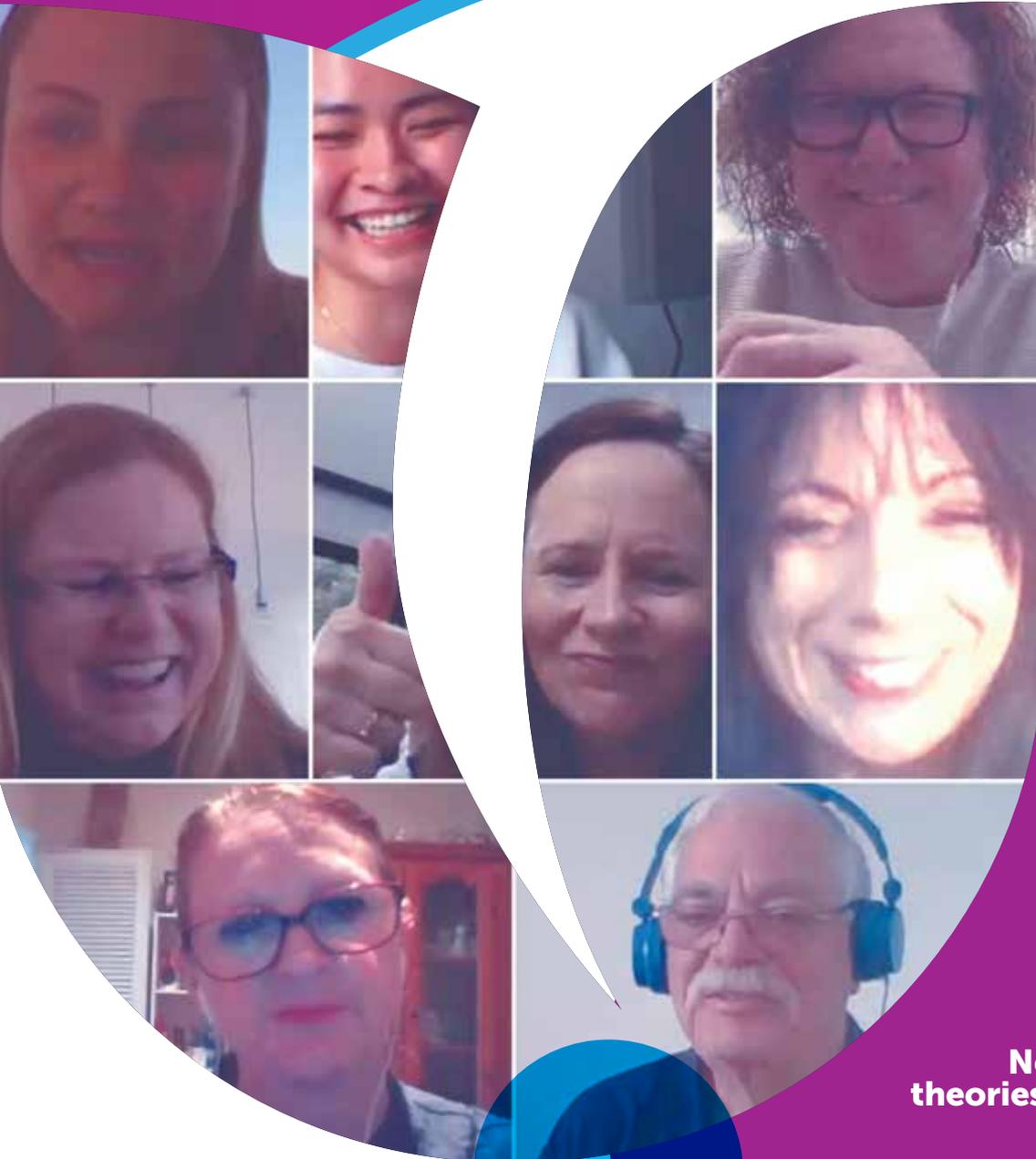


# STANDBYME

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# From the CEO

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

How the world has changed since I last wrote my message to you in the Autumn edition!

Since then we have started living through social isolation, physical distancing, and strict hygienic measures – and in some cases severe ill health due to the Coronavirus pandemic.

I hope this message finds you all coping well with our changed environment, or at least recovering from isolation as the restrictions start to lift.

Anyone who needs support for their physical or mental wellbeing should not hesitate to phone our Parkinson's Registered Nurses who staff the InfoLine: 1800 644 189.

We are always happy to hear from you. In fact, soon many of you will soon receive a survey asking for your feedback on the services provided by Parkinson's NSW. We are looking forward to hearing your input and suggestions.

In closing, I am pleased to report that we are on track to finish the financial year on 30 June in a good financial position.

This result reflects our tight management of expenses and positive returns from strategic investments in service growth and new approaches to fundraising over the past year.

**Jo-Anne Reeves**  
Chief Executive Officer



# Parkinson's NSW further strengthens Board

Parkinson's NSW has further strengthened its Board through the appointment of a Vice President and the addition of a new Director.

Margaret Scott has been voted into the position of Vice President of Parkinson's NSW. In this role, she will support the work of David Veness who remains the President of Parkinson's NSW.

Margaret is one of four new Directors who recently joined the Board following a talent search by an independent consultant.

She has more than 30 years of experience in senior fundraising roles for a variety of health and disability related not-for-profit organisations. In addition, she has operated her own business as a fundraising consultant since 2013.

Margaret was on the Board of the Fundraising Institute of Australia from 1998 to 2008. She held a number of key roles on that Board over the years including Chair, Vice Chair, and Chair of multiple Committees. She was also on the Bloom Asia Board from 2017 to 2019.

The most recent Director appointed to the Board is Denise Thomas – an accomplished senior health care executive who is currently the Chief Executive Officer of MetroRehab Hospital.

Denise began her career as a Registered Nurse at St Vincent's Hospital Sydney and then went on to hold management and senior executive roles in both public and private sector health care and in independent hospitals, publicly listed groups and government organisations.

In the private sector, Denise has managed large scale national and international projects and has worked in senior executive roles in acute and sub-acute hospitals, radiology and pathology businesses. In the public sector, Denise has directed state-wide screening programs and implemented programs to establish clinical services in areas of need.

Full biographies of all Board Directors are available on the Parkinson's NSW web site.



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# New study challenges theories on cause of motor symptoms

A new study may overturn existing theories on the cause of motor symptoms in Parkinson's.

It was conducted by a joint research team from the Institute for Basic Science, the Korea Institute of Science and Technology and the Asan Medical Center in South Korea.

So far, the prevalent view among Parkinson's specialists has been that the motor symptoms occur when dopaminergic neurons – the brain cells that synthesize the chemical messenger dopamine – start dying off abnormally.

Therefore, to offset motor symptoms, doctors may prescribe people with Parkinson's disease a drug called levodopa which helps boost the brain's reserve of dopamine.

However, the long-term use of levodopa can lead to serious side effects, including erratic, involuntary movements.

But what if motor symptoms do not start with the death of dopaminergic neurons? If this were the case, it could change how researchers and medical practitioners understand Parkinson's disease and the best way of treating it.

The South Korean research, which appears in the journal *Current Biology*, found that symptoms of Parkinson's appear before the premature death of dopaminergic neurons.

In their study, the investigators worked with mouse models of Parkinson's disease and analysed brain samples from both healthy people and people with Parkinson's.

They found that before the dopaminergic neurons die off, they stop functioning – that is, they stop correctly synthesising dopamine – and this sets off the symptoms associated with Parkinson's disease.

Looking at the mouse models of the condition, the researchers saw that astrocytes – star shaped, non-neuronal cells – in the brain started increasing in number when neurons in their vicinity began dying off.

At this point, a key chemical messenger called GABA also starts increasing in the brain, reaching an excessive level and stopping dopaminergic neurons from producing dopamine, though not killing them.

The researchers confirmed that this process occurs not just in animal models, but also in the brains of people with Parkinson's disease.

However, the researchers also found that there is a way to restore the function of affected dopaminergic neurons by stopping astrocytes from synthesizing GABA.

Doing this, they saw this significantly decreased the severity of motor symptoms associated with Parkinson's disease.

Further experiments in rats revealed another way of restoring function in dopaminergic neurons. The researchers inhibited dopamine synthesis in these neurons in otherwise healthy rat brains by using optogenetic tools – technology that uses light to control the activity of living cells.

This induced Parkinson's-like motor symptoms in the rats. But when the researchers used optogenetic tools once more, this time to restore function in the dormant dopaminergic neurons, the Parkinson's-like symptoms decreased in severity.

The team argues that in the future these findings may lead to better ways of treating Parkinson's disease – ways that may reverse some of the damage to important brain mechanisms.

## Resources

*Medical News Today*

Original article by Maria Cohut PhD

Lead researchers C. Justin Lee, Ph.D., Hoon Ryu, Ph.D., and Sang Ryong Jeon.

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Subscribe to the Parkinson's NSW newsletter

[parkinsonsnsw.org.au/subscribe](https://parkinsonsnsw.org.au/subscribe)

# Staying physically & mentally healthy in isolation

As humans we have strong physical and psychological needs. With the current Coronavirus (COVID-19) situation, these needs can be harder to meet.

According to the Self-Determination Theory, we have three psychological needs:

- **Autonomy** is about feeling that you have choices and can work with your values to follow meaningful goals.
- **Competence** is about feeling successful and proficient in overcoming problems.
- **Relatedness** is about feeling connected to others.

The satisfaction of these basic psychological needs leads to greater well-being, improved health and motivation.

However, on the flip side, living in social isolation tends to undermine these key needs. Here are some tips on maintaining your physical and psychological health during the current situation.

## Concentrate on what you can control and manage

Coronavirus is outside our control. However, we can control our thoughts and emotions, and how we respond to Coronavirus developments.

You can do something positive for yourself, like exercise – which delivers both physical and psychological health benefits in one activity.

Alternatively, have a warm bath, cuddle your pet, read an enjoyable book, play with your children or grandchildren, do some gardening or tidy the house.

Try to focus on the now, and the positive things you can control.

## Organise shared activities or objectives for the family

Maybe you and your family members are experiencing anxiety. You can respond by setting small goals for your family or partner.

Exercising together (while still practicing social distancing) is a great way to reconnect with your partner or a family member. An alternative could be to plan for the two of you to tackle a big job around the house that is physically challenging.

The whole family can reconnect through a new hobby or game, or possibly an obstacle course around your house and garden.

## Keep yourself physically and mentally active

Even if you cannot exercise outside the home, it is still possible to have a workout inside – even if you live in a small apartment.

Set up a regular exercise routine which suits your capabilities. There are many activities available via your computer or your smartphone including cardio workouts, stretching, mobility or even mindfulness.

There are also many other activities to be found online. Reading is an obvious mental activity. Many books are now online – along with movies, talks (podcasts) and tutorials which can help you learn anything from how to play a musical instrument to a new language.

All these activities will directly target your Parkinson's symptoms along with maintaining your wellbeing while we are in isolation.

## Acknowledge your thoughts and feelings

It is normal to feel anxious, annoyed and sad in situations that are beyond our control. Sometimes when we recognise our emotions and think more deeply about how we feel, it helps us to manage them.

One method is to summarise your feelings as short statements. For example: "I am sad because of the news", "I am feeling anxious because I may lose my job", "I am so angry because I don't feel understood", etc.

Stating them this way helps to externalise the stress into clearer thoughts and releases the emotional distress instead of storing it.

## Deal with your emotions in a healthy way

Everyone deals with emotional distress in their own way. However, some methods do more harm than help i.e. drug use, alcohol abuse or gambling. Arguing and violence create even more problems.

When you are looking for ways to help you through tough times, look for something you enjoy doing and use them as a release.



### Be alert for possible mental health issues

If you are experiencing shortness of breath, inability to sleep or sleeping too much, a change in eating patterns, tightness in the chest, headaches or impulses to hurt yourself or someone else – immediately make an appointment to see your health professional.

Being open about the things that trouble you may also help someone else to know they are not alone. Family and friends can be a great support system and sharing will help externalise your emotions and feelings.

The experienced Registered Parkinson's Nurses who staff the Parkinson's NSW Infoline can always assist. Just call: 1800 644 189.

### Give to others

By giving to others it makes us feel happier too. Check up on your neighbours and call your friends.

We all need more social connection, especially if we live alone. Sometimes getting in contact is very helpful and powerful for people who need some more social support. Be kind and caring.

### Online resources for maintaining wellbeing

**Beyond Blue** has helpful tips on how to look after your mental health during the coronavirus outbreak.

**The Australian Psychological Society** has an information sheet on how to cope with coronavirus anxiety.

The **World Health Organisation** has issued a statement about mental health and the coronavirus.

**RUOK?** has some tips about looking out for family members or friends who are struggling.

**Kids Helpline** is a phone counselling service for children and young people.

**Wayahead Directory** has a list of mental health and community services.

**Centre for Rural and Remote Mental Health** for resources, information and support.

**Roses in the Ocean** has mental health tips for working from home.

## Tips on managing carer stress

According to Carers NSW, key contributors to carer stress include:

- The daily physical and emotional demands of caring
- Lack of choice
- Conflict and frustration
- Lack of support
- Social isolation

The greater the physical and emotional demands of your caring role, the more likely you are to feel stress.

Many carers feel they have little or no choice in taking on caring. They may sometimes feel trapped and resentful.

Even the closest of relationships can fray under the pressures of illness and adversity. This may lead to increased levels of conflict and frustration within families.

Carers may even be supporting someone with whom they have always had a difficult relationship.

Many carers feel alone and unsupported. They may find it hard to access services and supports that meet the needs of themselves and their family. They may also wish that friends and family members would help out more.

Carers can become socially isolated simply because of their caring role. They may have to give up their job, or it might be harder to leave the house – particularly during the social isolation required during the Coronavirus (COVID-19) situation.

It is normal to experience an increased heart rate, increased blood pressure and shortness of breath.

Over time, this may lead to stress related illnesses such as heart disease, high blood pressure, mental health problems, decreased immunity or chronic fatigue.

This means it is important to learn ways to manage stress in order to look after your health and wellbeing.

See practical advice from Carers NSW on managing carer stress.

**Source:** Carers NSW

# Parkinson's NSW Trust appoints independent Directors

Following a search by a professional recruitment consultant, the Parkinson's NSW Trust has appointed two new, independent Directors.

Annabel Crookes who is a Legal & Risk Director and an Executive Director, Company Secretary at Laing O'Rourke and Andy Esteban who has been in the financial services industry for over 40 years – including 21 years as a senior executive for Perpetual Trustees.

The Parkinson's NSW Trust is a separate entity from Parkinson's NSW. Neither of the new Directors has any relationship with Parkinson's NSW nor the former Board members of the Parkinson's NSW Trust.



## Alternative to Sinemet during shortage

An alternative product to the Australian registered medicine Sinemet CR® is now available on a temporary basis under Section 19A of the Therapeutic Goods Act 1989.

According to Merck Sharp & Dohme (Australia) Pty Ltd Sinemet CR® is in short supply due to a manufacturing constraint with a third-party contractor. This affects Australia as well as other countries.

The alternative product is registered and marketed in the United Kingdom under the brand name Sinemet CR 50 mg/200mg Prolonged-Release Tablets.

The new tablets comes in blister packs of 60 rather than bottles of 100.

Although the new tablets have a score line, they should not be halved. Swallow tablets whole, with a glass of water. In order to maintain the slow-release properties do not chew or crush the tablets.

Australian product information for recommended dosing and notes on potential adverse reactions are available here: <https://www.ebs.tga.gov.au/>.

Consult your doctor about the availability and suitability of this alternative medication for your use.

For more information, phone the Parkinson's NSW InfoLine: 1800 644 189

The full Board of the Trust includes three representatives from the Board of Parkinson's NSW and two independent Directors.

The role of the Parkinson's NSW Trust is to manage the investment of donations and bequests intended to support people living with Parkinson's. The Trust allocates regular grants which further this purpose.

This includes providing seed funding to approved projects of Parkinson's NSW for assisting people with Parkinson's. Its focus is on activities which have the potential to deliver better quality of life now for people living with Parkinson's as the search for a cure continues.

## Pharmacy home delivery service

Australia Post has teamed up with the Pharmacy Guild of Australia to deliver medicines via a contactless pharmacy home delivery service.

The measures include:

- Continued dispensing arrangements for the ongoing supply PBS subsidised medicines without a prescription has been extended to 30 June 2020.
- A home delivery service for PBS and Repatriation Pharmaceutical Benefits Scheme (RPBS) medicines is now in place.
- Ongoing work with pharmacists, GPs and the States and Territories to allow medicine substitution by the pharmacist in the event of a shortage.
- Restrictions on the quantity of medicines that can be purchased to prevent unnecessary medicine stockpiling.



These temporary 'continued dispensing' arrangements allow people to obtain their usual medicines at PBS prices, even if they cannot get a new prescription from their doctor.

For more information, visit this web page:

<https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/ensuring-continued-access-to-medicines-during-the-covid-19-pandemic>

# My [Parkinson's] Life

## Singing Away The Parkinson's Blues

By Martin Pryor

It was an awkward moment.

My physio had just asked me to cross my arms across my chest. In doing so, my right hand started to shake rapidly. We looked at each other and simultaneously said, "What's that about?"

A week later, I was in the neurologist's office and after a surprisingly brief but utterly thorough observation and examination, he sat me down and declared I had Parkinson's.

Like most people receiving an adverse diagnosis, my reaction was one of shock, bewilderment and fear of the unknown. Telling the family was particularly hard but their strong positivity, and that of close friends, got me through those difficult initial days.

Then I got angry. Not in a complaining, "Why me?" sort of way, but more like "Bugger it, there is so much still left to do".

In a moment of frustration, I picked up my old guitar. I settled into a lazy 12 bar blues because it was easy, and I was well out of practice. Some words formed in my head and The Parkinson's Blues emerged out of my frustrations and helplessness.

My wife and I had already decided to throw a big 'That's Life' party and thanks to the forbearance of the band Blame Sally, I was able to debut the song to about 100 people. It went down a treat.

When people who had no inkling of my musical background, commented that it was a brave thing to do, I began to understand the change music was having upon me.

It wasn't bravery but rather, just my way of coping with what had happened to me and to my family. I realised it all came down to mindset.

Some weeks later, as I was leaving a choir rehearsal, one of the members was sitting on the steps looking glum. On hearing his story of marital failure and general depression, with it being so late, I offered to take him for coffee the next morning.

Driving home, stopped by a red light, the phrase 'men who care' popped into my head and I wrote it down.

The next morning, I put that title at the top of a piece of paper and without prompting, the song just emerged – all verses and choruses, yet to be changed to this day. I conjured up a little riff on the guitar and every chord fell into place.

I recorded it into my phone and that evening played it to my wife. She loved it and urged me to take it further. I recorded the song (and many more), produced two CDs and before long, there I was – a singer-songwriter.

By now hugely motivated, I became a founding member of a male choir and wrote a choral arrangement of the song for us to perform, which we have proudly done in concert.

There is an increasing body of research supporting the view that for Parkinson's, Alzheimer's, dementia and conditions of a similar ilk, music is a remarkable therapy.

I am astonished at the positives music has brought my life. I sometimes startle people who ask about my condition when I respond that, "The best thing about having Parkinson's is the music".

I admit I had no idea as to how valuable singing in a group, in a choir or even solo, would become to my life; how positive it makes me feel and how uplifting it can be.

Whether it's the cardiovascular benefit of singing for two hours, breathing deeply and getting all those endorphins going, the community spirit or just the fact that you have a goal to work towards and when you get it right it's a wonderful feeling.

Whether you have just been diagnosed or you are a long-time sufferer, even if you've never sung in your life, I urge you to try singing.

Should you be reticent to sing with others the innovative Couch Choir allows you to participate electronically whereby you can sing alone at home, video yourself and then submit it online. If singing is beyond you, listen to music.

Getting that diagnosis four years ago was the most confronting thing I have ever faced but knowing I have the joy and solace of singing and playing guitar to soothe me during the toughest times is a great comfort. I can't imagine my life without music.

### References

- <https://youtu.be/A8elkq7eYBQ>
- <https://youtu.be/HIP806ise2U>
- <https://www.parkinsonswa.org.au/research/latest-research-news/>
- <http://voicemale.com.au>
- <http://concreteplayground.com/sydney/event/couch-choir>





**We are here for you.**  
 #InThisTogether | 1800 644 189



# Help us deliver Parkinson's support in difficult circumstances



Like you, the uncertainty of what's going to happen during the Coronavirus Pandemic has left our Parkinson's community vulnerable, stressed about access to medical care, and feeling extremely isolated.

We've had to quickly adapt the way we work. Our dedicated team of community-based Parkinson's Specialist Nurses now extend support via telephone or various forms of videoconferencing – with technology training provided for anyone who requires it.

This enables them to provide personalised health advice to minimise Parkinson's symptoms and help people avoid unnecessary hospital visits. They can also connect people with Allied Health professionals and even neurologists without them having to leave their homes.

Critical face-to-face meetings also continue, with strict hygiene measures to ensure the safety of our staff and those they support.

The Parkinson's NSW InfoLine is staffed by experts including nurses, a social worker, a counsellor, and a Personal Trainer. They are supporting people in body and spirit throughout the pandemic.

If you have concerns about your health or that of your loved one, we encourage you to contact our InfoLine for support.

These services and our ability to respond to a changing environment are only made possible through the support of people like you.

Please consider a special gift today to Parkinson's NSW to support our urgent response to people living with Parkinson's in this pandemic emergency.



## Parkinson's by the numbers

Every hour of every day someone is diagnosed with Parkinson's

 <p>More than <b>200,000</b> people in Australia are affected by Parkinson's*</p>	 <p><b>9,780</b> people helped each year on our Infoline</p>	 <p><b>1 in 5</b> people living with Parkinson's are of working age</p>
 <p>Access to more than <b>80</b> support groups across NSW</p>	 <p>Prevalence of Parkinson's is higher than prostate, breast, colorectal and lung cancers combined.</p>	 <p>Education delivered to more than <b>850</b> people per year</p>
 <p>More than <b>500</b> counselling sessions delivered per year</p>	 <p>Parkinson's medication must be taken <b>on time every time</b></p>	 <p><b>\$160,000</b> average lifetime financial cost for someone living with Parkinson's for 12 years.</p>

\*Ayton, D., Ayton, S., Barker, AL., Bush, AI and Warren, N. (2018). Parkinson's disease prevalence and the association with rurality and agricultural determinants. Parkinsonism & Related Disorders.