in motion

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A MAGAZINE FOR THE PARKINSON'S COMMUNITY

WE ARE IN THIS TOGETHER

IN THIS TOGETHER
parkinson's
VICTORIA

CEO UPDATE

WE ARE IN THIS TOGETHER

As we reflect on the past few months, it's still hard to fully comprehend the level and speed of unprecedented change the coronavirus pandemic has made to our lives.

It has forced us to make difficult decisions, while introducing us to new ways to connect.

It has highlighted care and compassion and resulted in politicians of all persuasions coming together to take swift and decisive action to keep all Australians safe and avoid the tragedy and heartache we have seen in so many countries across the world.

Tough restrictions to community interaction to 'stop the spread' and 'flatten the curve' was the right action to take, but social isolation and changes to routine has resulted in increases in anxiety.

From the outset, our main priority has been to remain connected to our community; to adapt our offering to ensure people living with Parkinson's, as well as their families and carers, could continue to tap into the vital support, information and care we provide.

As soon as social restrictions came into place in mid-March, we implemented a member outreach program to make sure people had the right supports in place. We asked people to identify issues of concern. Unsurprisingly, they reported increases in depression and anxiety, as well as heightened levels of apathy as daily routines dramatically changed or stopped altogether.

Reduced exercise and physical activity, resulting in increased levels of stiffness and pain, fears around ongoing access to medications and aged care visitation were also identified.

As we continue to make outreach calls, we are working to ensure we can provide the right information and services to help alleviate these concerns.

We have also been working closely with Parkinson's Peer Support Group leaders to ensure they can continue to connect with members for the period when face-to-face meetings cannot take place (see page 21 for details).

Hand in hand with our focus on connection has been our commitment to safety, both of the community and the Parkinson's Victoria team that serves you.

In addition to calling a temporary halt to PSG meetings, we had to cancel our anticipated InSearch research lecture series, as well as Community and Recently Diagnosed Seminars. As you will read on page 3, we've had to make the difficult decision to change the concept of A Walk in the Park 2020.

But in the midst of this was one shining light - an online conference for people with Parkinson's. Event organiser, PD Warrior founder Melissa McConaghy, could never have envisaged how fortuitous the timing of this event would be.

Late last year, Parkinson's Victoria decided to join the 2020 INSIGHT into Parkinson's conference as platinum sponsor to help make the 3-day event, with its highly regarded presenters from around the world, free and accessible to all.

Held in early April, as Australians were bunkering down at home and starting to feel the initial effects of isolation, this event came at a time when the community needed an opportunity to come together.


Parkinson's Victoria CEO Emma Collin

More than 60 guest presenters, including scientists, medical and health professionals and patient advocates delivered pre-recorded presentations and live panel discussions viewed by more than 9000 people from the comfort and safety of their own homes.

I was proud to host one of these panel discussions, *Future Frontiers*, in which we had an inspiring discussion about the benefits technology can bring to better identify and manage Parkinson's.

You can learn more about this and some of the other presentations from Page 12.

Parkinson's Victoria will continue to closely monitor COVID-19 as it develops in Victoria and also continue to adapt our service offering.

We are also working with Parkinson's organisations globally on how to best support our communities and are collaborating to share ideas and resources in these financially challenging times.

Recognition of the financial impact of coronavirus is also something we are aware of and as such are pleased to announce the Parkinson's Victoria Board has agreed to waive the annual membership fee for 12 months.

As you know, being a Parkinson's Victoria member is a great way to stay connected, which, as I've said, is particularly important this year, so please recommend this opportunity to your friends.

I hope you enjoy reading this 'bumper' 24-page edition of *InMotion* magazine, which includes a major focus on getting through the pandemic. You will find information on communication, boosting immunity and keeping active.

I would also like to thank Sandra Watts and Sandra Smith from the Corryong Peer Support Group for sharing their stories of the bushfires that swept through parts of Victoria on the last days of 2019 and affected many of us before COVID-19 was even on our radar.

While we cannot be sure of what our immediate future holds, you should continue to follow instructions issued by our Government public health officials. And remember as difficult as this time is, it will pass.

In the meantime, stay connected to those who can help you and those who make you happy. Take the opportunity to learn a skill that will carry you into living a different way with Parkinson's now and into the future.

Emma L Collin

Emma Collin
CEO
Parkinson's Victoria

Cover: IN THIS TOGETHER - faces of the Victorian Parkinson's community.

NEWS & HIGHLIGHTS

a walk in the park

NEW LOOK AND A NEW DATE

All indications are that social distancing is going to be part of our lives for a while yet.

As a result, Parkinson's Victoria has made the difficult decision to change the direction of the traditional *A Walk in the Park* events for 2020.

The Melbourne walk was scheduled for Sunday 23 August, with regional walks planned from August- October.

Although more than two months away, all indications are that gatherings of large crowds will remain restricted for the longer term.

Parkinson's Victoria is aware many people hold *A Walk in the Park* close to their heart, as a special day to provide people living with Parkinson's the chance to celebrate and commemorate.

It's important that we do not lose this opportunity to unite our community. As such, the Parkinson's Victoria Board has committed to providing a new online virtual community event in 2020.

Full details will be provided in the next edition of *InMotion*. In the meantime, you can also keep an eye on our website and join our Facebook page for further announcements and updates.

MEMBERSHIP FEE WAIVED FOR 12 MONTHS

Now more than ever, Victorians living with Parkinson's need to stay informed and supported during this unprecedented time.

As a gesture of solidarity, the Parkinson's Victoria Board has agreed to waive membership fees for all members for twelve months from 1 April 2020 and 31 March 2021.

All current members will be sent their annual renewal notice as normal. This letter will indicate that your membership has been renewed for 12 months (at no cost).

There is no need for you to do anything as your 12 months' free membership will automatically commence from your renewal date.

However, if you do have any questions, call us on 8800 0400.

PS: This opportunity has been extended to the wider Parkinson's community. If you know someone who's been considering becoming a Parkinson's Victoria member, let them know they can call us for details.

John Young

MID-YEAR APPEAL

John Young is the face of the Parkinson's Victoria mid-year appeal. A loving husband and a doting father, John was diagnosed with early onset Parkinson's in 2012.

"I reckon the first signs of Parkinson's was when I got seasick in 2007. I had been in the Navy for 21 years by that time and spent most of it at sea. For me to get seasick was very unusual. But the doctors at the time told me it was just an ear infection."

John said he fell into "instant depression" after his Parkinson's diagnosis, but with the help of his GP and Parkinson's Victoria, he received the support, information and care he needed to manage and live well with his Parkinson's.

"My family and Parkinson's Victoria are my team. They give me a push along every now and then, they'll wrap their arms around me. I've learnt that you've got to allow them to help you with your condition."

Parkinson's Victoria CEO Emma Collin said living with Parkinson's presented physical, mental and emotional challenges, even before the impact of COVID-19.

"Living with Parkinson's means that you are in the most vulnerable category. Being in self-isolation may lead to increased depression, anxiety and fear. And it most likely means you have had to change the way you manage your Parkinson's," Emma said.

"What has not changed is that we are here for you, adapting our services and continuing to innovate so you will receive the support and care you need right now."

Your support is essential at this time. Donations to the Parkinson's Victoria mid-year appeal will help:

- expand our outreach program so we can identify those who are struggling right now and provide them with individualised support so they can better manage their Parkinson's
- innovate and further develop our telehealth, phone support and information, online education and peer support so we can help people with Parkinson's and their carers manage and live well during the pandemic and beyond.

To support the Parkinson's Victoria Mid-Year Appeal, visit parkinsonsvic.org.au/winterappeal2020 and donate securely online or call us on 8809 0400 for assistance from a team member.

COPING THROUGH COVID-19

The COVID-19 restrictions have placed extra pressure on people living with Parkinson's – but has also opened up a new world of connectivity and communication.

The following five pages are dedicated to helping you navigate restrictions imposed to reduce the risk of COVID-19 spreading throughout the community.

If you have any questions, the Parkinson's Victoria Health Team is here for you.

Call them on 1800 644 189 for information and advice (after hours phone calls will be returned the next day).

STAYING CONNECTED

Our ability to communicate with others affects our enjoyment of all aspects of our life. This makes social distancing a challenge – impacting our relationships with family, friends and colleagues.

Social distancing, let alone social isolation, is challenging and can impact not only our physical, but our mental wellbeing.

But when viewed from a 'glass half full' perspective, it can be seen as an opportunity to explore other tools and strategies we can use to enable us to continue to communicate and stay connected.

HOW HAS SOCIAL DISTANCING IMPACTED COMMUNICATION?

- seeing family who do not live with us
- catching up with friends
- accessing health services and other appointments
- shopping
- maintaining community supports, ie, personal care
- participating in work, activity groups and exercise programs
- engaging in Parkinson's Peer Support networks.

When you list the many interactions we have, it's easy to understand why we've been quick to find different ways to stay connected through the use of existing digital technology.

MAINTAIN COMMUNICATION SKILLS

In addition to receiving speech pathology therapy services to help you with your speech, there are ways you can actively help maintain communication skills:

- Make a conscious decision to **use your communication** – remain active in your real-life use of speech and language
- **Set 1 or 2 goals** to communicate each day. For example: phone a friend, write an email, or FaceTime a family member
- If you have trouble hearing the other person over the phone or vice versa, check if your telephone provider has a selection of phones with **built in amplifiers**
- Our use of the **phone is currently more important than ever**. If you find it difficult to talk on the phone or via a computer screen, ask your speech pathologist to work with you, specifically on these skills
- If your hearing has deteriorated, **consider an assessment with an audiologist**. A hearing loss can be a significant barrier to communication and staying connected
- If your Parkinson's affects your communication, **consider contacting a speech pathologist** to arrange an assessment and a suitable therapy program, tailored to meet your needs
- Work with your speech pathologist on designing a **'communication maintenance routine'** you can follow on an ongoing basis to reinforce your skills
- **Consider activities** you enjoy, which require you to communicate, express yourself or exercise your speech and voice, eg, singing, reciting poetry, reading a book or newspaper out loud
- Consider the **range of aids and equipment** to assist with everyday communication, eg, voice amplifiers, apps or devices that speak a typed message or communication boards can sometimes be helpful.

WHAT IF I'M NOT AN INTERNET USER?

Talking on the phone, or writing a letter or card, are important and effective means of communication. Emails are also a popular and highly convenient way to interact with others.

More sophisticated digital tools such as applications on a smart phone, tablet or computer, are efficient and powerful, enabling the user to connect virtually with others, almost as though in the same room.

If you're open to using the internet and applications but don't yet have the skills, ask family or friends if they can help get you started. It may be easier than you expect. Ask them to introduce you to tools you can use together.

If you don't have a smart phone, iPad or computer, family or friends may have a device they no longer use they could give to you. People who like to access the latest technological devices are sometimes keen to upgrade and make their older devices available to share with others.

Even beginner skills in using the internet can open doors to a wealth of information, activities, and tools to help you stay connected. If you find them useful, you may choose to keep using them post this current 'new normal'.

KEEPING ENGAGED

Taking conscious steps to stay connected is an important part of looking after ourselves:

- Post or arrange someone to personally deliver a note or card to family or friends
- Contact at least one person each day to check how things are going. Send a photo or video clip to family or friends
- Consider using social media tools such as Facebook or WhatsApp – your children or grandchildren could teach you how to use these
- If you have a smart phone, FaceTime allows you to see each other whilst you talk

- Consider using applications such as Skype or Zoom (video chatting tools) for group activities such Book Club or for virtual lunch or dinner gatherings
- Consider an educational course you can access online
- Explore with family and friends, potential applications that allow groups to enjoy activities together. There are numerous options for activities such as sharing movies, board games, playing cards or musical video clips.

HOW CAN I ACCESS HEALTH SERVICES?

The Government has taken measures to enable medical practices to stay open for services essential for conditions that cannot be treated via a computer-screen.

Some medical and allied health services are able to offer consultations over the phone, or via telecommunication applications such as Skype. This form of service is called Telehealth. It can be used for appointments with your GP, specialist, nurse, and allied health disciplines such as physiotherapy, social work, psychology, dietetics, speech pathology or occupational therapy.

ACCESSING TELEHEALTH

Accessing health services via a screen rather than being physically present, may initially feel awkward. As with every new skill, it becomes easier with more practice:

- Ask your clinic about **equipment and application requirements** for your telehealth appointment and details of when and how it will take place
- **Be prepared** for your conversation with your health professional, as you would do before a regular consultation. List any Parkinson's changes or issues, which you need to discuss. Have your questions ready
- **Set up your environment:** You need to sit comfortably, be visible on the screen and able to see the clinician clearly. Check that you have adequate light and a quiet location with minimal distractions
- **Test the equipment** before you start, so that you can address any issues – do a test run with the clinic or family member
- **Check sound and picture clarity**. Block bright light from windows and switch on a desk lamp. This can make a big difference to how well your clinician can see you
- Consider inviting a **family member to join you** for support. This person can take notes for you and also physically assist with tasks such as adjusting the camera whilst you demonstrate your walking or another task which requires you to move from your chair

Use video call technology to keep in touch with families and friends

- **Close other programs** on your computer, as video-streaming can take up a lot of bandwidth
- If possible, a **cable internet connection** may work better than Wi-Fi, as it's less prone to interruptions
- Have the **health professional's number handy**, just in case you lose the computer connection and you need to phone them
- Try to **maintain your eye contact, facial expression and body language**, as if you were in the same room
- If something during the appointment does not come across clearly, make sure you let the health professional know and **ask for clarification**, as in a regular appointment
- Give your health professional **honest feedback** on how smoothly the telehealth consultation goes. There will be many health professionals who are not used to telehealth and they need your feedback.

Choose an exercise program suitable for your needs and ability.

PHYSICAL ACTIVITY DURING COVID-19

For many people living with Parkinson's, one of the biggest changes is our ability to engage in physical activity which makes us feel better and may be having a positive impact on Parkinson's.

Parkinson's Victoria is pleased to support the Physiotherapists in Parkinson's Special Interest group, and in collaboration with members Dr Libby Proud, Dr Joy Tan and Professor Meg Morris, have developed information that may help in re-establishing physical activity into your routine.

During this time of social distancing and self-isolation, it is important to try to maintain your exercise routines and physical activity as much as possible. One simple way to exercise is to go for a daily walk.

THERAPEUTIC EXERCISE

If you have a specific exercise program provided by a health professional to manage your difficulties while moving due to Parkinson's, keep it going.

If you think you need advice from a physiotherapist who specialises in movement disorders to set up an initial exercise program, many health providers are now consulting via telehealth.

PHYSICAL ACTIVITY AND EXERCISE

There are many free online programs to help you maintain physical activity and exercise.

Consult your medical practitioner to check that you are safe to exercise, especially if you have advanced Parkinson's or other conditions that affect your safety.

Choose a program which is suitable for your needs and ability.

This self-assessment can help you to choose an appropriate program:

- Do you use a walking aid such as a walking frame or stick?
- Have you had a recent fall or more than two falls in the last 12 months?
- Do you freeze when walking, turning or taking the first step to walk?
- Do you have dizziness or light-headedness?
- Do you have multi-morbidity? (a number of medical conditions)
- Have you recently had surgery?

If you answered 'yes' to any of these questions, it's recommended that you consider a chair-based program and also hold on to a bench or other support when doing any standing exercises.

Some online programs include a modified version of the exercise program which allows you to stay seated or hold on while standing.

PRECAUTIONS WHEN EXERCISING

- Exercise when your Parkinson's medications are working well
- Avoid exercising alone
- Ensure your phone is within reach
- Avoid distractions, turn off other devices
- Exercise in a clear space. Remove tripping hazards eg, rugs
- Put pets in another room
- Wear loose clothing and supportive, well-fitting footwear.

If you are looking at exercise resources online, using this guidance is a great place to start so you can find the exercise that is right for you and most importantly is safe.

But where should you start?

If you were taking part in an exercise program prior to the COVID-19 restrictions, check to see if they can recommend any online classes you can take part in.

If you see a physiotherapist, you should also check if they are offering online classes.

Check out the following websites for resources developed specially for people with Parkinson's:

American Parkinson Disease Association:
apdaparkinson.org/community/oklahoma/local-resources/at-home-exercise-options/

Dance for PD:
danceforparkinsons.org/resources/dance-at-home

Power for Parkinson's, Fitness for Mind & Body:
powerforparkinsons.org

Re+Active, PD Online Exercise Resources:
reactivept.com/resources

EDPA Exercisecast:
epda.eu.com/latest/resources/epda-exercisecast

Parkinson's UK:
parkinsons.org.uk/information-and-support/your-magazine/experts/staying-active-home-when-you-have-parkinsons

You can also go to YouTube and search for 'exercise at home with Parkinson's' to find a range of instructional videos.

Resources on offer at the moment include a mix of free and paid programs, so make sure to check what you are committing to.

ATYPICAL PARKINSON'S AND CORONAVIRUS

People living with Atypical Parkinson's are particularly vulnerable to coronavirus. They have increased risk of experiencing more severe symptoms, including pneumonia, due to impaired ability to manage secretions and the reduced movement the condition causes over time.

Atypical Parkinson's - Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), Cortico Basal Syndrome (CBS) - are rare neurological conditions, so called because they initially present like Parkinson's but progress differently.

People living with Atypical Parkinson's – and their carers – should be taking precautions to prevent exposure to the coronavirus. That is because COVID-19 can infect the entire respiratory system and from what we have been able to observe in other countries, is likely to cause pneumonia, especially in people who are living with pre-existing conditions.

This can cause complications for people with Atypical Parkinson's, particularly those with more advanced symptoms, which may include difficulty swallowing or coughing up secretions that collect in the throat causing a gurgly voice or drip into the lungs causing chest infection and sometimes pneumonia.

In addition, a person with Atypical Parkinson's may have some difficulties coughing up of the lungs' secretions, allowing the secretions to fill spaces in the lungs where air should be flowing, reducing the ability of oxygen to reach the tissues.

Key areas in line with Government recommendations are practicing good hand hygiene, only go out if you absolutely need to and avoid interaction with others. This means people with Atypical Parkinson's – and their carers – should exercise more caution than others of their age and follow Government advice and restrictions to protect themselves.

For the latest information on COVID-19 and Atypical Parkinson's, check our website: parkinsonsvic.org.au/atypical

Parkinson's Victoria supports all Australians living with PSP, MSA and CBS, and their families and carers.

If you have any questions or concerns, the Parkinson's Victoria Health Team is here to help.

Call 1800 644 189, from 9am – 5pm Monday to Friday. Messages can be left after hours.

BOOSTING IMMUNITY

The COVID-19 pandemic created an unprecedented global health care crisis, challenging the community, creating confusion and becoming overwhelming for many.

No one has immunity to COVID-19 as it is a new or "novel" virus, however there are things that you can do to boost your immunity at this time.

SLEEP WELL AND MINIMISE FATIGUE

An often-neglected way of improving sleep is practicing good sleep hygiene; that is getting prepared for bed and sleep. Some tips are:

- try to go to bed and get up at the same time
- reduce stimulation, turn off the TV and avoid using electronic devices in the hour or so before bed
- read a book rather than a magazine (the coloured images can be stimulating)
- keep your bedroom cooler
- go to bed when you feel sleepy.

Get comfortable: If your symptoms are a bit worse at night, consider using a satin sheet which might make it easier to move in bed. Discuss with your neurologist to see if additional medication might help with night time mobility.

BLADDER AND BLOOD PRESSURE

Urgency, or not getting much warning when you need to pass urine, is common, as is a lowering of blood pressure causing fluid retention. These problems may combine to cause increased trips to the bathroom at night-time.

Having a nap with your feet up in the afternoon and reducing fluids after 4pm may help with this. Elevating the head of the bed can also help with this issue.

EAT WELL

A healthy and well-balanced diet is encouraged for people living with Parkinson's to ensure daily energy and nutrient requirements are met.

The best advice for a healthy immune system is to consume plenty of fruits and vegetables and those which contain Vitamin C, Folic Acid, Vitamin B, A and D.

When making food choices with your immune system in mind, the most important thing to incorporate is a wide variety of plant foods in every meal. This will ensure you get sufficient amounts of the nutrients your immune system requires to function well.

In summary, the human gut microbiome plays a significant role in immunity. To maintain its health, consume fermented foods such as yoghurt, avoid excessive alcohol consumption, exercise regularly, and as always, eat a variety of plant foods (vegetables, fruits and wholegrains).

A diet high in fibre will also help in keeping constipation under control.

MOOD MANAGEMENT

People with Parkinson's often experience symptoms of anxiety and depression. These symptoms are likely to be more pronounced at this time. The change to people's normal routines and restrictions placed on us, have occurred very quickly.

It is important to remain in contact with your friends and family through these hard times, but having to adapt to different ways of communicating with family, doctors and other providers in an online world can be stressful in itself.

Read more about COVID-19 and anxiety on Page 10.

MAINTAINING INTIMACY DURING THE CORONAVIRUS

by Gila Bronner

Most people in the world are in lockdown, experiencing major changes in their routine habits and behaviour. Consequently, we may anticipate changes in couple relationship, intimacy and sexual activity.

Intimacy and sexuality have a beneficial effect on health and quality of life of every person, especially people who live with a chronic and progressive disease like Parkinson's.

As much as we know, coronavirus does not appear to spread through sexual intercourse, but the combination of a stressful pandemic and a chronic challenging disease requires a sensitive consideration and efforts to support couple's harmony.

HOW TO MAINTAIN A GOOD COUPLE INTIMACY IN THE AGE OF CORONAVIRUS

The coronavirus has produced a unique challenge on long-term relationships: how to cope with too much togetherness? You are in lockdown, stuck together in a limited space. Feelings of frustration and hopelessness may surge, and couples find themselves in endless arguments, which keep them apart.

The main problem is to balance between two important aspects of love, attraction and intimacy – 'closeness and separation'.

If we use our imagination, we may find that it is similar to the popular musical instrument: the accordion. This instrument produces wonderful melodies by compressing and expanding. This principle may be quite helpful to couples in confinement. You should plan two different kind of sessions in your daily schedule, being together and separate:

PERSONAL TIME

Allow each one of you to take 1-2 hours a day for him/herself. Personal time will enable each, the care partner or the person with Parkinson's, to be alone, without a need to listen, to talk or be empathic.

Close the door and choose what you do (work on your computer, take a long bath, talk to friends, listen to music, read or sleep). It doesn't matter, as long as you are not disturbed.

If you still have children living with you, your partner will have to guard your separated, precious personal time. Couples who allow themselves short-term separations, may find that it empowers their need to be together and even may fuel their desire.

COUPLE TIME

Schedule a date. Choose a day, hour, location (living room, bedroom etc.). Now prepare yourself, exactly as if you're going out to a concert, a lecture or a restaurant. Take a shower, shave, put on makeup, perfume, get dressed (out of your training suit).

Now it's your special opportunity to enjoy some quality time together. Try to find something that you can enjoy: dance, browse old albums, reminisce about a vacation or a special event, play cards or dominoes, watch TV together (choose a comedy).

You can hug or touch one another gently (no sex!). This is couple time, designed to make you feel close and remind you of the friendship that maintains the relationship.

Time spent apart is as important as doing something special together.

Gila Bronner is the founder and the former director of the Sex Therapy Service, a researcher and senior sex therapist at the Institute of Movement Disorders at the Sheba Medical Center, Israel. She is a sought after speaker and is a member of the International Movement Disorder Society's Health Care Professional Special interest Group.

YOUR HEALTH

FOCUS ON OCCUPATIONAL THERAPY

Parkinson's Victoria has a new Occupational Therapist on its team. But what exactly is Occupational Therapy and how can it help you?

WHAT DOES AN OCCUPATIONAL THERAPIST (OT) DO?

An OT's role can be difficult to describe as there are many areas of work, but primarily, an OT works to improve and maintain function in everyday activities.

The term 'occupation' refers to the everyday tasks we all do - things that 'occupy' us - in order to bring a sense of meaning and purpose to our lives.

An OT uses an holistic approach and considers every aspect of a client's life; not only someone's physical and mental health, but also the social, cultural and environmental influences at play.

Spending time doing meaningful occupations is considered to positively contribute to a person's health and well-being. An OT uses a client-centred approach to improve or maintain performance of occupations that have been highlighted as important or meaningful to the client.

These occupations may be related to self-care, mobility, work, leisure, education or social participation.

There are many areas in which an OT can work, including disability, community health, mental health, acute care, inpatient and outpatient rehabilitation, paediatrics, work rehabilitation, driving, health promotion, hand therapy and more.

HOW CAN AN OT POSITIVELY IMPACT THE LIFE OF A PERSON WITH PARKINSON'S?

Living with Parkinson's and Atypical Parkinson's can present with challenges in managing everyday occupations within the home, community and work environment.

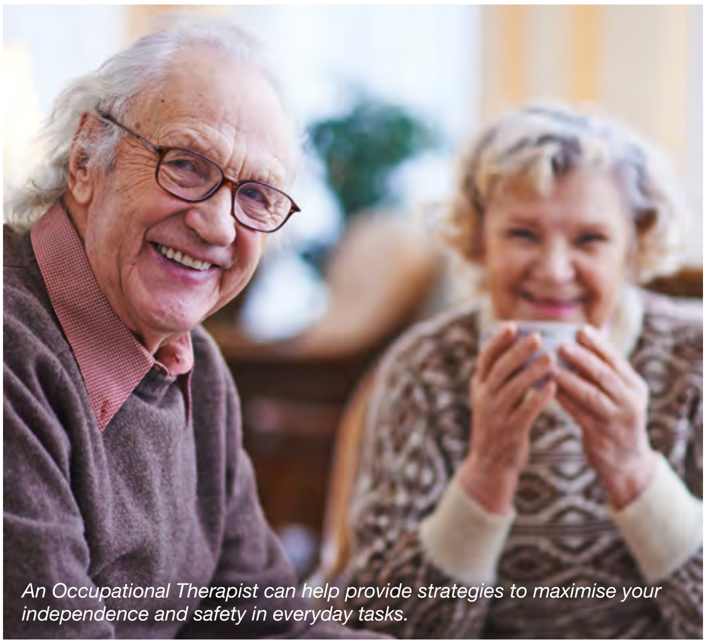
An OT can assist in providing strategies to maximise independence and safety in everyday tasks such as getting dressed, showering, eating, toileting, moving, sitting, sleeping, shopping, gardening, driving, cooking, handwriting, medication management and working.

OTs can also assist in providing specialised, assistive equipment and/or modifying your home or work environment to enable access, maintain function, reduce risk of falls and improve safety.

If you are concerned about how you can manage a specific task or activity, chances are an OT can help you. OTs are excellent 'problem solvers' and are skilled at 'thinking outside the square' to help you achieve your goals.

HOW DO I GET A REFERRAL FOR AN OT?

Given the many areas an OT can specialise in, it's important to engage an OT who has the expertise required to meet your needs. A good place to start is with the Parkinson's Victoria Health Team, who can discuss your needs and suitable options.



An Occupational Therapist can help provide strategies to maximise your independence and safety in everyday tasks.

Depending on your age and funding stream, there are several ways to see an OT:

- Complex Disease Management Plan - arranged through your GP to access up to five Medicare-rebated allied health sessions
- Private Health Insurance - depending on your policy and cover
- NDIS Plan - for those aged under 65 years
- Commonwealth Home Support Program (CHSP) - accessible through My Aged Care for those aged over 65 years
- Home Care Package - you may have funds available for OT services. Discuss with your Case Manager.

TWO TIPS TO IMPROVE SAFETY OUTSIDE THE HOME:

1. Wherever possible, focus on doing one activity at a time, eg, when you are walking outside, try to avoid talking and walking at the same time.

   When performing multiple tasks at once, the more automatic task is often the one that falters, eg, you may experience balance issues when your attention is more focused on conversation.

   To minimise balance issues and risk of falls, try to stop walking, have your conversation and then start walking again once your conversation has ended and you can concentrate solely on your balance and gait.

2. While gardening or hanging the washing out, consider standing with your feet a bit further apart, in order to increase your base of support and stability and minimize the risk of overbalancing.

TWO TIPS TO IMPROVE SAFETY INSIDE THE HOME:

1. Consider having your shower and getting dressed when your medication has had time to take effect and you are feeling at your best.
2. Ensure thoroughfares are clear of obstacles, remove loose mats or any trip hazards and if you have to get up to go to the bathroom overnight, consider adequate lighting.

Call Parkinson's Victoria on 1800 644 189 if you have questions about how Occupational Therapy can help you and for information on providers with specialist movement disorder knowledge in your area.

EXPERT OPINION

MINIMISING ANXIETY IN A CHANGED WORLD

The COVID-19 pandemic has changed almost every aspect of our lives – freedoms we took for granted just months ago have been shut off as the world fights a battle against an invisible enemy.


Dr Louise Cooper

It's a time when a hug is needed by many – but social distancing has put a stop to this form of compassion. It's little wonder that mental health is so prominent in the minds of politicians and thought leaders.

We spoke to Dr Louise Cooper about how to minimise feelings of anxiety during this unprecedented time. Dr Cooper is a Counselling Psychologist at Talking Emotions in South Yarra and Fitzroy, who has a special interest in working with people with Parkinson's, their carers and family members.

How normal it is to feel anxiety at the moment and what are some of the symptoms?

It's perfectly normal to be feeling anxious at the moment, I think everybody is feeling anxious to some extent because there is so much to be uncertain about.

Some things may feel like business as usual, but actually there seems to be an underlying stress there for all of us all the time, and it's popping out in different ways; for instance, people seem to be getting more irritated than usual with other members of their families, it seems we all have a slightly shorter fuse.

We may be finding it difficult to concentrate, to maintain our focus on things, we may be eating more or forgetting to eat, wanting to drink more alcohol, feeling agitated, getting headaches or feeling more tense than usual in our muscles.

These are all symptoms of anxiety. Anxiety can also lead to digestive problems, feeling on edge and an awareness of not breathing very deeply. Anxiety can show itself in many different ways, including sleep difficulties.

When we are anxious our minds churn over data at a faster rate, and have a particular attraction to negative thought patterns and we struggle to stop doing this when it's time to sleep. And there's currently plenty of data to fill our over active minds at the moment. It's no wonder people are reporting they are not sleeping well.

And, of course, these worries are about our health and the health of others, about mortality and the future of the world. Any time there are concerns for our lives and the lives of those close to us we are susceptible to experiencing particularly high levels of anxiety.

How does stress impact a person with Parkinson's?

Stress occurs when we don't feel we are capable of managing a situation or able to do what is necessary to deal with it. With COVID-19, normal routines have suddenly been disrupted and we find ourselves having to exist in a new kind of world and needing to manage things in different ways.

If you have Parkinson's you will already understand the stress involved in adjusting to new situations and COVID-19 is another new situation to adjust to. And stress often leads to experiencing the symptoms of anxiety. Stress can impact you in several particular ways if you have Parkinson's.

A night of little or disrupted sleep means your symptoms may be exacerbated the next day and this can create a kind of vicious cycle; it's easy to become frustrated (stressed) by symptoms and the more frustrated you become the worse the symptoms become. So movements may become more limited or exaggerated, concentration may lag, it may be difficult to get going or get organised and this may make you feel pretty miserable.

Parkinson's is a chronic condition so people with Parkinson's are considered 'vulnerable'. This means a few things. It probably means self-isolation, the disappearance of usual daily activities outside the home and no face-to-face social contact if you live by yourself. It may mean that your usual support network is no longer available or has changed in some way.

It's also difficult not knowing how long things are going to be like this. It's important to try and take some steps to improve your situation, and remember that anxiety can be managed.

TOP TIPS FOR MITIGATING STRESS

"Minimise your news intake – decide where you are going to get your news from, whether it's TV, online or radio, and stick to that because it's very easy to get sucked into a hole of numbers and misery and uncertainty."

Other tips include:

- Eat well and hydrate (drink two litres of water a day)
- Minimise alcohol and caffeine intake
- Get some exercise (take advantage of good weather to get outside)
- Maintain social contact, via the phone or programs and apps such as Facebook or WhatsApp
- Practice breathing and mindfulness – find useful tips at: headspace.org.au/blog/6-ways-to-practise-mindfulness
- Try Tai Chi – with many free group sessions online at the moment, it's a great time to have a go. Tai Chi can be modified to do while seated. The Arthritis Foundation has a special program, mostly suitable for people with Parkinson's. Learn more: arthritisaustralia.com.au/managing-arthritis/living-with-arthritis/physical-activity-and-exercise/tai-chi/
- Beyond Blue is offering a coronavirus mental wellbeing support service. See: coronavirus.beyondblue.org.au/

What about people who don't feel they are anxious?

In Australia we have a culture that expects a certain amount of extroversion and an ability to be socially competent. One interesting thing I've noticed is that for a lot of people who find socialising difficult, whether it's because of their Parkinson's or because they experience social anxiety or have a tendency towards introversion ... these people seem to be actually quite liking the COVID-19 restrictions, it means the pressure is off to be with people! There's always an upside somewhere if we look for it.

Also, if there's some kind of restriction on you already, for instance if you experience some of the limitations that come with Parkinson's, you've already learnt to adjust to that, to do without certain things, to do things in different ways. Your response to COVID-19 may be very different from that of a person who's never lost anything.

So, I'm not saying this is everybody, but for some people (with Parkinson's), you might actually be taking COVID-19 in your stride because you are practised in adjusting to new ways.

What about the role of carers in this?

Carers themselves need to be looking after their own anxiety levels, as they are likely to be restricted in the things they normally do for themselves and the time out that they usually have.

Carers' supports might have disappeared in some way, so there's likely to be a rise in stress between any couple who find themselves spending more time together, and I think the most important thing is to actually name that and make a plan around it, rather than pretend it's not happening.

It's an opportunity for everyone, carers and people being cared for, to explore what there is online at the moment, because there are lots of things out there that can be done together from your home, ie, tai chi, support groups. And if that seems a little mind-boggling, perhaps there is someone you can ask to help you access this kind of thing.

I encourage carers to make contact with other carers at this time, online or by phone, whether it's through Parkinson's Victoria or Carers Victoria.

SOME THINGS YOU CAN DO TO HELP KEEP UP COMMUNICATION AND REDUCE ANXIETY.

- Check in regularly with your family and friends and ask them to do the same for you. Ask for help to set up the technology you need to use to do this and to teach you how to use it for communication, information and activities.
- Speak to your doctor about accessing bulk-billed telehealth phone or video consultations for medical and psychological support (from 6 April – 30 September 2020, telehealth services are bulk billed for patients who are more vulnerable to COVID-19; this includes people with Parkinson's).

Feeling overwhelmed? We are here to help. Speak to us about coping with increased anxiety, details on counsellors and psychologists familiar with Parkinson's and how to get a referral. Call 1800 644 189.

2020 INSIGHT INTO PARKINSON'S

Future Frontiers

Proudly Hosted By PD WARRIOR

Proudly Sponsored By parkinson's VICTORIA

IN THIS TOGETHER

The 2020 INSIGHT into Parkinson's online conference came at what turned out to be a perfect time, just a couple of weeks after implementation of Australian restrictions aimed at slowing the spread of COVID-19.

This included a ban on public gatherings; events had to be cancelled, including our own InSearch research lecture series, which had been scheduled to be held in Echuca, Horsham and Melbourne in March.

Instead, people were able to watch, for free, 3-days' worth of streamed video presentations from international leaders in Parkinson's, including medical and scientific specialists, health professionals and patient advocates.

The event brought together 9000 registered attendees from around the world to hear about the:

- science behind our understanding of Parkinson's
- power of exercise
- collaboration in research and advocacy
- impacts of diet
- motor and non-motor symptoms and how to manage them
- role and challenges faced by carers
- power of positive thinking.

In addition, live panel discussions focussed on women and Parkinson's, Young Onset Parkinson's, Parkinson's-specific exercise and Future Frontiers aimed at ending Parkinson's.

The next few pages provides an overview of the inspirational people who took part in the event and the topics they covered to give you help for now and hope for the future.

IMPORTANCE OF EXERCISE

Prof. Bas Bloem

Exercise was a key theme at INSIGHT 2020, with keynote speaker, **Prof. Bas Bloem**, from The Netherlands, kicking off the conference with his presentation, Exercise Matters.

Prof. Bloem, who presented at Parkinson's Victoria Smart Health in November, said although a challenge for people with Parkinson's, there was growing evidence exercise works like a drug in Parkinson's and was a much-needed intervention.

"In order to take the big next step, where doctors, nurses, physios, write a prescription for exercise, we should develop an evidence base as robust as when we release a new drug on the market," Prof. Bloem said.

He spoke of two treadmill studies, one looking into dosing effects, the other into the use of virtual reality. Another study involved using a custom-designed app with an exercise bike, that motivated people to exercise with rewards.

Prof. Bloem's had many studies published and is excited about another soon to be submitted which involves imaging.

In the meantime, his advice: It doesn't matter what you do, as long as you do something that makes you pant. It's more important that you do something, rather than a specific type of exercise.

Parkinson's Victoria CEO Emma Collin (left) with PD Warrior's Melissa McConaghy, founder of INSIGHT into Parkinson's.

INTERGENERATIONAL EXERCISE

Erica DeMarch

Another interesting theme around exercise came from **Erica DeMarch**, a USA-based physical therapist. Her topic, Generations Balancing Together, discussed the benefits of play and intergenerational programs.

After noticing patients "made more effort" during a class when her children came along, Erica developed an intergenerational balance buddy program.

She spoke of the similarities between a 6-year-old not wanting to go to gymnastics because they were afraid of walking on the balance beam and an adult who no longer wants to go to a restaurant with friends because they are afraid to walk on uneven ground.

Over a lifespan, falls are more likely amongst children and seniors.

Just like the ABC television series, *Old People's Home for 4 Year Olds* highlighted the many benefits of seniors interacting with young children, Erica said there were a number of benefits of intergenerational programs for both older adults and children.

The overall goals of her program is to help older adults and children improve:

- social interactions - discuss different topics on balance, goal-setting and motivation
- fall prevention - learn and use health information focussed on falls reduction
- motor skill/balance development – explore and play together with a focus on balance systems and movement strategies
- cognition – reading together, singing, discussion.

Erica said there was limited evidence of the effectiveness of the intergenerational approach for balance programs, but believed this would be a good project for someone to research.

LIVING POSITIVELY THROUGH EXERCISE


Allison Toepperwein

Following her diagnosis at age 37, with a 4 ½ year old child, **Allison Toepperwein** had become a "single mum who was a basket case, crying all the time – it was like a bowling ball had just punched me in the stomach".

With confirmation of Parkinson's coming on 30 December, Allison decided to put her "crummy" year to bed, determined that this was not how her story was going to end.

First came a blog, then a movement disorder neurologist told her to start moving.

Allison then 'went back to her roots' as a runner. She started running at her own pace. After a month, she was going five days a week and felt better.

"I went from talking with a slur, not being able to type, choking on food, water and air, dragging my left foot, with no use of my left arm to being able to run about 10 seconds slower than my fastest time in high school. It was an amazing feeling."

It grew from there. Allison was asked to run in an alumni track meet, did a mud run, then she started playing on the jungle gym at her daughter's playground, and someone told her she looked like an American Ninja Warrior (TV show).

In 2015, Allison applied to appear on the show and was called to compete in April 2016. She has since run a marathon.

"Faith has played a huge role in my life. I have been guided, and anytime I don't know where to go, doors open. When you fall, it's a perfect point to do a push up, you are primed to push up and when we push up, we have hope."


Christine Jeyachandran

Christine Jeyachandran was also diagnosed with Parkinson's aged 37. Her video, *Handstand for Parkinson's*, which documented her determination to complete a handstand, was a finalist in the 2019 World Parkinson Congress video competition.

Following her diagnosis, Christine initially resisted exercise. That changed when she came back to Australia (from Peru where she lives with her husband and family) and saw a dietician, physiotherapist, social worker and attended PD Warrior as a patient.

She returned to Peru "super motivated", joined a gym and prepared for a family trek in the mountains. But then a sore knee led to apathy and inactivity until the day she realised she could no longer move her arms around. Not long after, she did a video for the #uniteparkinsons campaign.

"I'd seen comments people had written about my video, people said I'd been inspirational. I thought I could do better. I couldn't change my diagnosis, but I could stop making fear lead me."

So at the age of 42, she took up artistic gymnastics. After a few months, Christine decided she wanted to do a handstand.

"I struggled with fear, frightened of throwing myself head first on the floor. Little by little, I got closer until finally I got my handstand; it was not perfect but I got it. I finished the video and put it in for the WPC competition and it was chosen as a finalist.

Christine now runs an activity group for people in Peru – a place they can go where they are understood and learn about Parkinson's together and where Christine can encourage them to exercise – the opposite of what some are told by medical professionals.

FOCUS ON CARERS

EUROPEAN RESEARCH


Francesco De Renzis

European Parkinson's Disease Association (EPDA) Information Manager **Francesco De Renzis** shared details of the organisation's 2019 data collection initiative focussing on challenges facing carers of people with Parkinson's.

The project assessed the physical, medical, financial and emotional challenges of Parkinson's carers across Europe. It involved a review of existing research, interviews with carers and a workshop, which led to the development of a survey completed by almost 3000 people in 14 languages.

While unable to release the findings of the research – which has been submitted for peer-review – Francesco spoke about what they had learned from previous European research and the process that led to the development of the survey questions.

It started with a "simple and clear" definition of what a carer is.

"Many carers do not like the term; they see their role as a natural extension of the relationship they have with someone who is important to them, so it's not surprising a lot of carers are not identified as such, so are not fully appreciated," Francesco said.

He said carers of people with Parkinson's typically had to deal with a variety of challenges, from helping a person with movement difficulties to managing a complex medication schedule; from organising medical appointments to coping with cognitive difficulties of the person they care for.

"Parkinson's is such an individual condition so in the same way, experiences of carers may have a lot in common but at the same time will be different and unique."

Another issue was that caring for someone with Parkinson's could consume a lot of time and energy, leading to carers neglecting their own health and emotional needs.

"It's very clear the impact of the challenges carers face are not only a personal or family matter, they are a societal issue with important effects on healthcare and welfare systems," Francesco said.

Collaborating with partners across Europe, as well as carers and people living with Parkinson's, key financial, emotional and physical challenges were identified to be included in the survey, along with information about access and use of support services.

Among challenges identified included:

Economic	- increased medical and healthcare costs, impacts on employment
Emotional	- burnout, anxiety, worries about the future and social isolation
Physical	- lack of sleep, exhaustion, chronic stress and carer health issues

As well as collecting quantitative data, the survey focussed on qualitative, with participants asked to describe their unique situation in their own words.

> "The aim is to provide evidence that carers have been too long ignored in terms of the physical and emotional challenges they face at individual and societal levels and use the results to develop tangible tools and solutions."

The research results have been submitted to a leading peer-reviewed scientific journal and are expected to be published by the end of 2020, after which they will be publicly available.

CARING FOR A LOVED ONE

USA-based **Lianna Marie**, a trained nurse, was her mother's caregiver and advocate for more than twenty years through the many stages of Parkinson's. She shared what she had learned as a caregiver.

Plan for Parkinson's

"Parkinson's is unpredictable. How do you plan for a future that is unknown?"

Lianna said it was important to be flexible, eg, if a person's mobility was better at certain times of the day, plan any outings around that, and to let go of the need to control the situation.


Lianna Marie

"Planning around on/off times is ideal but not always possible as cycles can be unpredictable.

"The most important thing to remember is timing of meds is crucial - even a delay of five minutes can cause a person to lose their ability to move, walk or speak," she said.

She said caregivers could help by knowing what foods should and shouldn't be eaten so medications are properly absorbed and by keeping a daily diary of on/off periods and dyskinesia, which can be shown to the doctor.

Watching out for shuffling and dizziness on standing can help with falls prevention – encourage them to do physical activity to help increase muscle strength, stability and balance and see a doctor for any blood pressure issues that may cause dizziness.

Know what motivates them

"You can be their biggest cheerleader"

Lianna suggested doing things such as watching funny shows or listening to music – something that inspires people – will help get them moving. For her mother, it was music with a strong beat.

"One key way to help someone with Parkinson's to get going and keep going is to find an exercise or activity they enjoy."

Make life easier

"Avoid stress as much as possible. Later, mum experienced freezing. This was often triggered by emotions – when mum felt anxious or rushed – narrow doorways, changing directions and walking through crowded spaces."

Lianna said as a caregiver, it was important to know some of these triggers – and ways to help mitigate them (eg, for freezing, use strategies such as counting as walking, or walking sideways through doorways).

Lianna said the best way to help make life easier for your loved one was to Parkinson's-proof your home. This could include adding voice-activated lighting, getting rid of rugs, installing grab bars and putting night lights in sockets.

Set them up for success

"One thing I learned early on, I am not my mother – acknowledge questions, concerns and viewpoints. If you are feeling stressed, remember it's the Parkinson's you are angry at, stressed about or resentful of, not your loved one. And don't forget to have fun."

FUTURE FRONTIERS

If there's a positive to come out of the COVID-19 pandemic, it's the attention focussed on our medical professionals and researchers.

The same can be said for those working within the Parkinson's sphere – and INSIGHT 2020 brought some of them straight into our homes.

While passion alone cannot find a cure or develop a better treatment, it's heartening to know these dedicated and committed individuals are on our side, working towards the same goal – treatments to cure and prevent Parkinson's.

Future Frontiers was the theme of INSIGHT 2020 and the live Future Frontiers Panel brought three innovation leaders together in a discussion led by Parkinson's Victoria CEO, Emma Collin. They included:

- speech language pathologist **John Dean**
- tech-savvy Parkinson's advocate, **Kevin Krejci**
- Professor of Neurology and co-author of *Ending Parkinson's Disease*, **Dr Ray Dorsey**.


John Dean

An advocate of the inter-disciplinary approach to care in Parkinson's, John is currently working with Portuguese-based therapist Josefa Domingos on an exercise app called *Triad Health Ai*.

"The exercises combine movement, voice and recognition - the triad - taking those exercises onto smart speakers to deliver interactive exercise and collect interesting data to get health insights," he said.

John said quiet voice was a common hallmark, a "vital sign" of Parkinson's.

Moving on from previous research into telephone voice recognition of Parkinson's, Triad Ai also provides a way to capture information and insights from an individual and helps to improve their voice.

"For someone living with Parkinson's, dealing with some of the fine motor issues, visual and spatial changes, having the voice is valuable. Alexa can do stuff but only if you talk to it clearly. That has a lot of power."

When asked for his current take on technology for the Parkinson's community, John said there were lots of "cool things out there, but I don't see any home runs yet".

"We haven't really figured out how to use technology properly. On the flip side, it's exciting to see more ways we are capturing data in the background. Asking someone to start pressing buttons as regularly as you can is a lot to ask of someone with Parkinson's.

"So getting to something that can capture that information in a natural state, I'm very hopeful for that."


Kevin Krejci

Kevin agreed that trying to manually input information into devices could be frustrating.

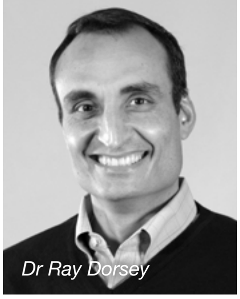
In 2013 Kevin was already working in the tech industry when he was diagnosed. He was knowledgeable on new technologies and applications and even before his diagnosis, was part of a meet-up group "measuring things in our lives just for fun".

"One of the big challenges is the fluctuations we go through, from dyskinesia to bradykinesia and everything in between. All the symptoms make for a unique challenge and are not a simple issue to deal with.

"So I've been trying to do everything I can to look at all my symptoms and what therapies are improving my life, but it's kind-of hard. I collect a lot of data but I can't analyse it really well."

He said having an artificial intelligence (AI) or data scientist working with neurologists would be beneficial to helping people work out a plan and make the best of the wearable technology.

> "I feel there's so much data we as patients could be collecting that could help contribute to science and research, not only for our personal benefit and for our conversation with our doctor, but also for the research community."


Dr Ray Dorsey

Dr Ray Dorsey is one of the doctors making it his mission to improve outcomes for people with Parkinson's, the world's fastest growing brain disease which has doubled over the last 25 years and "will double again in the coming 25 years if we don't act."

But as co-author of a new book, *Ending Parkinson's Disease*, he goes a step further.

Dr Dorsey wants the Parkinson's community to be vocal in not accepting the status quo. He cites the community uprisings against polio in the 1950s and HIV Aids in the 1980s as evidence that disease can be treated and eliminated if people become activists for the cause.

"The number of people with Parkinson's is rising rapidly, yet it is under treated and under-appreciated.

"There's been no been therapeutic breakthrough this century. One reason is that we don't have objective real world measures of the disease that can tell us in a short period of time if a drug works or does not work. We need them to get treatment breakthroughs."

Dr Dorsey said *Ending Parkinson's Disease* highlighted stories of people with Parkinson's and had a four-element PACT to end Parkinson's:

1. **P**revent individuals from ever developing Parkinson's
2. **A**dvocate for additional resources and better policies
3. **C**are for everyone affected by the disease
4. **T**reatments and therapeutic breakthroughs

"We need to end our silence. We can make our voices heard and end this debilitating disease," Dr Dorsey said.

Kevin agreed it was important to keep building the community through social media and events like the World Parkinson Congress, where researchers and practitioners come together with people living with Parkinson's.

The COVID-19 pandemic has also seen people move more quickly towards virtually building connections, with the INSIGHT 2020 online conference a great example of people from around the world coming together.

And this is something we don't want to lose after the world gets back to 'normal' after the COVID-19 restrictions are lifted.

"We can't lose the opportunity to make telemedicine permanent so anyone, anywhere can gain access to their neurological care," Dr Dorsey said.

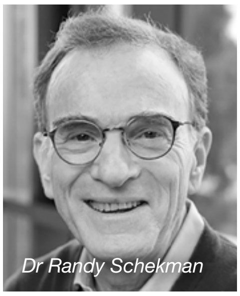
John agreed, citing exercise programs that had been online during COVID-19.

"Access to treatment by people with expertise and experience working with people with Parkinson's is the most important thing anyone can do - providing a telemedicine platform so you get to a larger group of people is very valuable."

On the prevention side, Kevin said he would like more data points to help identify patterns.

"I grew up in a valley and saw crop dusters fly over every day – that may explain something. A lot of people had some sort of virus when younger; what did we eat, what were we exposed to, did we have concussion? Collect more data to try to drive the science a bit better."

ALIGNING SCIENCE ACROSS PARKINSON'S


Dr Randy Schekman

Keynote speaker Nobel Laureate Dr Randy Schekman, Professor in the Department of Molecular and Cell Biology, University of California, Berkeley, spoke about the upcoming ASAP initiative, of which he is a Scientific Director.

Aligning Science Across Parkinson's (ASAP) is an initiative to build an international network of scientists to uncover the basis of Parkinson's – how it originates and progresses to, hopefully, lead to new therapies.

"The disease is probably of multiple origins, yet it is treated as a single disease. Neurologists, based on movement disorder, classify all patients as (having) one disease, said Dr Schekman.

"As a result, the drug industry focused on finding therapies, some of which perhaps only benefits a small number of people, so the trials have failed."

ASAP is a coordinated research initiative funded by the Sergey Brin Family Foundation. Google co-founder, Brin has donated millions of dollars to Parkinson's research, with personal experience of the condition through his mother and great aunt.

The project will:

- identify teams of investigators from around the world who are actively engaged in a vital effort on the basic science of Parkinson's
- provide a scientific strategy based on fundamental research
- direct a "considerable philanthropic effort" to funding these teams to work in a collaborative mode to create an international consortium of investigators.

> "We hope within this next decade to have a new basic understanding of the targets that could then permit the pharmaceutical industry to devise drugs that may really attack the fundamental basis of the disease," Dr Schekman said.

The problem so far is that there isn't a lot of funding available for the fundamental research on one gene in one protein, and understanding how they work. He likened it to a puzzle, with different pieces (genes).

"Our task during this effort is to collect these pieces and fit them together so we have a big picture of this disease."

"We've just begun this effort, we've just sent out a call for proposals around the world. We've had 150 teams who applied – half from the USA, half from elsewhere around the world. We want to pick those teams who already know what it means to collaborate.

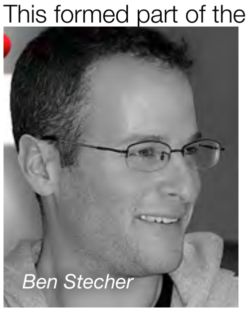
"We want to attract diverse people from all different fields and will insist every team will have a young investigator with new knowledge, fresh ideas and energy. And we will embrace the values of openness and transparency," Dr Schekman said.

Successful teams will be announced later this year.

YOUNG ONSET PARKINSON'S

Around the world there is a growing movement to recognise Young Onset Parkinson's (YOPD) as a sub-set of Parkinson's that not only has its own set of challenges but could offer a greater understanding of Parkinson's in its purest form.

This formed part of the discussions of the live YOPD panel at INSIGHT 2020, chaired by Canadian **Ben Stecher** and featuring **Gaynor Edwards** (UK), **Charlie Appleyard** (UK) and **Hugh Johnston** (Canada).


Ben Stecher

Ben, diagnosed at the age of 29, is an author and actively involved in Parkinson's research advocacy.


Gaynor Edwards

Gaynor was diagnosed aged 42 and in 2016 launched Spotlight YOPD, a charity representing and focussing on the specific needs of those diagnosed under the age of 50.

Charlie is MD of an international recruitment company and captain of the UK Parkinson's Football team. He was diagnosed with YOPD in 2016 and is an ambassador for The Cure Parkinson's Trust.


Charlie Appleyard

Hugh's career focused on strategic planning, business analysis, and fact-based decision making. When diagnosed with Parkinson's, he set out to learn everything he could about the condition to become a Parkinson's advocate.

WHY DO WE NEED A SPECIAL DESIGNATION FOR YOPD?

"Because it's different! You are more prone to have the '3 Ds' if you have Young Onset Parkinson's – depression, dystonia and dyskinesia," Gaynor said.


Hugh Johnston

"You've got your umbrella of Parkinson's, under that you've got your umbrella of Young Onset Parkinson's, within that it's divided up, I believe, into different genetic types. Some of them we know, others we are discovering.

"And then there's a mix with some, where it's part genetic, part environmental factors, then there's the trigger, which is the thing that just tips you over the edge."

Ben co-authored a paper around this theory, *Triggers, Facilitators, and Aggravators: Redefining Parkinson's Disease Pathogenesis*, published last year.

The paper proposed a definition of the pathogenesis (development of the disease) into three progressive phases: triggers (eg, viral infection, environmental toxins), facilitators (that allow the Parkinson's pathology to develop, eg, inflammation) and aggravators (that directly promote the neurodegenerative process).

Both Gaynor and Hugh are proponents of a greater focus by researchers on those with Young Onset Parkinson's as the "purest version" of Parkinson's because they haven't got other conditions that other people would naturally get in older age to "muddy the waters".

"So if you have a relatively fit person and the only thing wrong with them really appears to be Parkinson's, let's look at why they have that Parkinson's," Gaynor said.

The panel also touched on the definition of Young Onset and whether a person is considered to have YOPD when they are older.

"At the moment we are doing it just to ring fence a group of people that we can do more research with," Gaynor said, adding there will be a time when we know more about what genetic types they are, that they will grouped by symptoms.

"There are so many different types of this disease, yet often what we do is lump it together in one big umbrella. It's not so much about age, but what is the type you have, why do you have it and what is driving it?" Hugh added.

WHAT ARE THE REAL PRACTICAL SOLUTIONS TO SOME OF THE PROBLEMS YOU FACE?

"The first thing people need to look at is it's not the end of the world. If you get it quite young, you've still got your responsibilities, you've still got to try and get on with life," Charlie said.

"I found one of the best things to do was be very open and honest about it."

Charlie said he had become fed up with people asking why he was limping or moving so slowly that as soon as he was diagnosed, he went public with the news.

"Being really honest and open about it, it's easier, fair to other people as well. I tell people straight. I'd rather people knew I had Parkinsons than 20 pints."

Charlie still runs his own business, now working four days a week – and says his business had gone from strength to strength.

Apart from the right drug regime, Charlie said exercise was the main thing that had help him.

"In the first year of diagnosis I was ok, in the 2nd year, I was doing exercise and sport but not the right forms. I went to see a specialist neurological physiotherapist and he transformed the way I did my exercise," Charlie said.

He said he'd since seen significant gains, ranging from winning tournaments and taking part in international football tournaments.

> "Sometimes people do get apathy and it's hard to get out and about, but the more exercise you can do, no matter what sport it is, the better and more positive you will feel."

The panel also touched on the cost of YOPD – both mentally and financially.

As well as increased medical costs and the cost of Parkinson's-specific exercise programs, people with YOPD can also be forced to give up career progression because they can't put in the hours or stress that comes with it. Others retire early.

As well as building a support team of health professionals, the panel spoke about the importance of a social network. There is no doubt there is a growing world-wide camaraderie in Young Onset Parkinson's and they are keen to support each other.

"All the specialists in the world can't help you as much as people with lived experience can," Ben said. "At the end of the day, we are the living, breathing experts on this disease."

Interested in joining a Young Onset Parkinson's Peer Support Group? Call us on 1800 644 189 for information.

WOMEN AND PARKINSON'S

Men are 1.5 times more likely to have Parkinson's than women – so it's easy to understand why women may sometimes feel more isolated in their condition.

This can be amplified for younger women. That's why a growing band of vocal female advocates from around the world are so important.

Listening to the Women in Parkinson's live panel, it's impossible not to be inspired. These "accidental advocates" are strong, compassionate, brave and frank.

Heather Kennedy

Emma Lawton

Vicki Dillon

Dr Maria De Leon

The Women in Parkinson's Panel was led by **Heather Kennedy** from the USA. Diagnosed at the age of 40, Heather is a writer, speaker and founder of an advocacy site offering resources and connection through social media.

She was joined by **Emma Lawton** and **Vicki Dillon**, from the UK and **Dr Maria De Leon** from the USA.

Maria was a movement disorder neurologist, with a passion for Parkinson's and diagnosed her own grandmother with the condition.

Then, at the age of 36, she started having symptoms, including pain, fatigue and visual disturbances.

"I spent two years of my life trying to see every specialist, because everyone was focussing on my pain. We still weren't sure about my pain and my visual problems, but once I started treatment for Parkinson's, those symptoms went away."

Maria said this started her thinking, maybe women were presenting with symptoms differently from the men.

"There was no literature, so that's been my passion - to bring awareness for young women, so I wrote one of the first books on the subject, The Parkinson's Diva."

The book covers "all the things we don't want to talk about that are kind of taboo in our society".

Vicki Dillon is 48 years old and living in the UK with her partner and two sons. She was working as a paediatric nurse when diagnosed at age 35.

"It's been one hell of a journey, the guilt of being a mum with Parkinsons, pretending that all is well, having to work twice as hard as before to prove you can still do your job, pushing yourself to your limits, painting on that smile, tears of the clown when no-one else is around – it's exhausting."

Vicki is very open about her Parkinson's "for people to see it all in its raw glory". It's not always been easy and has put her under intense public and media scrutiny at times, particularly around her experiences with dopamine agonists and compulsive behaviour.

"That experience cost me greatly, but I'm not bitter; it led me down a different path for a different reason and made me stronger."

More recently, Vicki has been in the media in the UK as part of a campaign for further research into a protein known as GDMF.

Vicki was part of a trial and says she experienced a vast improvement in her symptoms. She was 'devastated' when the trial ended without enough evidence to show the efficacy of the drug.

"I'm an ordinary woman who's made plenty of mistakes, and then opened her mouth and told the world all of them. I wear my heart on my sleeve and share my deepest thoughts.

"This journey of mine has been horrendous at times, but joyous at others. It's got me to where I am today and that's pretty good place," Vicki said.

Emma Lawton was working as a graphic designer when diagnosed with Parkinson's at the age of 29 and has made it her mission to raise awareness about the condition and continue her life as she planned.

She has worked with Parkinson's UK, written a book and been in a BBC documentary, *The Big Life Fix*, in which a vibrating watch that allowed her to write was designed for her.

This year Emma is doing something new every day and blogging about it to shine a light on the importance of investing in our own development and happiness. She is also does stand-up comedy.

"I do it with a puppet, Edna and she has Parkinson's too. We talk about dating, and boys and all sorts of silliness. Dating with Parkinson's is great comedy fodder."

When first diagnosed, Emma said she used to speak positively and although still positive, is more realistic about the condition and the challenges.

"I call it positive realism. The fact we are surviving makes us special, but actually what we are doing is the thing that is special. Sometimes I feel like I am a mouthpiece for people that don't have the opportunity to speak - I take great responsibility in that."

The women also touched on self-love and deflecting cruel comments from others about being drunk or faking symptoms.

"You will save a lot energy, grief and heartache if you just let it go, rather than try to explain to everyone, this is my illness. It's hard and you do get upset and want to lash out but it's not really about you," Maria said.

All spoke of embracing and living your best life, and the importance of friendship and finding people on a similar journey.

> "Learn who you are with Parkinson's, love who you are. Don't stop learning, don't stop growing, don't stop being sparkly. Do what makes you happy. It's really important that you try and stay as 'you' as you can and fill your life with people that love you for who you are." - Emma Lawton

John Morse (right) with his Lego Technic Club members and mates.

BONDING OVER LEGO

One of the positives to come out of the coronavirus has been the focus on acts of kindness – our social media feeds are filled with photos and stories of acts of kindness as people lost jobs and became isolated from family and friends.

But the fact is there were people carrying out acts of kindness everywhere, every day before COVID-19 hit, and they will continue to do so after.

One such person is John Morse, who is bringing joy to a number of elderly men in Warrnambool, where he volunteers at two aged care facilities, running Lego Technics clubs.

John, who was diagnosed with Parkinson's in 2016 and is a member of the Warrnambool Peer Support Group, comes from a family of local designers. His grandfather started a family business in the 1880s designing and manufacturing coaches and buggies.

The business progressed to automotive repairs, which John and his brother ran until 2010. Six years later he was diagnosed with Parkinson's after experiencing symptoms including a shaking right arm, watery eyes and lack of facial expression.

"People wondered why I wasn't happy when I was," John said laughing.

In 2014, John decided to volunteer at Lyndoch Living Aged Care, where his wife Liz had been working.

"I ran into an old bachelor, who lived with his brother. They were both bachelors, with no family left. He wouldn't get out of his room, wouldn't associate with anybody. He was mechanically-minded, a do-it-yourself kind of farmer," John said.

They started building Meccano together, but with "tiny screws and nuts", decided to move onto Lego Technic, which snaps together.

"It's not like blocks. Lego Technics is more advanced, with gears and electric motors," John explained.

As the man became older and unable to take part anymore, a couple of others came along. Before long, a small group of up to five men were meeting.

"The fellas love it," John said.

The Lego is separated into plastic trays, with parts divided up between the men, who are aged from 78-93 years.

"I haven't been there since the COVID-19 (restrictions), but they are still doing the Lego. They just sent me a photo of where they are up to with their latest model," he said, adding a staff member who was a motor mechanic was helping them out.

The club runs weekly for a couple of hours – with each kit costing from $250-$400 each, they don't want to complete them too quickly. But once built, they are put into a glass display cabinet. About eight have been completed.

"When the residents' grandchildren come in, they will get them in and fire them up. They've got motors in them, one's even radio controlled – a great big front end loader."

John said the Lego club provided an opportunity for the men to socialise, joke about and reminisce about their lives in Warrnambool.

"I know a fair bit about the history of Warrnambool. A lot of them talk about the old things that happened around Warrnambool years ago – and I can still remember all of that stuff."

So John took a step further. After two hours of Lego Club in the morning, and after the residents have their lunch, John escorts a group of up to 10 of them around town in a 12-seater bus.

"We just go for a drive for an hour and a half and we will go everywhere – we've been up every back road. I take them up around the industrial estate, sometimes drive into the yards of people I know so they can have a look."

Last year, John expanded the concept, starting a Lego club in June at Mercy Place, another aged care facility in Warrnambool where Liz currently works.

And in October, together with Liz, he attended a gala dinner in Melbourne as a finalist in the Life Activities Clubs Victoria Senior Achievement Award at the 2019 Victorian Regional Achievement and Community Awards.

John was nominated by Lyndoch Living, for "helping male elders find their sense of purpose" through the Lego Club. Although he did not take out the award, there is no doubt John is a winner in the eyes of those he has helped bring a new sense of social integration and friendship to.

Corryong Peer Support Group members Sandra Watts (third from right) and Sandra Smith (fourth from right), shared their stories of living through bushfires and COVID-19 isolation.

PSG MEMBERS IN THE MIDDLE OF BUSHFIRES

It was late December when devastating bushfires swept through parts of Victoria, including the far North-East. A month later, with bushfire fundraisers still in full swing, a new, silent threat was making its way into Victoria.

By 16 March, Victoria had declared a State of Emergency in response to the COVID-19 outbreak. By the end of the month, strict rules were in place to prevent the spread of this deadly virus.

"It's been quite a year," admitted Sandra Watts, a member of Corryong Peer Support Group, one of the state's most isolated groups, in an area hit hard by the summer fires.

Sandra lives neat Tintaldra, a small country town 20km from Corryong, and an hour and 20 minutes out of Albury-Wodonga. She moved there with husband Phil about 14 months ago to be closer to their adult daughter, having lived most of her life on the Sunshine Coast.

They live in a rented house, one of many on a large cattle holding, drawn to the peace and quiet of rural life.

At 76 years, Sandra has been living with Parkinson's for 16 years. Her father also had Parkinson's and she feels lucky her progression has been slow. Life was going well until 30 December 2019 as fires quickly flared and spread.

"We were certainly right in the middle of it. It came on very quickly actually," Sandra said.

"I was in town the day I was evacuated, to get some scripts made up. That was lunchtime. By late afternoon we'd moved out, gone to our daughter's place on the other side of the Murray River."

By then, the fire was coming in from Walwa and Cudgewa, heading to Corryong and Tintaldra.

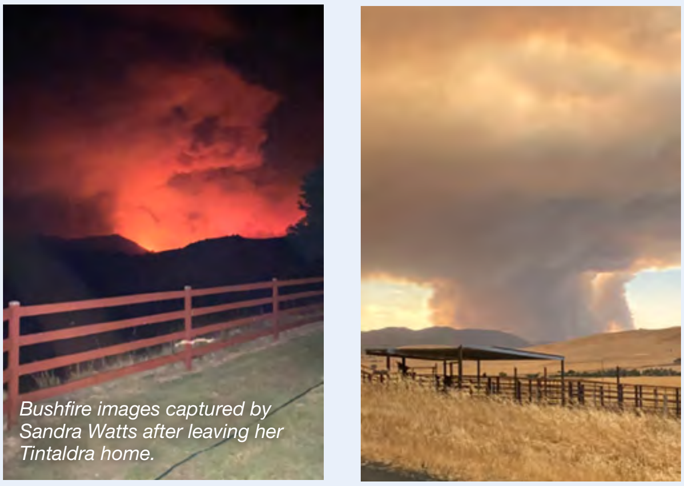
"Our daughter Peta rang and said they are advising everybody to get out. She came over and loaded her car and ours, with as much as we could, and took it down to her place," Sandra said.

Peta's husband Wade was working in WA when the fires started. He flew home, arriving on New Year's Eve. The next day, they too were under threat and the extended family – with prized horses including a week-old foal – made their way to a friend's place half way between Tumbarumba and Wagga.

Peta and Wade returned to their Murray River property to defend it, which Sandra said was "a very worrying time as communication was non-existent". Just days later, the fire swung around. Sandra and Phil went to Wagga, where they stayed with friends for three weeks, not knowing if they still had a home.

"Coming home was dependent on getting new power poles installed along our road and as our water came from Cudgewa Creek, we had to start getting tanker loads in for both us and the cattle as the creek was, and still is, polluted with ash from runoff."

When they did return, the fire had burned to either side of their house, but it was still standing – others in the road were not so lucky.



Bushfire images captured by Sandra Watts after leaving her Tintaldra home.

SUPPORT FOR YOU

Sandra says there was one thing that saved their home; winter cattle feed stockpiled between their house and the creek. The property owners and staff had fought to save this feed from being burned and so were around to protect the property.

"From that point of view we were extremely lucky," Sandra said.

"The Army and BlazeAid were also absolutely brilliant, as were the Police in protecting the locals and their privacy. We certainly are lucky living in a country town where everyone cares."

Sandra said because everything had happened so quickly, there was no time to be prepared. She had Parkinson's medication on hand and took scripts with her. She also had her annual neurologist appointment scheduled in Wagga for mid-January, but was able to get in earlier.

"I knew my medications needed to be increased, which he did, but I do feel that, combined with this coronavirus isolation, it has had an impact on my overall Parkinson's symptoms," she said.

"It's taken it to another level slightly, for example, my ability to handle things. That's why we enjoy living where we do: normally it's stress-free and relaxing, which is why we opt for this sort of lifestyle," Sandra said.

The small Corryong PSG has about 10 members (half of them with Parkinson's) and only meets a few times a year. But it is a support and helps with finding out information that might not be so readily available, such as accessing the isolated patient's travel allowance for medical visits.

While the group is too small to hold its own activities, Sandra said it was important to tap into wider health opportunities and services. She said the local Corryong Health had a gym, held swimming classes in summer and also ran Making a Move falls prevention classes.

Overall, there are more pluses than minuses about living in such an isolated area, with a lifestyle that includes getting milk straight from a local dairy farmer, not to mention living amongst the beauty and tranquility.

And when travel restrictions are lifted, locals including Sandra are hoping tourists will again come to support the area, which is already recovering. This Man from Snowy River country is renowned for its natural beauty.

"It's amazing since the fires, it was so black and now it's green and really very pretty," she said.

Sandra Smith is another Corryong Peer Support Group member who lived through the fires and shared her story with us. She was in Corryong when the first fire front came through, before evacuating to Wodonga with family. Read her story online: parkinsonsvic.org.au.

The burned out entrance to Corryong, after the bushfires swept through at the end of 2019. Photo courtesy CFA.

HELPING PSGS STAY CONNECTED

Parkinson's Peer Support Groups (PSGs) are an essential support arm, an invaluable platform through which individuals impacted by Parkinson's can come together at a local level. This vital service is conducted via a comprehensive network of more than 70 regional, clinical and shared interest groups.

In early March, as the seriousness of the COVID-19 pandemic was emerging, Parkinson's Victoria took the difficult step to request all PSGs hit the pause button on group meetings to keep everyone safe.

The Parkinson's Victoria team called every group leader to advise them of the decision personally, and unsurprisingly, many were already considering cancelling meetings until the situation became clearer.

At the time of our calls, we encouraged leaders to think of ways members could keep in touch with each other. Since then, we've been working behind the scenes on a major project to help PSGs set up Facebook group pages.

These pages will provide an opportunity for greater social connection between group members, who can share experiences and keep supporting each other online.

Amongst the feedback we have received was concern around the lack of opportunity to participate in exercise during the social restrictions. We have worked with some senior Parkinson's physiotherapists to provide an easy guide on selecting exercises to suit your needs (see Page 6).

We have also started planning for virtual PSG meetings via ZOOM, an easy-to-use online meeting platform that can be used on computer, tablet or smart-phone.

In the meantime, as part of our COVID-19 outreach program, our Community Development Coordinator continues to call and check on PSG leaders to keep the conversation going. We know a number of PSGs have already changed the way they are meeting to stay connected.

Here we share some of the innovations and ideas they have implemented to help to keep the community connected.

TUNE IN TO PARKINSONG LANGWARRIN

Group facilitator Cathy Crerar explains how ParkinSong Langwarrin adapted to #stayathome.

"The challenges of general understanding of different technology and platforms and its availability within the group needed to be considered. We felt it best to stay simple and basic with emails and SMS communication seeming preferable and manageable by all.

Since our last face-to-face, and to reiterate that we are in this together, I've been in regular, ongoing weekly contact using a short text message to say hello and a reminder to check emails for links to a relevant song, information and exercises that may be of interest.

Meanwhile, our wonderfully talented music therapist, Megan Goodwin was busy behind the scenes putting together pre-recorded video sessions, similar to our regular format, in preparation to make them available from the group's Term 2 scheduled start date.

And here we are with our ParkinSong, somewhat different and aptly named TUNE IN to ParkinSong Langwarrin.

The members receive an email with a Dropbox link. There they have access to video sessions which consist of similar content to our regular ParkinSong meets. One video is the warm up exercises, and another with the sing-along component.

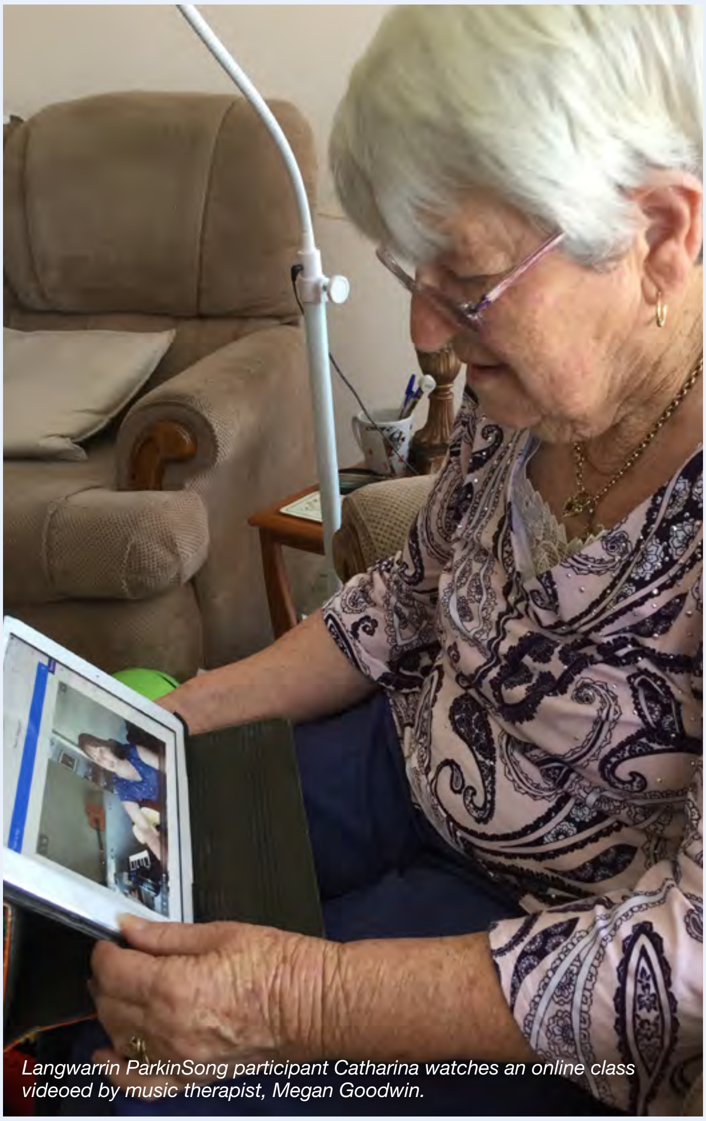
To help make the initial experience less daunting, we are revisiting some familiar songs as well as adding new songs. We believe this supports bridging on our established connections and makes the introduction of remote delivery even more enjoyable and beneficial to positive wellbeing.

These video sessions, in turn, will form a collection available at leisure and as many times as members are enthused to practice and take up a voice strengthening opportunity.

It was encouraged that members at least endeavour to utilise the usual scheduled meeting day of Thursday for routine. But this type of delivery is fantastic to cater for flexibility and fitting in with daily changes or different lifestyles, as well as offering choice.

It is still early days of the TUNE IN experience, but the feedback after a one-on-one phone check is that it's working ok and easy to manage and is already delivering positive vibes. Singing will help us through."

Continued over page.



Langwarrin ParkinSong participant Catharina watches an online class videoed by music therapist, Megan Goodwin.

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KARAOKE CLIPS AT WILLIAMSTOWN

ParkinSong Williamstown had only met once in 2020 before restrictions came in, so group leaders, Lynne Georgiadis, Jenni Mitchell and Joanne Wheelahan decided continued communication and contact was more important than ever.

"We do have a large number of our members online receiving our emails, and 14 members who are on our postal mailing list," Lynne said.

"We still do a mail out once a month, but we decided that Weekly Karaoke clips would keep our group singing. I have asked for requests for any particular artist and have received a few. The feedback from a few has been positive.

"The list of clips is cumulative, so members don't have to re-open or find old emails. For our postal group members, we can make hardcopy lyric sheets available for their interests and (music) collections at home."

DAREBIN CARE PACKAGES

Darebin Painting with Parkinson's had to try to find a way to keep - and use - a City of Darebin community grant in light of the suspension of the regular group sessions.

Co-facilitators Sarah Lumley and art therapist Bec McBurney decided it was important to ensure that each of our group members could continue art-making during the pandemic.

"We hit upon the idea of using much of our remaining grant money to create an individual care package of quality art materials, plus special tea or coffee, for each core member of our smallish group," Sarah said.

"We were also keen to see if we could continue with our sessions with an online platform such as Zoom," Sarah said.

"I think the Zoom session went well. Although it wasn't really possible to engage in art while zooming, it was fantastic to get together and see all the art that people have been doing."

Darebin Painting with Parkinson's participant, Jaffer, with his painting care pack.

Call our Health Team on 1800 644 189 for information on peer support and staying connected during COVID-19.

UPCOMING EVENTS

Parkinson's Victoria raises awareness and funds for services and research that improves the quality of life for 27,000 people with Parkinson's in Victoria.

In line with Victorian Government COVID-19 restrictions, all Parkinson's Victoria face-to-face events have been cancelled until at least 30 June.

See our website events page for all re-scheduled and new events, including online seminars: **www.parkinsonsvic.org.au/events**

! Do you want to alert visitors to your home that you are vulnerable to coronavirus?
We have produced two posters to cut out and place in your front window or front door.

I have an underlying health condition that makes me vulnerable

Please leave your delivery or stand 1·5 metres from my door

IN THIS TOGETHER
parkinson's
VICTORIA

parkinsonsvic.org.au

#COVID19

! Do you want to alert visitors to your home that you are vulnerable to coronavirus?
We have produced two posters to cut out and place in your front window or front door.

I have an underlying health condition that makes me vulnerable

Please be extra careful around me

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