year it has been! The pandemic disrupted lives, businesses, and not-for-profit organisations across the state, and we are only now at the beginning of the post COVID-19 recovery.

However, I'm pleased to report that – after facing many challenges – Parkinson's NSW ended its fiscal year with a profit of \$334,748, an increase of 26 percent over the previous year's result.

Our voluntary Board Members, staff and service delivery partners all did outstanding jobs – staying cool and often innovating on the fly under the pressure of evolving pandemic restrictions.

Yet service delivery adapted, and in many cases increased as circumstances changed. A few examples:

- Parkinson's Specialist Nurses managed a 164 percent growth in new referrals and a 35 percent increase in home visits.
- Parkinson's NSW Counsellors pivoted to accommodate the needs of locked down people living with Parkinson's and their caregivers by delivering 79 percent of their sessions via telephone and video-chat.
- Our Fundraising team also effectively used the telephone to drive a 27 percent expansion in our base of generous regular givers.
- The 1800 InfoLine team distributed 52 percent more information packs in response to caller requests this year than last.

Participants in Parkinson's NSW Support Groups also had to adapt to changed conditions during the year, when they were often unable to meet face to face due to health restrictions. The content of this magazine reflects these changing conditions. In particular, I recommend the article entitled *adjusting to life after the pandemic*. It contains valuable advice from The Black Dog Institute as well as our own Counsellors.

Enjoy the read, and my best wishes for a peaceful and connected Christmas and holiday season coming up.

Jo-Anne Reeves
Chief Executive Officer



Meet two new team members

Tamie Harvie has joined Parkinson's NSW as the new Parkinson's Specialist Nurse for the Shoalhaven region.



Tamie brings to the Shoalhaven role 21 years of nursing experience, spanning complex care, acute care, emergency, pathology, and palliative care – and has a particularly strong background in mental health care.

"I joined Parkinson's NSW because this role offers me a unique opportunity to help people along their Parkinson's journey," said Tamie.

"It allows me to bring just about all of my nursing experience to bear, offering personalised care – and the opportunity to be part of something really positive.

"Having worked for NSW Health so long in the area, I also bring with me a network of relationships with hospitals, consultant physicians and diagnosticians," she said.

Cassie Morgan has been appointed as the new Support Group Coordinator.



She succeeds Felicity Jones in this role. Felicity has moved to the role of Client Services Coordinator for Parkinson's NSW.

Cassie moved from her hometown in Warrnambool, Victoria, to take up her new job.

She completed a Bachelor of Health Sciences degree at Deakin University before conducting research in the Aged Care space, and then worked in local government delivering Social Connection projects.

"My studies in Health Sciences have enhanced my understanding of Parkinson's and how the disease can impact a person's physical, social, and mental health and wellbeing," said Cassie.


"I'm excited to use my background in community engagement to connect people living with Parkinson's and their carers to Parkinson's NSW Support Groups across the state.

"I'm passionate about increasing the reach and engagement of Support Groups – and look forward to working closely with them to provide a safe space and social connections for people living with Parkinson's and their carers."

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Is Parkinson's hereditary?



Dr Patrick Lewis, a biochemist at the University of London, discusses the "huge challenge" in trying to understand the role of genetics in Parkinson's disease.

Can genetic factors play a role in Parkinson's disease?

Yes, they can. But the role that genetic background plays in Parkinson's varies a huge amount between individuals.

For a relatively small number of people with Parkinson's, genetics can play a defining role in their risk of developing Parkinson's – for others, essentially no role at all.

Estimates vary, but somewhere between 5 and 10 percent of people living with Parkinson's have a genetic change that either caused their Parkinson's, or had a strong influence on their risk of developing the condition.

What do scientists know about the link between genetic factors and Parkinson's?

Working with families, geneticists and neurologists have been able to study their DNA – the complex molecule that provides the building blocks for our genes – and identify specific mutations that are found in certain genes only in members of the families that develop Parkinson's.

These mutations, which can be thought of as spelling mistakes in the genetic code, either cause someone to develop Parkinson's or greatly increase their risk.

Over the past 10 years – and building on the huge increase in genetic research that came out of the sequencing of the human genome in 2000 – geneticists have moved beyond rare inherited forms of Parkinson's to look at how more common genetic variants can influence how likely you are to develop Parkinson's.

What are scientists trying to find out?

One of the biggest challenges in understanding the link between genetic factors and Parkinson's is figuring out precisely what a particular DNA change in a particular gene does to the function of that gene.

We've made huge advances in picking out DNA changes in the last 20 years, but we are not quite so good at understanding what these DNA changes actually do to make brain cells more likely to die.

This is where a lot of research is now focused – moving from identifying genetic changes to really understanding the function of those changes.

Do genetic factors and environmental factors have a combined effect, in terms of the risk of developing Parkinson's?

Yes. But there is a huge difference between knowing that genetics and the environment combine to impact the risk of Parkinson's, and really understanding how this happens.

In a way, the genetics bit is relatively straightforward. For the most part your genome stays the same from the day you are born to the day you die, although you can develop mutations through your life of course.

But the environment in which you live is much more dynamic, changing and fluctuating from day to day and through the years. In some cases – for example, when considering the link between smoking and cancer – the impact of environmental factors is so strong that it becomes clear quite quickly.

This has been the case in Parkinson's for some toxins, such as the synthetic drug MPTP (1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine), which causes very specific and catastrophic damage to the bit of the brain that initiates and helps control movement.

The bulk of environmental factors are more subtle in their impact and much more difficult to identify and understand. This, in turn, makes it difficult to untangle how that might interact with an individual's genetic background to increase or decrease the risk of developing Parkinson's.

Take, for example, the observation that people who drink quite a lot of coffee have a slightly lower risk of developing Parkinson's. This might be due to a chemical in coffee directly protecting your brain cells.

But it might also be due to a wiring of your brain, which is partly genetically determined, that makes you more likely to drink coffee and simultaneously gives your brain more capacity to resist brain cells dying.

Or it could be that there is something protective in coffee – but that there is a genetic contribution, in that some people's genetic background makes them more likely to drink coffee. Clearly, this becomes complicated quite quickly.

Why do we need to better understand the link between genetics and Parkinson's?

A better understanding of the genetics of Parkinson's could help in developing new approaches to slow down or even stop the progression of the condition.

The concept is pretty simple: if there is a change in a gene that causes someone to develop Parkinson's, then reversing that change – either using a form of gene therapy or a small molecule to modify the function of the gene – can prevent the change that leads to the death of brain cells.

Source: *Parkinson's Life*

Adjusting to life after the pandemic

As the NSW Government has started to navigate its roadmap to post COVID-19 recovery, it is time to start thinking about life after lockdown.

But even though many of us have been dreaming about the day that things go back to normal, Professor Vijaya Manicavasagar of the Black Dog Institute cautions that re-entry into the real world might not be all smooth sailing.

For a start, we can expect to see lots of changes when we emerge into the world – ranging from a favourite café that didn't survive the shutdown to greetings between friends that now consist of a nod or a wave, rather than a warm hug.

Practical activities like driving a car or catching a train may feel strange, and for many of us, the desire to pick up old hobbies and habits – a drink at the pub, a dinner party with friends and family – might be tinged with concern about whether it's really wise to socialise in close contact with others.

But for others, the changes might be deeper. The unexpected nature of the pandemic and its sudden and intrusive arrival in our lives will leave some of questioning whether the world is still a safe place.

"The world might actually be a different place when we get out of this," says Professor Vijaya Manicavasagar, a senior clinical psychologist at the Black Dog Institute who specialises in adult separation anxiety disorder.

"The fact that we've had a pandemic in our lifetime, for a lot of people that would shake their beliefs in the world, the stability of the world, that nothing bad can happen. It's a shock."

Practical concerns

For those who have lost businesses or jobs, there are also practical concerns to grapple with – finding work, meeting financial commitments, applying for Centrelink benefits, or negotiating with landlords and banks to manage rent, mortgages, and credit card payments.

These financial pressures will be front and centre of many people's lives for the foreseeable future and could have a significant impact on their mental health.

"A lot of things that people are going to be worrying about [will be economic issues] – their future, their career, their training. There are some very practical pressures that are going to drive some of this anxiety – it's not all just about reintegrating into society," Manicavasagar says.

The good news is that if research tells us anything, it's that shared experiences of stress can actually bring communities together in way we may not have experienced prior to COVID-19.

"When you read the academic literature on natural disasters, as horrible as they are, [in the aftermath] people help each other and there's often a sense of shared humanity," Manicavasagar says.

"The fact that we're actually doing so well [in terms of flattening the curve of infection] indicates that we're all trying to do the right thing for each other."

Tips on easing back into life after lockdown:

- U Take it slowly. Simple things like doing the grocery shopping, driving a car, or spending time with friends might feel strange as you move back into your post-lockdown life. Take note of how you feel and consider speaking to your GP if feelings of anxiety persist or worsen.
- U Rebuild your relationships. It's been a while since you've physically seen your friends and family members – and remember, they've changed as much as you have. Spend some time together processing the experience, rebuilding bonds, and supporting one another as you move into the next phase of your relationship.
- U Seek help early. Everyone reacts differently to change. Feelings of anxiety, difficult sleeping, changes to your appetite, irritability and bouts of crying are all signs you may need some extra support. Speak to your GP about a referral to a mental health resource.
- U Reflect on your experience – Rather than focusing on going 'back' to your old life, take some time to think about whether the lockdown experience could help you make positive changes going forward. Have you realised you want to work less, exercise more, make more effort to spend time with friends and family? Make a list of new habits you'd like to embrace and start implementing them one by one.

Sources: The Black Dog Institute

Professor Vijaya Manicavasagar is a senior clinical psychologist at the Black Dog Institute and the author of *Separation Anxiety Disorder in Adults*.

Winner of Pitch in for Parkinson's Winter Raffle #2

The second Pitch in for Parkinson's Raffle has been won by Mr. B of Macquarie Fields.

He had never won anything in his life before and was very excited when contacted about his winning ticket – and also a bit worried that it might be a prank call. A second phone conversation cleared that up!

Mr. B's wife is now driving a brand-new Suzuki Swift GL Navigator from Nepean Motor Group – and the couple is looking forward to going on a shopping spree with the other part of the prize, a \$1,500 gift card from Harvey Norman.

The second prize of a \$3,000 Harvey Norman gift card was won by Mr. H of Yarramundi. He plans to invest in a new air conditioner for summer, and to buy gifts for his children.



Impact on people living with Parkinson's

"Some of the psychosocial aspects of Parkinson's may have become accentuated during lockdown," says Shushann Movsessian, Parkinson's NSW Counsellor.

"People may experience anxiety, some paranoia, and possibly impulsive and recurring negative thinking tracks. They could feel like they have lost some physical and mental skills due to the closing of health and fitness amenities, travel, hospitality, and social services.

"In other words, we have had limited or no access to programs and outlets that have helped promote a sense of wellbeing for us," says Shushann.

There have also been more pressures on loved ones who are feeling more isolated in their care for a person living with Parkinson's – which can have a variety of negative consequences.

Their usual coping strategies and outlets have not been as available – such as meeting with a friend at a local café or restaurant, going to a movie or the gym.

Isolation during lockdown may also have increased feelings of being disconnected from meaning in life, and from family and community.

There can also be a feeling of loss of control over the progression of Parkinson's. A person living with Parkinson's may already have a fear of the future with the disease, but this is further aggravated by fear of the future due to the pandemic lockdown.

"I recommend one of the best things that caregivers and family members can do is to make sure the person living with Parkinson's does not withdraw into apathy and self isolation; encourage them to re-engage with services and activities that promote wellbeing," says Shushann.

"Lockdown has thrown many people's routines out, so try to develop some post-pandemic structure. Having regular weekly routines helps people reconnect to a sense of purpose, meaningful structure and control."

For example, every day starts with a walk, Monday and Tuesday are for the physio and the gym, Wednesdays are coffee catchups, attend regular Support Group meetings, and so on.

"Try to recognise those things we have control of and bringing our focus back to that," emphasises Shushann.

Shushann Movsessian is a Psychotherapist, Counsellor and Coach with 30 years of experience. People living with Parkinson's, caregivers and family members can seek support from Shushann by calling the

Parkinson's NSW InfoLine: 1800 644 189



Returning to exercise after lockdown

After months of lockdown with fitness centres and recreation programs being closed, we've all struggled to keep up our exercise and activity levels.

It is essential you do resume your fitness activity as muscle loss can lead to long-term problems with mobility and balance. Those in turn can trigger or aggravate a whole range of subsequent serious health conditions.

Now that restrictions are easing here are some tips for how to get back into a good exercise routine. So, let's get your body moving again!

After time off exercise, don't expect to do the same amount as before lockdown. Remember any activity is better than doing nothing.

If you're doing less than you hoped don't be too hard on yourself. It's important to be realistic so you don't end up pushing your body too hard, giving yourself an injury, getting frustrated and giving up completely.

After a long break from exercising or playing sports the safest thing, is to start at a manageable level and gradually increase. Jumping straight back into an activity you haven't done in a while and expecting to start where you left off may lead to unwanted aches, pains, and injuries.

Taking things slowly when you resume your routine can ensure you have the correct techniques again before building up the intensity.

Make sure you do an appropriate warm up and cool down for your activity. These include slow, large, rhythmic movements and stretching before and after your activity.

If you are having trouble motivating yourself to get back into activity, minimising the mental barriers to exercise can help. Here are some suggestions that may help.

- 👉 Locate and contact your exercise and activity provider again. Many facilities and instructors may have had to close, change their location or class schedule.
- 👉 Lay out your exercise gear the night before, so you don't back out in the morning, frustrated by trying to find things.
- 👉 Make a specific schedule for what activity you will be doing and when you'll be doing it.
- 👉 Incorporate activity into your daily routine. Then it quickly just becomes part of your day. It's important to find a way to exercise which fits into your schedule so it becomes a habit, not a chore that you end up putting off.
- 👉 Make sure your activity is something that you actually enjoy. This will make it something you look forward to rather than dread.

If you've got out of the habit of exercise during lockdown, give yourself one less reason to avoid getting back into it now.

So now you have the tips and tricks to safely return to being active, get to it!

Our next Pitch in for Parkinson's Raffle is now open.

For your chance to drive away in a brand-new Suzuki Swift call the dedicated Raffle Hotline to purchase your tickets

1800 806 277 Purchase your tickets by 23 February 2022

(Permit Number NSW GOCAU/2362)

7 walking strategies for people living with Parkinson's

Various strategies can help people living 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 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:

1. Internal cueing, like walking to a count in your head
2. External cueing, like walking in rhythm to a metronome
3. Changing the balance requirement, like making wider turns
4. Altering mental state, which includes relaxation techniques
5. Action observation and motor imagery, which includes watching another person walk
6. Adapting a new walking pattern, like jumping or walking backwards
7. 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 living 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 living 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
American Academy of Neurology Journals

The Parkinson's Voice Project takes off

Bonnie Nilsson and Sally Ireland make a great team.

Bonnie is a Music Therapist and Sally is a Speech Therapist with a background in music and singing.

Together with Vince Carroll – a Parkinson's Specialist Nurse based in Coffs Harbour – they developed the Parkinson's Voice Project which is now poised for launch across the state.

The Project had its beginnings in the pre-COVID era when Bonnie was delivering the program in person for the Nambucca Parkinson's Support Group with Vince's support.

Up to 90 percent of people living with Parkinson's experience speech issues including reduced loudness, limited respiratory support, a monotone voice and reduced voice quality.

The voice intervention project addresses these speech challenges through high-effort vocal and respiratory tasks, speech exercises, and group singing – as well as providing social communication opportunities.

Seeing the success that Bonnie was achieving, Vince asked her to work with him to start up a voice development program for the Coffs Harbour Parkinson's Support Group.

They felt that the program could be further developed with the addition of a Speech Therapist to the team, so they approached Sally – both for her professional skills and passion for music.

The Parkinson's Voice Project was established as a face-to-face program in February 2020 but had to transition online due to COVID-19 restrictions in the ensuing months to help participants maintain social connections.

The Project began a formal eight-week online program in October 2020. It was delivered in 90-minute sessions including voice warm-up, high-effort vocal and respiratory tasks, speech exercises, group singing and social communication.

The online program's objective was to improve participants' voice-related quality of life and voice intensity by 50 per cent.

The results it delivered included:

- U All participants maintained or improved their voice-related quality of life
- U All participants reported being satisfied with the program
- U Pulmonary function improvements in individuals ranged from three to 37 per cent

The Voice Project also achieved significant peer recognition when it won the Keeping People Healthy category of the Mid North Coast Local Health District 2021 Health Innovation Awards.

"While working with Zoom does not allow real-time interaction – so assessment of individual progress can be tricky – it does have other advantages. For example, Zoom has 'break out rooms' which allow myself and the person I am assessing to virtually step aside from the main group so we can work one-on-one," explained Sally Ireland.

"We are learning what works and what doesn't in the online space as we go along, so the project is evolving," said Bonnie Nilsson. "We can certainly assess functional improvements using questionnaires, and we are able to directly observe rhythm, coordination and facial expressions. And there is no doubt this program – whether face-to-face or online – has a positive impact on the mental health of people living with Parkinson's."

While Bonnie, Sally and Vince are the public faces of the Voice Project, it would not have been possible without the financial support of:

- U The Rotary Club of Coffs Harbour Daybreak
- U Palm Beach Bowls Club
- U Charles Sturt University
- U Parkinson's NSW, and
- U Mid North Coast Local Health District

Interested in participating in the Parkinson's Voice Project in your area?

Call Vince Carroll,
Parkinson's Specialist
Nurse on
02 6659 2333



Support required more than ever as we 'live with COVID'

After some very tough months, things are finally looking up. We're not sure exactly what 'living with COVID' will be like, but we do know that your support has made this challenging year much easier for people living with Parkinson's.

Your contributions make an incredible impact when someone needs help.

This pandemic has been especially challenging for people with Parkinson's, putting a magnifying glass on the isolation and worry they always feel. But your support has ensured life-enhancing services like our InfoLine, and Parkinson's Specialist Nurses were just a phone (or video) call away.

So, if you can, please support Parkinson's NSW this Christmas.

During this time, vulnerable people living with the physical and psychological symptoms of Parkinson's – and their dedicated carers – need extra support. Your gift, large or small, will give people hope and a safe place to turn to when times are hard.



parkinson's IN THIS TOGETHER
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Parkinson's NSW help me and I'm very grateful for that. Please donate this Christmas - Martin

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

**THANK YOU
FOR YOUR SUPPORT**
Donations of \$2
and over are tax
deductible