

April 2020

Welcome

Our world is changing! As we are now practising social distancing and some of us are self-isolating, remember it's really important to stay in touch with people. Try to call a couple of people per day, or even make a video call. Remember to keep a sense of humour and look for things in your day to make you smile. We can help you stay connected; see how on page 2.

If you have any questions or concerns, call the Parkinson's NSW InfoLine to speak to the Nurses or Counsellors on **1800 644 189**. You can also go to our website via this link for more regular updates on what's happening with the Coronavirus: <https://www.parkinsonsnsw.org.au/coronavirus-and-parkinsons>

My DBS Journey

Mick, aged 65

Had DBS surgery in October 2010

I was diagnosed with Parkinson's in August 2002. My father had it and I went through the symptoms I had developed with him and was able to self-diagnose. My GP then confirmed it.

I had dyskinesia (which is abnormal or impaired voluntary movement) and rigidity. My steps were involuntary, and I was swaying. I couldn't write clearly anymore, and I couldn't sit still.

I looked at getting DBS surgery when these mobility issues began to affect my life.

Assessment took a while in 2010 because there was confusion between the specialist thinking I wasn't sure and was hesitating, and me thinking they were still assessing me.

I started the process in early 2010 and it took longer than it should have. The surgery was then done in October 2010.

I chose to have a battery inserted – which needs to be replaced every two or three years – rather than the other option which would require me to find the time to recharge it.

I made this decision because my wife and I are

quite active and trying to do as much as we can, while we can.

After the surgery I felt euphoric. There were no infections or anything. It took about ten days to make minor adjustments to the settings and then I was off home in just over a week.

My balance is slightly off a bit more than it was before, but that was one of the possible side effects.

We are doing all we can now. I'm back to playing golf again, although I do have some balance problems. I can't play tennis anymore because sometimes my legs don't coordinate well enough when I'm rushing, and I have falls – so my doctor said no more tennis.

But we can travel, and we've done a lot of trekking – including the Milford Track in New Zealand and a fundraising trek of 180 kilometres around the base of Mont Blanc in Europe. We are enjoying life while we can.

I'd advise anyone thinking of DBS surgery to check if they're suitable and go ahead. There's no point in worrying about the surgery if you're not suitable in the first place.

Do you require Aged Care advocacy?

The Seniors Rights Service offers aged care advocacy to people using in-home and residential aged care services.

If something goes wrong, Seniors Rights Service can guide you in raising your concerns with your service provider.

Seniors Rights Service provides free, confidential support and advocacy for anyone receiving Commonwealth-funded aged care services. It also promotes the rights of older people to aged care service providers.

Aged care advocacy means offering information to people receiving aged care services about their rights and responsibilities and assisting them to uphold their rights.

If you are concerned about any aspect of your aged care or services and you want to speak to someone about this, Seniors Rights Service is available to help you.

An aged care advocate can speak on your behalf, when you feel disadvantaged, in a way that represents your best interests. The advocate will always ask your permission before taking any action.

Seniors Rights Service aged care advocacy services are free, confidential and independent. It is the NSW part of the national Older Persons Advocacy Network (OPAN), serving aged care recipients across the state.



To learn more about what the Seniors Rights Service does and the services it offers, visit the web site here: <https://seniorsrightsservice.org.au/about-us/about-us-overview/>

You can also call for advice: 1800 424 079

Source: Seniors Rights Service

New Director appointed to Board

The Board of Parkinson's NSW has been further strengthened through the appointment of Denise Thomas.

She is currently the Chief Executive Officer of MetroRehab Hospital.

Denise started her career as a Registered Nurse at St Vincent's Hospital Sydney and then went 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 addition to being a Registered Nurse (St Vincent's Hospital), Denise has a Masters Degree in Health Law (University of Sydney), Bachelor's Degree in Health Management (University of New England), and an Acute Care Certificate (NSW College of Nursing).



Research

New study challenges current theories on cause of motor symptoms

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

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 synthesising GABA.

Doing this, they saw, also 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 action 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.

In the future, argues the research team, these findings may lead to better ways of treating Parkinson's disease — ways that may reverse some of the damage to important brain mechanisms.

Sources:

Medical News Today

Original article by Maria Cohut PhD

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

Meet & Greet: Ashfield

The Ashfield (Sydney) Support Group was established in March 2019, so it is now celebrating its first anniversary with Parkinson's NSW.

The Group meets in the Cardinal Freeman Village – a retirement community – and is open to members of the public as well as residents of the Village.

Support Group Leader Irene Sykes is not living with Parkinson's but has close connections with people who are, so she was keen to start up a group to help people living with Parkinson's in the Village come together and support each other.

She describes the style of the Group as: "...informational, over a cuppa."

Ashfield attracts up to 16 participants per meeting and includes a Carers Group which was established within a week after the main Group's first meeting.



The Support Group meets monthly from February to December, with a party in the final month of the year. The two groups come together to celebrate at the Christmas party.

"Our Group's main strength is our regular gatherings that are both sociable and informational. We do practical things together like share exercises downloaded from YouTube – and on the social side, we enjoy bus trips and other excursions," said Irene.

Fundraising is not a formal policy of the Group and a joint decision was made to leave it to the

discretion of individuals to make donations as they wish.

Irene explained: "We find that it is working well for us having a Group Leader without Parkinson's – but of course we encourage input, advice and shared experiences from participants who are living with Parkinson's.

"If I had to summarise our Support Group's approach, it would be: 'Keep it simple, practical and social – and listen a lot!'"

Irene commented that living in this retirement village for a number of years has taught her about the bravery of elderly people. "I have become aware that it is usually the person living with the most difficulties who manages a cheery smile and a pleasant greeting. This has been most humbling," she said.

"In 2015 my husband died, and I was quite lost for a few years while coming to terms with this new way of living. My family were very supportive but had to get on with their own lives.

"It was about that time that many new residents came into the Village and I became aware of some of the daily problems with which they have to cope. There seemed to be a number of people living with Parkinson's.

"I approached our Wellness Officer, our Manager and Parkinson's NSW and was given the 'All Clear' to start up a Support Group for those people living with Parkinson's and a second group for all Carers in this village," said Irene.



COTA supports Government advice on COVID-19

Council on the Ageing (COTA) Australia has endorsed Government advice that all older people should remain at home as much as possible and to take precautions when outside their home.

COTA Australia Chief Executive, Ian Yates AM, said the Prime Minister's advice for all Australians over 70, all Indigenous Australians over 50 and any Australia over 60 with a chronic illness, to primarily stay in their home was a sensible, measured approach to an evolving situation.

"The Government has most strongly advised everyone over the age of 70 to stay home for their own protection," Mr Yates said.

"However, this does not mean that older Australians should shut themselves in their homes and not go outside at all. Exercise and fresh air are critical for keeping people healthy, and for mental health and wellbeing."

He advised that with precautions older people can still walk the dog, go for a walk by themselves, or undertake other regular activities that will help to maintain their muscles and fitness, and enjoy the outdoors in a safe way.

They should also continue to shop for essentials

where it is not possible for someone else to do this for them, but they should also consider trying out online ordering and home delivery if they have access to the internet.

The Government has also boosted telehealth resources so people can see a doctor online rather than visiting a medical centre. It has also delivered funding increases to the Community Visitor Scheme and Meals on Wheels to assist vulnerable and isolated consumers get the emotional and practical support they need.

COTA is providing regular updates for older Australians about COVID-19 here: www.cota.org.au/covid19

Source: Council on the Ageing (COTA)

If you exhibit flu-like symptoms (elevated temperature, coughing, runny nose, fatigue, shortness of breath etc.) then self-isolate and consult your doctor or Emergency Department. **However, please call ahead before attending.**

Alternatively, you can call Healthdirect Australia on 1800 022 222 for 24-hour health advice, or see their website at: <https://www.healthdirect.gov.au/>.

What are you grateful for today?

Due to the COVID-19 pandemic, many of us are in quarantine or social isolation.

Parkinson's NSW Program Officer Exercixse Alyson Blanks came across this list of Daily Quarantine Questions on Facebook and thought it was worth sharing with our Parkinson's community.

She recommends that thinking about how to achieve some of the things on this checklist will go a long way to maintaining a sense of overall wellbeing.

- Who am I checking on or connecting with today?
- What expectations of 'normal' am I letting go of today?
- How am I getting outside today?
- How am I moving my body today?

- How am I expressing my creativity today?
- What type of self-care am I practicing today?
- What am I grateful for today?

Staying focused on something you'd like to achieve (big or small!) will go a long way towards helping you stay positive and helping to build the resilience for you to be there for your family, friends and neighbours.



Living Well

How to fit regular exercise into your day.

We all seem to be busier than we've ever been before and fitting exercise into your day can be hard – especially now there are voluntary isolation and social distancing requirements to meet.

However, if you have Parkinson's you need to find time. So you need to get creative!



Park the car a few blocks further away and walk to your destination. Take the stairs instead of the lift or do a couple of laps around the oval or park. It all counts, and a little bit here and there soon adds up.

One of the best forms of exercise is walking.

By stepping out your front door and pounding the pavement you can improve your functional

mobility, strengthen your cardiorespiratory and vascular systems – and it is fabulous for your mental health too.

All it takes to change your body and your life is 30-minute walk five days a week.

By including walking in your daily routine, you can lower your blood pressure along with the risk of heart disease and diabetes while improving your mood, energy and weight loss.

Team up with a friend or family member and walk together. Remember to practice social distancing while you're exercising and work out with only one other person.

You'll be improving your Parkinson's and building a stronger relationship at the same time.

If you already walk regularly you will need to challenge yourself to keep on top of those Parkinson's symptoms, particularly now that we have so many restrictions on our usual activities.

You could try using some of your walking time doing a different activity that your body hasn't already adapted to. Something like dancing or boxing.

Try Nordic Pole Walking, or just increase your distance and walking pace. Then you can plan your walk for a favourite holiday destination in the future knowing you are fit enough to make it!

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 will be 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 about this new service, click on the link [here](#).

Importance of planning ahead for carers

Carers are often focused on the immediate challenges of caring that it can be difficult to find time to make emergency or long-term plans, or to make sure their expertise is passed on to people who can cover for them when needed.

The vision of Carers NSW is for an Australia that values and supports all carers. It emphasises the value of planning ahead through:

- Emergency Care Plans
- Putting in place an Enduring Power of Attorney
- Creating an Advance Care Directive



An Emergency Care Plan is a document that provides instructions and guidance to allow someone else to step in and provide the care which you would normally provide.

It can give reassurance to carers that if anything should happen to them, the person they care for will still receive the support they need.

A General Power of Attorney gives someone the legal ability to act on someone else's behalf in financial matters such as paying bills and managing money if for any reason they are unable to manage financial matters themselves.

An Enduring Power of Attorney will operate when a person can no longer make decisions or act on their own. A person must appoint their enduring power of attorney before they lose capacity.

Enduring Power of Attorney arrangements can be made so that they come into effect immediately or remain dormant until a specific event or circumstance arises.

Advance care planning is an important part of planning for the future, particularly for people who are older and frail, or who have a chronic illness, disease, and early cognitive impairment, or are approaching their end of life.

For step-by-step advice on how carers can plan ahead, visit the Carer's NSW web site here: <http://www.carersnsw.org.au/advice/plan-ahead>

Source: Carers NSW

Discounted stays at Regis facilities for carers

Parkinson's NSW will be working in partnership with Regis Aged Care to deliver Parkinson's specific training to their Care Staff and holding Information Seminars open to the public across New South Wales.

Selected Regis Aged Care facilities are offering a 50 percent discount off respite stays for carers until 30 June.

The participating homes are

- Belmore
- Hornsby
- Hurstville
- Port Macquarie
- Port Stephens
- Rose Bay

For more information, visit this web site: www.regis.com.au/nswrespiteoffer

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 to visit friends and do the activities they enjoy.

When you feel stressed your heartbeat, breathing rate and blood pressure all increase. The longer you feel stressed, the greater the impacts on your body.



This may eventually 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 by clicking [here](#).

Source: Carers NSW

Use technology to socialise while in isolation

As most of us are at home practising social isolation, video-chatting can help you stay in touch with your fellow Support Group participants, friends and family.

A guide on how to make a video call using a smart phone, or your desktop or laptop computer has been added to the Parkinson's NSW web site.

To protect you while using this technology, an introduction to the basics of online safety is also now available on the site.

For information on how to use technology to socialise with your group and others

while in isolation, visit this page: <https://www.parkinsonsnsw.org.au/support-group-info-support/>

Contact Support Group Coordinator Felicity Jones for assistance: felicity.jones@parkinsonsnsw.org.au

